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

Contents

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 team of the Department of Aging Disability and Home Care, NSW Family and Community Services, and NSW Department of Education and Communities. We are extremely proud to present these ideas and invite you as authors to help develop this field and the knowledge base to help support children and adolescents.

On our Website:
www.schoollink.chw.edu.au
The website will be playing a crucial role in the information that CHW School-Link can provide to you.
- *The collection of previous and current editions is located there with the ability to download articles separately.*
- *An invitation for contributions can be found on the website with instructions for authors.*
- *Upcoming training at conferences, workshops and other professional development opportunities will be continuously updated.*

Editorial

Jodie Caruana
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www.schoollink.chw.edu.au

Dear Readers,

Please find attached our latest edition of the School-Link Newsletter.

Welcome to the latest member of our School-Link **team Kim Eisler. Kim is covering Hebah's maternity** locum and brings a wealth of experience from her role in School-Link at Sydney Local Health District.

As most of the state is transitioning to the National Disability Insurance Scheme (NDIS), our colleagues at Ageing Disability and Home Care (ADHC), Department of Family and Community Services are preparing to transition to their new homes within the non-government sector.

In March this year, it was announced that disability clinical services within ADHC would be transferring to The Benevolent Society on 1 August 2017. Across the state, referrals are still being received by ADHC field staff in the lead up to this transfer.

In late June, it was announced that our collaborative partners within the specialist Statewide Behaviour Intervention Service (SBIS) and most of the Clinical Innovation and Governance Directorate of ADHC will also be transferred to The Benevolent Society on 31 July 2017.

The Department of Psychological Medicine at the Children's **Hospital at Westmead would like to sincerely** thank SBIS for their collaboration, partnership, expertise, innovation, dedication, and professionalism over the last 30 years to improve outcomes for children and young people with a disability. We wish them all the best in their new organisation and look forward to continuing our partnership in the years to come.

Enjoy this edition of the journal.

Any feedback or comments can be sent to: schoollink@chw.edu.au
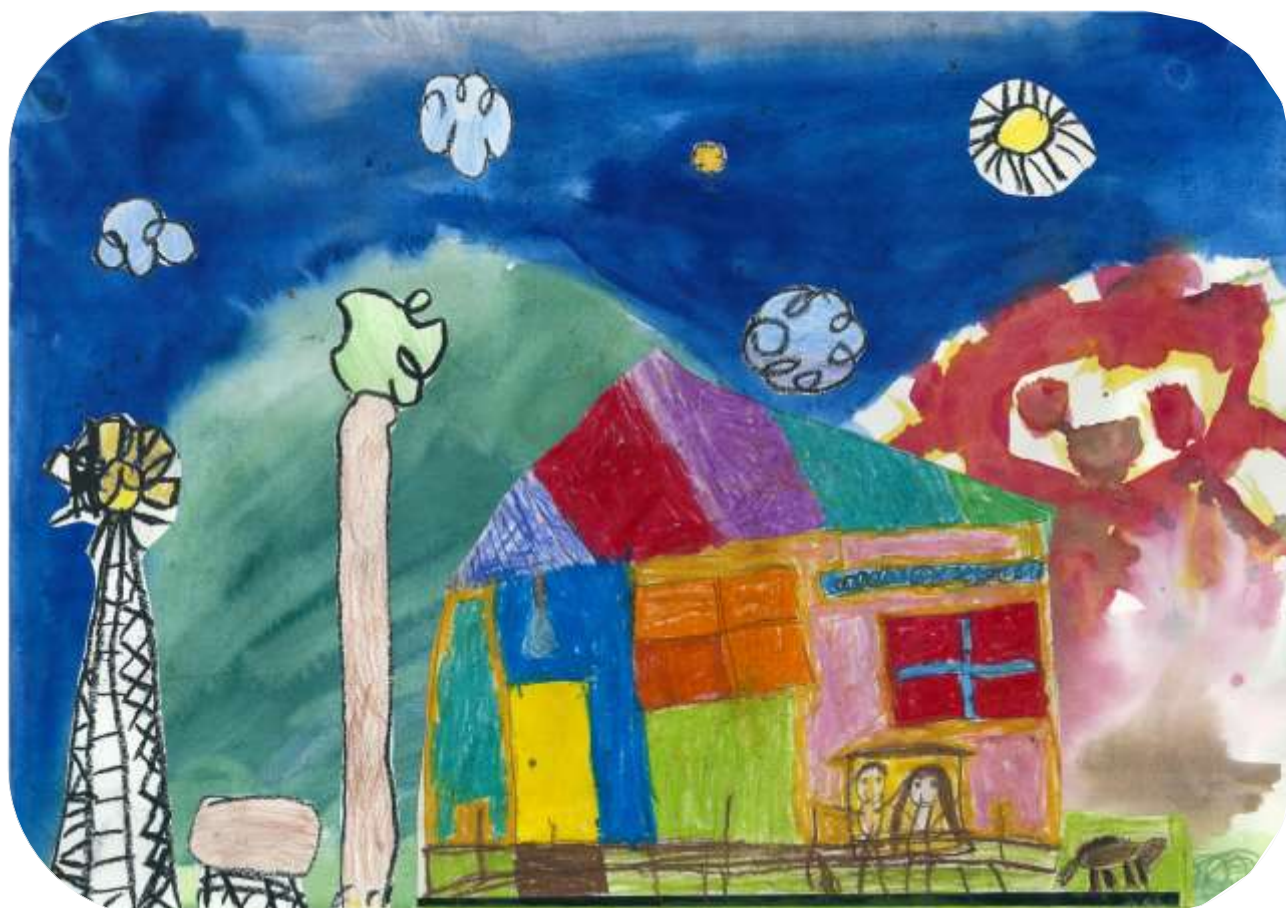
Catatonia: an under-recognised, acutely treatable condition in young people with intellectual disability/ASD.

Associate Professor David Dossetor

The Children's Hospital at Westmead
Area Director for Mental Health
Child Psychiatrist with a Special interest in Intellectual Disability

A case example

A 15-year-old girl with Down Syndrome was referred to neurology due to a neurocognitive decline over a two-month period. She had been socially active, happy, cheeky, talkative and an enthusiastic school attender. She had acquired basic self-care and hygiene skills, and achieved primary school educational skills. At a school swimming carnival, the girl was severely sunburnt. That night she became a little delirious and was uncharacteristically incontinent; this incontinence persisted. The next day she was found sitting in bed with arms out stiff and staring blankly. A GP review revealed nothing, with a normal urine screen. Over the next month she became progressively quieter until she became mute. She also became apathetic and lost interest in her craft activities and watching DVDs. This progressed on to the girl struggling to dress herself, and appearing confused.

Thorough neurological investigation for a progressive neurocognitive decline revealed nothing, including an EEG which was normal, and MRI which showed non-specific findings. Her course was somewhat fluctuating, recovering approximately 40% of her function before deteriorating again. She had also been eating less and lost some weight. At meals she would not hold her cutlery or would continue to spoon her food into her mouth when her bowl was empty. A differential diagnosis of post traumatic stress or catatonia was considered and she was referred to the Developmental Psychiatry Team approximately 6 months after the initial presentation. Presenting symptoms included [anhedonia](#) (see pg 10), decreased appetite, hypersomnia. She had mutism, withdrawal, immobility, bizarre posturing, muscle stiffness, waxy flexibility, extreme slowness, stereotypies, and was getting stuck in doorways. She was thought to have had seizure activity, for example, going stiff in her limbs following nocturnal [enuresis](#) (see pg 10). She was attentively cared for by her family. On examination, she had marked motor retardation and had a halted, slow, wide-based gait. She whispered inaudible words in the consultation and didn't respond to questions. She had waxy flexibility and mild increased muscle tone. She drew a few small indistinct pictures and was eventually able to write her name. She appeared to respond to unseen stimuli. There was no access to her internal mental state but she did laugh to herself regularly, out of context. It was not possible to assess her cognitive skills.

The girl was diagnosed with a psychotic disorder with catatonic features and started on olanzapine 2.5mg three times daily (tds), adding 0.5mg lorazepam tds a week later which was increased to 1mg tds two weeks later. There was clear improvement of about 35%, with the girl becoming more mobile, verbal and interactive but still extremely impaired. The olanzapine was changed, due to marked weight gain, to aripiprazole increasing from 5mg to 10mg and finally 15mg. She continued to slowly improve to 45% functional gain. On the assumption that lorazepam was a short term treatment, it was withdrawn after 6 weeks but there was an immediate deterioration back to a 20% gain and it was promptly restarted. However, her previous progress was not recaptured. Accordingly, 6 weeks later fluoxetine was added gradually, increasing from 5mg to 20mg.From this point, she made slow and steady improvement. The girl was able to restart school, began to slowly re-engage with peers and other family members, and she regained her pre-morbid personality with an increase in happiness and cheekiness. She became more relaxed and more able to contribute to the clinical interview. Her full recovery took 9 months from mental health presentation.

Description

Catatonia is a state of apparent unresponsiveness to external stimuli in a person who is apparently awake. It is a potentially life-threatening neuropsychiatric syndrome characterized by a variety of behavior and

movement traits. The individuals often can't provide a coherent history and family members describe the typical primary features including: immobility, stupor, posturing, rigidity, staring, grimacing, and withdrawal. The behavioural history includes mutism, negativism, echopraxia, echolalia (see pg 10), waxy flexibility and withdrawal. It also involves stereotypies, mannerism, verbigeration (stereotyped repetition of words or phrases) and rarely priapism. Patients are often immobile, mute, grimacing, posturing, rigid and refusing to eat or drink.

Alternatively, catatonia can present as an excited state possibly with impulsivity, combativeness and autonomic instability. This excited state is often short lived and not reported by family members. The excited state is often associated with bipolar disorder. Psychomotor manifestations of catatonia, when analysed by latent class statistics divided into four classes: withdrawal, automatic, repetitive and agitated/resistive.

Catatonia is difficult to differentiate from diffuse encephalopathy (see pg 10) and non-convulsive status epilepticus . Since I trained its status has **changed from a dramatic presentation of 'non**-verbal psychosis' to a broader neuropsychiatric disorder. Its presentation is observed in a wide variety of disorders with a considerable differential diagnosis and an urgency to identify treatable medical conditions.

Associated Medical Conditions
An initial interview with a patient must consider precipitating events including infection, trauma and exposure to toxins and other substances. In the emergency department treatable common causes need to be rapidly considered, including neuroleptic malignant syndrome, encephalitis, non-convulsive status epilepticus and acute psychosis. Comorbid disorders include affective disorders (46%), schizophrenia (20%), schizoaffective disorder (6%), psychological stressors, medical, neurological and obstetric conditions (16%), benzodiazepine withdrawal (4%) and other psychiatric disorders (8 %). It can be caused by various drugs such as levetiracetam, levofloxacin and rimonabant. Nine to fifteen percent of patients admitted to an acute care psychiatric service meet criteria for catatonia. The medical causes are varied, including neurological disorders (e.g., frontal tumour, petit mal epilepsy, metabolic disorders (including porphyria and ureamia), endocrine disorders (e.g., hyperparathyroidism), autoimmune disorders (e.g., systemic lupus erythematosus), intoxications (e.g., organic phosphates, carbon monoxide), and drug treatment (e.g., neuroleptics, disulfiram).

Treatment
One of the most dramatic clinical phenomena is the response of catatonia to treatment with benzodiazepines. In fact, catatonia has been conceptualized as a GABA (gama amino butyric acid) deficiency state. Within three hours of receiving lorazepam 1-3mg sublingually or intramuscularly, the majority of patients enjoy complete release from their frozen state (80% affective states, 70% schizoaffective, but less with schizophrenia). Some standardise the lorazepam test to last for 5 days. Electroconvulsive therapy (ECT) is the second line treatment. Case examples in the literature describe those that died, the life saving capacity of ECT in those that failed to respond to lorazepam and other psychotropics, but also how occasionally heroic doses of lorazepam and lorazepam for up to a year may be needed.

Literature review
Although Kahlbaum first described catatonia in 1874, his work was only translated into English in 1973. Kreplin included catatonia in his description of Schizophrenia or dementia praecox in 1896. Autism was first described in connection with schizophrenic **negativism by Bleuler in 1910, although Kanner's** description of autism was not published till 1944. The identification of catatonia as a distinct condition has

only occurred in the last 20 years, with factor analysis studies using reliable rating scales. Modifications of diagnostic categories in DSM-5 (APA, 2013) emphasises the importance of medical/neurological disorders.

Catatonia in ASD/ID

Catatonia is significantly associated with Autism Spectrum Disorder (ASD) and intellectual disability. The longitudinal study of ASD by Lockyer and Rutter (1970) found that 12% of the subjects showed neurologic regression marked by loss of language skills, inertia and intellectual decline accompanied in many cases with onset of seizures.

Wing and Shah (2000) did a diagnostic study of Catatonia in ASD, in which of 500 presentations to their ASD service, 17% (n=30) of those aged between 15-50 were diagnosed with catatonia which constituted 6% of all presentations. Their findings included:

- *Onset:* The age of onset for the vast majority (23) was between 10-19 years. A further eight had intermittent episodes, sometimes in only one setting such as school. In 15 individuals, the onset was immediately preceded by a period of very disturbed, often aggressive behaviour. Eight individuals developed obsessive-compulsive symptoms before they became catatonic. Six of these were among those who had shown disturbed, aggressive behaviour before the onset of catatonia.

- *Precipitating factors:* Possible precipitating factors were suggested for another 13 including bereavement, pressure at school, lack of structure after leaving school, and lack of occupation. These individuals did not communicate their feelings about these events and the connection with the onset of the catatonia was made by the parents or other caregivers.

- *Course:* Three individuals experienced a slow but steady deterioration in mobility and practical skills, 17 had a steady course once the catatonia was established, while four had shown minor and six

had shown major fluctuations in severity.

- *Abnormalities of movement:* Most of the abnormalities of movement resulted in slowing or stopping activities, but episodes of excitement and sudden impulsive actions also occurred. Some could not stop actions once started. Incontinence resulted when the individual concerned did not initiate the movement needed to reach the toilet.

- *Other behaviours:* 12 individuals showed bizarre behaviour that could not be classified under other headings. For example, two individuals would never use one arm and hand (the left in one case and the right in the other), although no physical reason could be found. One man walked the same route to the same destination each day in order to stand motionless, staring for 2 hours at a spot where a building used to be before it was pulled down. Others had occasional visual hallucinations or paranoid ideas that did not fit any particular diagnosis. According to the accounts given by relatives or carers, none had ever had the first-rank symptoms of schizophrenia.

- *Communication skills:* All subjects showed abnormalities of speech, but these were indistinguishable from those found in autistic disorders. The quantity of speech was in all cases markedly reduced or absent when catatonia was present. Catatonia was seen more often in those who had impaired expressive language, and those who were passive in social interaction, before the onset of catatonia. Within the group of those who developed catatonia, however, the number of catatonic features and the degree to which the catatonia limited everyday activities had no significant relationship to expressive language ability or type of social interaction.

- *Level of intellectual disability:* Catatonia was found slightly more in those with profound or severe intellectual disability, although there was no significant association.

The main limitation of this fascinating clinical cohort is the lack of any account of treatment. Wing and Shah

(2000) considered these were manifestations of a motor/neurological disorder akin to an extrapyramidal disorder or parkinsonian syndrome or even comparing the features of encephalitic lythargica (caused by the influenza epidemic in the 1920s). Their findings emphasized the frequency in children and adolescents.

Catatonia in children and adolescents
Ghaziuddin and colleagues (2012) did a retrospective case review of 'high risk' child and adolescent psychiatric patients at a university hospital and found 17.8% met criteria for catatonia. Their selection of high risk cases included pervasive developmental disorder, psychosis not otherwise specified, intermittent explosive disorder, mental retardation, catatonia and neuroleptic malignant syndrome. The study's defined criteria were three or more of the following: unexplained agitation/excitement, disturbed or unusual movements, reduced movements, repetitive or stereotyped movements, or reduced or loss of speech. This was a strict criterion as DSM-IV (APA, 2000)only required two symptoms.

Analyses of the findings from the Ghaziuddin, Dhossche, & Marcotte (2012) case review revealed that only two out of their 18 cases were diagnosed by their treatment providers at the time, whereas others didn't receive the recognised treatment. Those identified in the study with catatonia who weren't diagnosed at the time included those presenting with pervasive developmental disorder, mental retardation, psychosis-NOS, intermittent explosive disorder, and neuroleptic malignant syndrome. Aggression was a common presentation in both those with catatonia and those without. Stereotyped or repetitive movements were poorly documented. Psychomotor retardation was less prominent than agitation/excitement, which should be considered a hallmark symptom. Males and previous use of antipsychotics were associated with catatonia, but there was only one case of schizophrenia in the series which was in the non-catatonic group.

The implications of the study are that catatonia is frequently missed, rarely treated with benzodiazepines, and CPK and EEGs are rarely performed. The agitated form of the catatonia is more frequent than the the classical motor retardation form. Although this study was limited by being a retrospective chart review, it does suggest that catatonia is not rare in child and adolescent psychiatry. In the 1980s catatonia was thought to be almost extinct , but recent adult prospective studies suggest that there is a prevalence between 7-17% in acute admission with affective or psychotic disorders. Identification can be increased with familiarisation with commonly used rating scales such as the Bush Francis Catatonia Rating Scale (Bush,

et al., 1996), the Bräunig Catatonia Scale (Bräunig, et al., 2000) or the Northoff Catatonia Rating scale (Northoff, et al., 1999), that can measure change in symptoms. Catatonia needs to be separated diagnostically from psychosis and schizophrenia, as it is more associated with ASD and developmental disorders. It is also in the differential diagnosis of presentations of aggression or increasing obsessive/repetitive behaviour.

DSM-5
DSM -5 (APA, 2013) diagnostic criteria requires three of the following the symptoms: Stupor, negativism, waxy flexibility, posturing, mimicking others' speech or movement, lack of response, agitation, grimacing, catalepsy, repetitive movements, echolalia, echopraxia. Although in DSM-5 (APA, 2013) catatonia remains a sub-specifier of psychosis and affective disorder, it has added a category of 'unspecified catatonia' which aims to increase the recognition in paediatric patients, on top of catatonia associated with another mental disorder, and catatonia associated with another medical condition (Dhossche, Goetz, Gazdag, & Sienaert, 2013).

"Catatonia is significantly associated with Autism Spectrum Disorder (ASD) and intellectual disability..."

Catatonia in paediatric patients
In paediatric patients catatonia can be associated with:
- *Developmental disorders:* ASD, childhood disintegrative disorders, intellectual disability of any cause, and Prader-Willi Syndrome.
- *Medical and neurological disorders:* A general medical condition (e.g., brain structural damage), seizures, metabolic, endocrine, and autoimmune disorders.
- *Psychiatric Disorders:* Psychotic disorders, mood disorders, substance-induced disorders, medication-induced movement disorders, tics and Tourette's Disorder.
- *Other disorders:* NMDAR encephalitis, paediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS), other aseptic encephalitides, Kleine-Levine syndrome, anaclitic depression and pervasive refusal disorder.

Catatonia may be more common in paediatric patients than realized. Prospective studies have found

catatonia in 12% of those with ASD, or 18% in psychiatric clinics, or in 33% in a retrospective study of first break adolescent psychosis. Benzodiazepines and ECT, including maintenance ECT are considered safe and effective in paediatric treatment. The range of aetiology indicates the extent of a medical work up that is required. Neuroleptics should be considered with caution because of the risk of Neuroleptic Malignant Syndrome. Although the lorazepam test is helpful, ECT may still be needed, even for a maintenance treatment. The concept of unspecified catatonia aims to draw attention to catatonia in milder mental disorders, and as a side effect of medications especially in the context of neuroleptic malignant syndrome, or where an associated condition is not identified and to support further research.

The diagnosis is under recognized because of unfamiliarity with the diagnosis, diagnostic overshadowing, where the symptoms are attributed to another condition such as ASD or neurodevelopmental disorders, segregation of mental health patients from mainstream medicine, perceived lack of effective treatment for catatonia, and the neglect of physical and neurological examination by child psychiatrists. Conversely the psychosocial contributors tend to be ignored such as deprivation, abuse or trauma, and labeled anaclitic depression or quasi-autism, reactive psychosis, dissociative disorders or pervasive refusal syndrome. This is then followed by the ambivalence to treatment with high-dose benzodiazepines or ECT. Under treatment or failure to treat, sometimes from legal barriers can have high costs for the patient.

> *"The diagnosis is under recognized because of unfamiliarity with the diagnosis, diagnostic overshadowing, where the symptoms are attributed to another condition such as ASD or neurodevelopmental disorders.."*

Investigation should include: 1 Full blood count, 2 Renal function tests 3 Liver function tests, 4. Thyroid function tests, 5 Blood glucose measurement, 6 Creatine phosphokinase measurement, 7 Drug screen of urine. Further investigations depending on findings on physical examination include: 8 Electrocardiography, 9 Computed tomography, 10 Magnetic resonance imaging, 11 Electroencephalography, 12 Urine culture, 13 Blood culture, 14 Test for syphilis, 15 Test for HIV, 16 Heavy-metal screen, 17 Auto-antibody screen, 18 Lumbar puncture (Rajagopal, 2006).

The mechanisms of catatonia

The exact cause of catatonia has not been elucidated, but a number of hypotheses have been offered (Rajagopal, 2006). These include a '**top**-down **modulation' of basal ganglia due to deficiency of** cortical gamma-aminobutyric acid (GABA), the primary inhibitory neurotransmitter of the brain. This explanation might account for the dramatic therapeutic effect of benzodiazepines, which cause an increase in GABA activity. Similarly, hyperactivity of glutamate, the primary excitatory neurotransmitter, has also been suggested as an underlying neurochemical dysfunction.

Alternatively, catatonia may be caused by a sudden and massive blockade of dopamine, explaining why dopamine-blocking antipsychotics are not generally beneficial in catatonia. Indeed, antipsychotics may actually precipitate a worsening of the condition by exacerbating dopamine deficiency. Clozapine-withdrawal catatonia is postulated to be due to cholinergic and serotonergic rebound hyperactivity.

In chronic catatonia with prominent speech abnormalities, positron emission tomography (PET) has identified abnormalities in metabolism bilaterally in the thalamus and frontal lobes. One interesting hypothesis suggests that catatonia may be understood as an evolutionary fear response, where **catatonic stupor may represent a common 'end-state'** response to feelings of imminent doom, originating in ancestral encounters with carnivores whose predatory instincts were triggered by movement. This response, of remaining still, is now expressed in a range of major psychiatric or medical conditions.

Conclusions

Catatonia is a not-uncommon and treatable condition that can have an acute or acute on chronic presentation in emergency medicine, in developmental and general paediatrics, and in child and adolescent psychiatry. The four subtypes include withdrawal, automatic, repetitive and agitated/resistive. Assessment includes consideration of a range of serious medical and neuropsychiatric disorders, and lorazepam 1-3mg IM can help as a diagnostic test. Of psychiatric causes, mood disorders are more common than schizophrenia. Amongst the

difficult to diagnose and treat adolescent presentations in developmental psychiatry, we need to actively look for and provide the test treatment for catatonia. Does the frequency of catatonia in ASD reflect difficulty in communicating subjective mental phenomena and difficulty in diagnosing comorbidity? However, with the availability of SSRIs and greater sensitivity to identifying depression in ASD, I wonder whether we see catatonia less frequently than the literature might suggest?

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Glossary of Terms

Anhedonia [an"he-do´ne-ah]

inability to enjoy what is usually pleasurable.

Enuresis [en"u-re´sis]

a type of urinary incontinence, usually referring to involuntary discharge of urine during sleep at night (*nocturnal enuresis* or bed-wetting)

Echopraxia [ek"o-prak´se-ah]

stereotyped imitation of the movements of another person; seen sometimes in catatonic schizophrenia and Gilles de la Tourette's syndrome.

Echolalia [ek"o-la´le-ah]

stereotyped repetition of another person's words or phrases, seen in some cases of schizophrenia, particularly in catatonic schizophrenia, in Gilles de la Tourette's syndrome, and in neurological disorders such as transcortical aphasia.

Encephalopathy [en-sef"ah-lop´ah-the]

any degenerative disease of the brain.

Reference:

Miller-Keane Encyclopedia and Dictionary of Medicine, Nursing, and Allied Health, Seventh Edition. © 2003 by Saunders, an imprint of Elsevier, Inc. All rights reserved.

http://medical-dictionary.thefreedictionary.com/

The Medicine Cabinet:
Some Medicines Don't Mix

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Interactions between drugs can have desired, increased, reduced or unwanted adverse effects. The probability of these interactions increase with **each medication added to a person's treatment** regime. Medications taken can include prescription medication, complementary or alternative medicines (CAM) and pharmacy medicines. Pharmacy (or over the counter) medication is medication purchased in a community pharmacy, does not require a prescription, and is often recommended by the community pharmacist, medical practitioner, allied health clinician or anybody else. Complementary or alternative medicines include:

- natural and herbal medicines
- alternative or holistic remedies
- traditional remedies
- homeopathy
- aromatherapy oils
- vitamins and minerals (although these can be part of medical treatment too).

People assume that taking medications will make them better or help with a specific health issue for which they were prescribed, but sometimes medications cause adverse effects (see previous article in Journal of Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities: An Educational Resource Volume 6 issue 1). When a person is already taking medication, adding an additional prescription, pharmacy or over the counter medication, or CAM preparation may have beneficial effects but the interactions between them may also cause increased adverse effects or even serious side effects.

When a patient is being treated by one medical specialty team it is important that all professionals **who are involved in the patient's treatment are** informed about changes in medication regimen (e.g., changes in doses or types of medications). This is important for people with intellectual or developmental disabilities and/ or autistic spectrum disorder (ASD) who may be taking a number of different medications, and may also be treated by numerous health professionals, all of who may have a different perspective on the use of medications.

> *"Medication changes should not be considered in isolation but in the context of the whole clinical picture to minimise adverse events."*

Medication changes should not be considered in isolation but in the context of the whole clinical picture to minimise adverse events. Medications are eliminated from the body in many different ways. Accordingly medications can compete with each other and may also be affected by diet. The lack of clinical trials of combinations of medications also adds to the complexity. Further, several individual medications may need to be trialled to establish a suitable regimen. Even a stable regime can be upset due to subtle interactions occurring between the medications or due to other factors such as illness. However there are some examples in the literature where several medications, for example for high blood pressure, minimises the side effects and have mutually additive effects to improve management.

Drug interactions occur at two levels, that is at pharmacokinetic or pharmacodynamics levels.

Pharmacokinetic interactions occur through the absorption, elimination and metabolism of the drug. Pharmacodynamics interactions are the additive or antagonistic effects of medication at the cellular receptor site.

Metabolism Interactions (body interacting with medication)
Interactions affecting medications can be caused by the competing nature of metabolic enzymes in the body. All medications are xenobiotics or foreign chemical substances to the body, and are predominantly metabolised by the enzymes in the liver called CYP450 enzymes (CYP450 is named cytokines identified by the X-ray crystallography at a wavelength of 450). These enzymes are being closely studied but as yet only some can be identified by their genetic profile. These genetics are used to identify drug metabolism patterns, for example, poor, extensive and ultra-fast metaboliser. The genetics have been established for 2D6 and 2C19 isoenzymes but the main metabolising enzyme for most pharmaceuticals is 3A4; for which the genetics have not yet been established but for which variation between people has been recognised.

When medications are metabolised by these isoenzymes, there may be natural competition in the metabolism. Medications can be inhibitors or inducers of the isoenzymes and thus affect another **medication's metabolism. A common example of** this is carbamazepine (Tegretol®, Teril®) and erythromycin, whereby as the blood levels of carbamazepine are increased, the effectiveness of the erythromycin given in combination is decreased. Another example is the interaction between lamotrigine and the oral contraceptive pill. Stopping the oral contraceptive pill increases the lamotrigine level by 33%, and the dose should be reviewed to avoid side effects.

Grapefruit and its juice is a food example of this interaction, and is oftenindicated by this auxillary label that may be attached to prescription medications. Grapefruit juice contains a number of polyphenolic compounds including flavanone naringin and furanocoumarins which inhibit the metabolism of CYP3A4, leading to increased blood levels of some medications. The effects of grapefruit juice on the metabolising enzyme can last up to 24 hours.
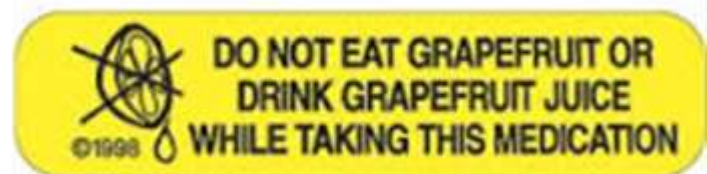
Pharmacodynamic Interactions (medication affecting the body systems)
Medications can interact with bodily functions. For example, clonidine and quetiapine or olanzapine given together can cause an increase in the sedation, dizziness and a drop in blood pressure. Other medications when given in combination can increase the risk of urinary retention or an increase in dry mouth, for example when amitriptyline and olanzapine are given together.

SSRI antidepressants can interact with St John's Wort, a herbal product known to be helpful in mild depression. This combination can lead to serotonin toxicity, which if severe, can be fatal.

Continuing medicines no longer prescribed

As a person's health condition changes, or when new treatments become available, it is important to follow the advice of the treating doctor and the recommended medication regime. Changes in the medication regimen from the original could lead to new adverse effects. As always, changes should also be shared with all the **healthcare professionals involved in the person's care.** This also involves making sure the community pharmacy managing the prescriptions is aware of the changes so that accidental dispensing of ceased medications does not happen which could cause both financial and medical damage. This is especially important if the patient/carer has signed up for automatic or courtesy refills.

Tips to prevent interactions between drugs

- Tell all health professionals about the medications and complementary products that are being taken. An easy way to remember them all is to have them stored on Medicines App (see the example below).

- Make sure everyone is aware when there are changes in the types of medications or doses.

- When switching between medications make sure that the plan is understood and adhered to, so that one medication is ceased when another is started. Too many medications in the same class may lead to many adverse effects.

- Dispose of unused or no longer required medications so that they are not taken or given by mistake.

- If unsure about changes in medication, consult the prescriber and make sure that they have shared this information with all professionals or teams involved.

- Refer back to the GP if experiencing new symptoms or sudden health changes as these could be medication related.

Other resources:

From ISMP newsletter Safe medicines accessed 16/2/17 http://www.ismp.org/newsletters/consumer/showarticle.aspx?id=19

SafeMedicationUse.ca – **Some Medicines Don't mix** accessed from www.safemedicationuse.ca accessed 16/2/17

http://www.nps.org.au/topics/how-to-be-medicinewise/side-effects-interactions accessed 22/2/17

http://www.nps.org.au/topics/how-to-be-medicinewise/using-complementary-medicines accessed 22/2/17

Grapefruit juice https://www.fda.gov/ForConsumers/ConsumerUpdates/ucm292276.htm accessed 28/2/17

Say Less Show More: Visuals improving health care delivery

Dr Jacqueline Small

Developmental Paediatrician

Children and adults with intellectual disability (ID) and other developmental disabilities (DD) experience significant barriers to accessing the healthcare system, yet have higher rates of many treatable health conditions compared to the mainstream population (Williams, et al., 2005; Ackland & Wade, 1995). The health disparities continue through the lifespan with adults with ID experiencing premature mortality and over-representation of potentially avoidable deaths (Trollor,Srasuebkul, & Howlett, 2017). There are many factors contributing to this, with a key issue being communication barriers between patients and health professionals.

Augmentative and alternative communication strategies (AAC) are widely used outside healthcare settings to assist communication with children with ID/DD. Parents of children with ID/DD recognise that their child often finds it difficult to know what is expected in healthcare, and that visuals would make it easier for their child to share "a story" with his/ her nurse or doctor.

Say Less Show More visuals were developed in response to the limited resources and skills in supporting children with disabilities in healthcare. They also acknowledge the growing expectations that all children will be supported to access mainstream services in line with the National Disability Insurance Scheme (NDIS).

Intersectoral partnerships critical to project success

At the outset of this project, creating and sustaining effective and relevant partnerships across professionals and agencies has not only brought together a relevant mix of skills and expertise for this project, but it has also demonstrated a genuine and shared responsibility for improving health services for children and young people with disabilities. Parents of children with disabilities have also provided valuable guidance and feedback for each stage of this project. Key members of the team have included professionals from: the Disability Specialist Unit and Emergency Department (ED) from the Children's Hospital at Westmead; Agency for Clinical Innovation - Intellectual

Figure 1: SLSM team wins Judges Choice Award at SCHN for Implementing Evidence Based Practice

Disability Network; Lifestart Early Childhood Intervention and School Age Services; and, Ageing, Disability and Homecare (NSW Family and Community Services). Members of the team can be seen in Figure 1.

Introduction of Visuals to a Paediatric Emergency Department

Three sets of visuals were developed and included: Taking blood/putting in a cannula, physical examination, and seeing the dentist. The visuals were introduced to a paediatric emergency department following staff training that was undertaken by a clinician who had been specifically trained by a specialised speech pathologist. This training involved exposure to visual use in the community sector and instruction from the speech pathologist. The clinician trainers were supported by a PowerPoint presentation that provided background information about communication difficulties for children with ID/DD, and the role of AAC. Training utilised coaching, positive reinforcement and other strategies to encourage staff to use the visuals in clinical practice in the ED.

> **"Improving communication between clinicians and children with ID/DD would address one of the widely recognised barriers to good healthcare."**

Evaluation of both the training and impact of visuals was undertaken. The training was found to be beneficial. A staff member noted that the training, "*Makes you more aware of the needs of children with disabilities & how we can help them with their* **hospitalisation experience".** It was also noted that after even a short training session, staff felt a reasonably high degree of confidence in using the visuals. Staff found the visuals to be easy to use and often quite helpful, as one staff member said, "*I was sceptical of the benefit of this tool; we cannulated a child presenting with behavioural issues who was stressed about procedure; the tool completely calmed the child*". *Another staff member commented, "Tool used effectively for mental health patient who was refusing procedure and then agreed to procedure after tool".* Carers also reported that the visuals were appealing and welcome, with one carer saying, "*Thank you for helping make him understand the process. Very happy!*"**.**

Figure 2: SLSM elearning module is part of the SLSM online resources

Say Less Show More: Accessible tools for health professionals

Say Less Show More visuals are likely to be of benefit in all health care settings such as primary care. A suite of resources are now available online at: https://www.aci.health.nsw.gov.au/resources/intellectual-disability/childrens-services/say-less-show-more. These resources include a training module, the three sets of visuals, and tip sheets for health professionals who wish to individualise or personalise the visuals for their own contexts (Figure 2).

Improving healthcare: Time for change

Given the persisting health disparities, the ongoing difficulties that children experience when they see a health professional, and the justified expectations that children with ID/DD will receive high quality healthcare, it is time for health services to provide the necessary resources and ensure health professionals are trained. Improving communication between clinicians and children with ID/DD would address one of the widely recognised barriers to good healthcare and increase inclusion in mainstream healthcare.

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Tips to develop your own visuals

Say Less Show More

It's easier than you think to develop your own visuals. Here are some simple tips to make visuals for use **with your patients. Remember when using visuals it's** important to involve both the child and their carer:

- Use a mobile device, e.g. smart phone or tablet with a camera to take photos of each step of a common routine or procedure. Share these pictures by scrolling through them to show what will happen step by step.

- Use the internet to search for images of unfamiliar places e.g. hospitals or procedures.

- Show the pictures and talk about what they can expect to happen.

- Use a notepad and pen to draw some simple pictures and talk about what may happen.

- Some children may be able to read simple words or sentences.

Use computer programs such as Microsoft Powerpoint or Word to cut and paste photos into a story.

Some programs and applications that help you make visuals

There are several applications that can be used to create and share visuals on a smart phone or tablet device. Many applications will allow you to print the story to share.

- Special Stories (iPad and Android devices) specialiapps.org/en-gb/special-stories.html

- I Get... Going to the Hospital (iPhone and iPad only) igetitapps.com/app/i-get-going-to-the-hospital

- Social Stories (iPhone and iPad only) pufferfishapps.com

Some websites that have visuals to download and use

- Taking the Work out of Blood Work. A guide to blood draws for children with ASD vkc.mc.vanderbilt.edu/asdbloodwork/

- Widgit Health. A range for resources to support communication in healthcare. www.widgit-health.com

I want to be a ballerina

Reading List

Mahoney-Davies, G et al (2016). An evaluation of the effectiveness of a 'Five Ways to Well-being' group run with people with learning disabilities. *British Journal of Learning Disabilities:* November 2016

Aubrey Hui Shyuan Ng, Kim Schulze, Eric Rudrud, and Justin B. Leaf (2016) Using the Teaching Interactions Procedure to Teach Social Skills to Children With Autism and Intellectual Disability. *American Journal on Intellectual and Developmental Disabilities*: November 2016

Larue, C., Goulet, M.-H., Prevost, M.-J., Dumais, A. and Bellavance, J. (2016), Identification and Analysis of Factors Contributing to the Reduction in Seclusion and Restraint for a Population with Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*: December 2016

Malovic, A., Murphy, G. and Coulton, S. (2016), Finding the Right Assessment Measures for Young People with Intellectual Disabilities Who Display Harmful Sexual Behaviour. *Journal of Applied Research in Intellectual Disabilities:* November 2016.

Bridgette L. Tonnsen, Andrea D. Boan, Catherine C. Bradley, Jane Charles, Amy Cohen, and Laura A. Carpenter (2016) Prevalence of Autism Spectrum Disorders Among Children With Intellectual Disability. *American Journal on Intellectual and Developmental Disabilities*: November 2016.

Katherine M. Walton (2016) Risk Factors for Behavioral and Emotional Difficulties in Siblings of Children With Autism Spectrum Disorder. *American Journal on Intellectual and Developmental Disabilities:* November 2016.

Hindmarsh, G., Llewellyn, G. and Emerson, E. (2017), The Social-Emotional Well-Being of Children of Mothers with Intellectual Impairment: A Population-Based Analysis. *Journal of Applied Research Intellectual Disabilities, 30: 469–481.*

Book Review:"Interventions for Autism: Evidence for Educational and Clinical Practice"

Phil Reed, Professor of Psychology, Swansea University, 2016. Published by Wiley Blackwell (1-360pp).

Reviewed by Associate Professor David Dossetor,
The Children's Hospital at Westmead
Area Director for Mental Health
Child Psychiatrist with a Special interest in Intellectual Disability

The treatment of ASD raises significant controversy in research and service provision at a time when awareness of ASD has reached a new peak. This comes with the establishment of a world-first Autism Cooperative Research Centre in Australia in 2013, and government funding for early intervention in 2008 which is currently transitioning to the National Disability Insurance Scheme. It is therefore timely for a comprehensive review.

Setting the scene

Reed (2016) had the view that it was changes in criteria and greater skills in identifying ASD that led to the massive increase of ASD diagnoses (from 5/10,000 to 100/10,000). He reported that there was evidence to suggest that the new DSM5 criteria has reduced the number of people with ASD by 30%, with other cases falling into alternative diagnoses. ASD has huge economic costs, possibly somewhere between one to 25 billion pounds in the UK per annum, with the lifetime cost for an individual between two and four million pounds. However, such costing depends highly on assumptions of lost earnings and care costs. De-institutionalisation has shifted the cost to the informal care of the family. Intensive early intervention Applied Behaviour Analysis (ABA) can cost up to one million US dollars. Others have suggested that ABA intensive treatment **saves money spent on 'treatment as usual' of** 11,000 UK pounds a year.

Prognosis has changed with this widening of diagnostic criteria. Older studies suggested that 50% of people with ASD were institutionalized 10 years after diagnosis. More recent data has suggested that those with good outcomes have increased from 10% to 20%. Of those with an IQ of 110 or more, 50% now achieve independence. The **50% 'cure' reported by Lovaas, the founder of ABA,** has been disputed by subsequent researchers. Reed (2016) divided treatments into behavioural approaches, environmental systems approaches, and developmental approaches. The evidence did not support the notion of cure but improvement.

Strength of evidence has its criteria and the best studies are characterised by independent, blinded assessors of diagnosis and change, randomised

allocation design (i.e., RCT), a range of measures with blinded assessors, and assessment of the fidelity of intervention. Fifty four percent of acceptable studies were behavioural; 10% used facilitated communication. Part of the problem is that children with ASD are exposed to multiple interventions at one time, which range between 4.5 to 8.7 interventions for different levels of severity. Studies can be divided into randomised control trials (RCTs), control studies and observational studies with a trade-off between methodology and approaches to overcome potential selection bias. RCTs and control studies enable the comparison between two interventions, yet may select for a homogenous group with ASD. However, the real world also includes pre-existing interventions. Observational studies have the ability to include two or more interventions over a greater time span.

Is ASD a unitary disorder?

Reed (2016) raised a number of issues that related to this question, such as what are the core symptoms of ASD when DSM5 has reduced the essential criteria from a triad to a dyad of problems, putting communication together with socially impairing symptoms? Is Social Communication Disorder distinct from ASD? The DSM5 clusters five DSMIV disorders into one. Surely the clinical knowledge of Disintegrative Disorder of Childhood has a value, but it has now been clustered with ASD with the inclusion of late onset ASD.

Sensory responsiveness problems are now recognized as a core part of the disorder. Should level of IQ or intellectual disability be taken into account? Should co-morbidity be taken into account? Seventy percent of people diagnosed with ASD have one psychiatric co-morbidity and 40% have two psychiatric comorbidities. Disorders that occur more commonly in people with ASD than in the general population include: ADHD, Anxiety, Disruptive Behaviour Disorder, Depression, Intellectual Disability, Motor Coordination Disorder, Schizophrenia and sleep disorders. Does that mean these comorbidities are part of the ASD phenotype? How should the problems of assessing internalising disorders in lower functioning individuals be addressed? Reed reviewed the psychometric properties of different diagnostic instruments, and their limitations in assessing the whole phenotype.

Reed (2016) divided theories of ASD into *within-person* and *environmental*. A *within-person theory* included high-level and low-level theories (although perhaps it would be more descriptive to call it an

interpersonal model). High level theories include emotional recognition skills and deficits of theory of mind. However, these deficits are also found in other disorders such as schizophrenia. Baron Cohen, a leading figure in ASD research, added the male brain theory and the influence of testosterone on pattern recognition versus emotional recognition. Interventions challenging one or other **deficit don't have strong evidence. However, some** intervention approaches such as social stories have resulted from recognising these problems.

> "*Seventy percent of people diagnosed with ASD have one psychiatric co-morbidity and 40% have two psychiatric comorbidities.*"

Low-level theories look at cognitive processing and identifies problems at every point. This includes difficulties with eye gaze, attention, memory, executive control and retrieval problems, with notions such as weak central coherence and executive dysfunction (i.e., planning, impulse control, working memory, behavior inhibition, flexibility and action monitoring, and a weakness in 'delayed rule-shift' skills). **However, these cognitive** processing problems are also all found in schizophrenia and acquired brain injury. The diversity of findings in low level measures between individuals makes it difficult to consider a unitary concept with some researchers saying that there can be no unitary disorder.

The environmental or learning-social and behavioural theories derive from Soviet Psychology. They focus on the development of behaviours, with theories of conditioned stimulus and response, progressing onto unconditioned stimulus and response as an explanation for perseverative behaviours. Linked to this was the notion of abnormal attentional focus and abnormal attachment behavior like imprinting behavior in birds described by the Tinbergens. The strength of this theory has been in its evidence from using operant behavioural conditioning to change behavior and develop language. This contrasted with the within-person theories which lacked a unitary model, from which it was difficult to provide clear effectiveness.

Overview of Interventions

Reed finished his book with an overview of interventions, that is, *what is known about what works*. While ABA proponents suggested that ABA was the best, there were those who said that it was ineffective. The question is really this: *How does ABA fit in with a wider range of approaches?* Reed summarised the impact of: 1) Behavioural (e.g. ABA); 2) Environment – alterations/systems (e.g., TEACCH, the treatment and education of children with ASD and related communication disabilities); 3) Developmental (e.g., Early Start Denver Model, (ESDM)); 4) Sensorimotor (e.g., sensory integration and massage); and 5) Eclectic treatments. Lastly Reed looked at the educational evidence for mainstream schooling.

The treatments reviewed were chosen on the range of evidence available for them, and the extent to which they were well known. However, these treatments had many overlaps. For example, pivotal response training and functional analysis to determine individualised components of learning or behavior occur in many programs. Both behavioural and developmental approaches discuss developmental steps in ASD. The value of comparisons between approaches is to establish best practice, although each approach may not be as different from each other. It was determined that all comprehensive intervention strategies should have: An individualised approach, focus on assumed core deficits, use naturalistic teaching opportunities, and involve professionals and parents.

> "*When research participant characteristics were examined, all intervention types tended to work better with participants who had better language and adaptive social skills.*"

Reed compared treatment across three main domains: 1) intellectual/cognitive; 2) linguistic/ communicative; and 3) adaptive-social behaviours, using pre-post intervention effect sizes. ABA had the strongest effect on intelligence, even if that is not part of the core symptoms. However, there were

effects on all three domains for ABA and ESDM. However, the effects on Adaptive-Social were as large from massage and TEACCH, although data was not as extensive for these approaches. Conversely, the impact on ASD diagnosis was positive in 25% of those treated with ABA, ESDM and developmental treatments. Of concern is that ABA also had 18% of young people that got worse! It must be remembered that most studies were a year long, which is a short time to bring about diagnostic amelioration.

Some of the treatment effect differences may have been related to dose, that is, the number of hours per week of intervention, and the number of months' duration. ABA and TEACCH tend to be more intensive and longer. In general, the longer the duration of the intervention, the more the improvement. However, improvements also become less pronounced the longer the intervention, whilst effects apply more across all three domains. Only ABA and TEACCH had data for two to three years or more. When the intervention was limited to 15 weeks there was a small advantage to behavioural and ESDM programs. One comparative study that looked at treatment intensity in terms of hours per week found that 'Portage' (a home visiting early intervention development enhancing model), and 'special nursery school' (i.e., preschool) had a greater effect with greater hours. However, ABA had a lesser effect as hours increased, possibly because reinforcers, which are generally limited, became less effective. When programs (conducted for up to one year) were compared between those providing one to 19 hours versus those over 20 hours/week it was found that ABA did better on IQ but that there was no advantage on communication or adaptive/social behaviours.

When research participant characteristics were examined, all intervention types tended to work better with participants who had better language and adaptive social skills at the start of intervention. In terms of age, the younger the participants, the greater the gains. This was especially the case for IQ and adaptive-social gains in behavioural programs, but older individuals demonstrated greater adaptive social gains for both developmental and eclectic programs. Curiously, both less and more able individuals (measured by IQ) fared less well for behavioural and ESDM models in IQ and language gains. That is, young people with ASD and higher IQ may do better on programs other than behavioural programs. In two

to four year olds, behavioural programs had more impact on those with more severe ASD symptoms; milder ASD faired similarly well on all programs studied. Accordingly, behavioural intervention was better for severe ASD and/or those who were lower functioning. In the domain of adaptive–social skills, eclectic or school-based programs deliver outcomes that were as good as each other, and behavioural programs may be less optimal.

Delivery by parents or professionals, which was better? IQ outcomes were better with more professional implementation. This applied to outcomes of language for behavioural interventions but there was no difference between environmental interventions, TEACCH or ESDM. Adaptive-social outcomes were better with parent implementation in TEACCH and eclectic programs. Some studies showed less parental effect when they were highly stressed. These parents had greater difficulty engaging in programs, had less effective limit setting, and greater problems of attachment. Conversely, parental involvement may help with understanding their child and the attachment. Parents may benefit from interventions aimed at reducing stress.

Over time the debate should move from "what works" to "what works best for whom?" Overall, *within-person* treatments made little impression compared with treatments that emphasised the 'person's interaction with the environment'. For individuals with severe ASD and those with significant linguistic problems, behavioural approaches were indicated or TEACCH (which has significant ABA embedded within it but delivered for less time per week). However, Reed suggested that there was a law of diminishing returns and that it would be wise to have an exit point from these approaches, and then think more about therapy to improve adaptive-social functioning. Similarly, behavioural treatment of more than 25 hours/week had a law of diminishing returns.

If the individual has less severe ASD or less intellectual impairment, or their needs are largely in the adaptive-social domain, then TEACCH might be the initial choice, or the option to follow on from ABA. In both situations it would be best to place the child in a social setting such as school, with appropriately trained staff and work closely with parents. For high functioning ASD with social anxiety problems, massage therapy could be considered along with other approaches. Reed suggested that it was necessary to be aware of the impact of parental stress, which can increase the need for behavioural interventions.

Summary of the main types of intervention
Some of the main types of interventions presented by Reed (2016) included:

Behavioural interventions:
The original research from *UCLA/ Lovaas' behavioural intervention* was a game changer, but it used a case selection process for the original 40 hour-a-week program. This behavioural approach has now been extended by the Verbal Behaviour Program, which is done at home, and includes using naturalistic situations and pivotal learning. The *Complete Application of Behaviour Analysis to Schools* (CABAS) applies behavioural intervention through the behavior of teachers. Students engaged in the program for two years have shown an increase in IQ from 75 to 100. However, when comparing CABAS to preschool training, it was suggested that ABA improves behavioural problems and hyperactivity, but not emotional problems.

Overall 85% of behavioural studies were effective in controlled studies, but only 25% in RCTs. Such intensive studies tend to have small numbers, and achieve better outcomes with younger children (i.e., under three years old) and children with better cognitive abilities. The best outcomes of behavioural interventions occur for children with normal IQ, although there is improvement for children with a mild ID but poorer outcomes for

children with more severe ID. Similar effects were found for those with better language skills and adaptive behaviour scores. The measures of language and adaptive behavior probably were also associated with severity of ASD. However, this did not mean that older children, or children lacking language skills did not respond to treatment, indeed some seemed to be more responsive to the intervention than others for unknown reasons.

Teaching Environment Modification Techniques (TEMT):
These are mainly represented by *TEACCH* (Schopler & Reichler, 1971), which is characterized by the following: A highly structured learning environment that is adapted to the limitations of the child with ASD and maximises opportunities to learn; highly structured instruction techniques; and provides clear social models.

TEMT approaches, also include *Leap* (Learning Experiences and Alternative Program for Preschoolers and their parents, from Pennsylvania) and *Daily Living Skills Therapy* (Higashi from Tokyo) share qualities in common. They are delivered by skilled professionals (teachers). Environmental input in the school setting is controlled through the physical structure of classroom, schedules and tasks. Interventions are individualised, involve multidisciplinary participation and include parents in treatment. Additionally, they use visual cues, incorporating inclusion and the influence of typically developing peers, and rely on special interests to motivate and promoting self-initiation of communication.
TEMT approaches may also include physical therapies such as music, dance and art therapies. TEACCH is generally effective on the skills it targets, especially in the adaptive-social domain. Again it is generally focused on preschoolers and can have effects across all three target domains of intellectual/cognitive ability, linguistic/ communicative ability, and adaptive-social behaviours. However, there is little evidence that ASD children learn by imitation of normal peers.

Developmental and Parent Mediated Treatment Models:
This is exemplified by the *Early Start Denver Model* (Sally Rogers; UC Davis), which is intended for preschool settings for children aged 12 to 48 months. It is based on a Piagetian model or Vygotskian social-developmental framework of

development and therefore relates to in-person (or interpersonal) models of ASD. Developmental and Parent Mediated Treatment Models focus on enhancing skills in social communication and interactions (including joint attention and imitation), linguistic behaviours and challenging behaviours. These are related to interactions with parents and peers.

Developmental and parent mediated treatment models often address both social and functional communication such as *Social Communication, Emotional Regulation and Transactional Support* (SCERTS; Prizant, et al., 2003). Over time the emphasis on parent mediation of the intervention has become central, facilitated by professional contact. One principle of parent mediated intervention is that treatment goals depend on individual analysis, motivation from building on **child's interests and strengths, using natural** opportunities to teach, and a focus on all attempts to communicate.

> "*Over time the emphasis on parent mediation of the intervention has become central, facilitated by professional contact.*"

Other related programs include *Floortime* (Developmental, Individual-difference, Relationship-based Model (DIR), Greenspan & Weider; www.floortime.org), *Options-Son-Rise* (Kaufman, www.autismtreamentcenter.org); *Relationship Development Intervention*, (Gutstein, www.rdiconnect.com); Hanen More than Words (Sussman, 1999; www.hanen.org); Stepping Stones Triple P (Sanders, www.triplep.net/glo-en/home).

While the whole framework of these interventions may have reasonable evidence individual components, like Pivotal Response Training, does not. Similarly, while there is evidence that parent training helps modify behavior with people with ASD, there is little evidence that it helps ASD per se. Furthermore, in moving from expert therapist intervention to parent intervention, there is a drop in the effect size. However, this difference highlights the problem of providing university-based interventions versus making interventions available to a wider population and geography.

SCERTS is an individualized, multidisciplinary approach that focuses on Social Communication and Emotional Regulation facilitated by Transactional Support. Transactional support refers **to using a child's interest in learning, altering the** environment to maximize learning, and using enhanced techniques such as picture communication. SCERTS is designed around pre-linguistic developmental skills and initially focuses on shared attention and promoting parental **sensitivity to the child's needs and attempts to** communicate. After an initial training workshop, **parents video their child's play sessions and these are used by therapists to improve parents' skills.** Parents implement strategies for 30 minutes each day, hoping to generalize across other daily routines. An RCT showed that individuals improved social interactions and communication, but there was less gain in adaptive-social skills. However, a replication **in a 'local authority' observational study didn't have** strong effects, with little gain in cognitive function or language.

In recent empirical studies of *Floortime,* one study showed no difference to Lovaas, while another longer study showing a large effect size and improvement in social interactions but less in social **emotional functioning, depending on the mothers'** responsiveness.

Hanen More than Words **(MTW) doesn't rely on** spoken language, but social behavior and interactions as forms of communication, which suits children with ASD with delayed language development. Like other interventions, MTW relies on early intervention by parents and carers using natural opportunities to teach. It depends on initial parent training of eight sessions to promote practical strategies. This focuses on enhancing **parental responsiveness to child's attention and** communication attempts, and the number and

quality of parent-child interactions in daily life. It looks at early two-way interaction, conventional communication, social communication and language comprehension. This involves responding to communication attempts, following the child's lead, joint action and play, using positive affect, predictability and structure. The approach uses visual supports and daily routines and activities for teaching. The studies have shown particular improvement in language.

Generally, studies of developmental interventions have been less rigorous and one cannot discriminate effectiveness between these studies. The strength of evidence supporting their benefits come from the validity of the principles of the approaches, the support and experience of teachers and parents and accordingly their ecological and social validity. However, none of the interventions should be dismissed lightly. Earlier evaluations of Developmental and Parent Mediated Treatment Models suggested that there was not much evidence for efficacy, but later reviews indicated effectiveness, especially in language and communication and in developing parenting skills. Pooling results from 42 studies indicated that there was a moderate effect size for improved cognitive function, a moderate to strong effect in communication abilities and adaptive-social behavior was moderate.

Sensory and Physical Stimulation Treatments :
These include sensory integration therapy and massage therapy and tend to focus on externalizing, challenging behaviours or internalizing anxiety. Up to 90% of people with ASD have abnormal sensory reactivity, that is hypo or hyper-sensitivity, and 70% receive some intervention.

Sensory Integration Therapy research suggested that it doesn't improve any area with consistency, although it may have some benefits for social-emotional functioning. A range of Auditory Integration Therapy studies found outcomes at best have been equivocal for ASD. Visual therapies such as ocular-motor exercises, prism lenses and Irlen lenses have even less evidence of value, with best benefit for lenses that correct visual problems! Physical Stimulation Therapies such as holding or squeezing therapy is used in theory for attachment problems and is not specific to ASD. The self-applied 'squeeze machine' described by Temple Grandin, a renowned adult with ASD, applies pressure for five to 15 minutes, although rolling up in a blanket can be used. There was some evidence that the squeeze machine reduced anxiety although it may have reflected that the treatment group had higher levels at outset.

"Generally, studies of developmental interventions have been less rigorous and one cannot discriminate effectiveness between these studies."

There has been a range of massage treatments described, initially with case reports, although Silva and Cignolini have published RCTs using Qigong Massage from Chinese medicine which showed moderate effect sizes on ASD severity, social, behavioural and sensory outcomes, and greater effect with parent led approaches. The latter may lead to improved attachment and limit setting, associated with less hyperactivity, stereotypies and sleep disturbance and not necessarily neurological change. Nonetheless, even if sensory intervention can be helpful, it is not a comprehensive treatment.

Eclectic Interventions:

In reviewing *eclectic interventions,* Reed (2016) found that intervention effect was moderated by therapist motivation, the extent of training, and a coherent treatment philosophy or theory with clear targets of change, rather than a mixing up of approaches.

Inclusive or Special Education:

Inclusive or Special Education is the practice of mainstreaming children with special educational needs (SEN). It has been driven by a 'rights-based approach' with 'moral and social imperatives' to challenge stigma and exclusion, which is countered by the 'rights-base' that education should be based on individual needs not social imperatives. Reed focused on the evidence of educational attainment not the effect on stigma. Generally, special education was developed to provide education to those children who were excluded from mainstream! However, Howlin (1997) argued that after 50 years of educational intervention the prognosis of ASD was not improved. The Warnock Report (1978) rode on the back of 'normalisation' in education and aimed to combat discriminatory views, creating welcoming communities and improving cost efficiency. However, mainstreaming led to low levels of acceptance in schools and a lack of educational gains. Even Dame Warnock recanted. There is great variation in mainstreaming internationally: 25% in the USA, 60% in UK and 80% in Australia. This is slightly more for ASD spectrum and less for ASD with co-morbidity. On top of that Baron Cohen estimated that 40% of ASD were unrecognized and therefore received no support.

Although there is little evidence on the effect of mainstreaming, children with ASD are 20 times more likely to be excluded, and 20% are suspended. The measures of successful inclusion are academic progress, social progress and the child's happiness and compliance. Although some academic gain can be seen in those with mild disabilities, for those with behavioural difficulties progress was better in special schools. In one study where TEACCH was being provided in special schools and in mainstream schools outcomes were similar and better than in mainstream schools that weren't so structured. Similarly, those with greater disability generally fared better in special schools. Other factors that were identified as important were such things as noise in the classroom, teaching style in mainstream schools, and the pupil's level of disruptive behavior. However, in Strain's study (1983) for pupils with ASD in mainstream schools

there was evidence of more pro-social behaviours and play skills. However, this was not replicated in a range of other studies, indeed several studies found high levels of exclusion in mainstream schools.

These effects are worse for ASD than other SENs (e.g., dyslexia). High levels of bullying are especially pronounced in high functioning individuals. ASD children have difficulty imitating others without special training. They are also more likely to imitate peers with similar problems. Furthermore, the mainstream peers are just as likely to model antisocial behavior.

While most parents want mainstreaming, as they believe it avoids the stigma of special schooling, evidence suggested that children suffer more from mainstreaming which leads to greater psychiatric co-morbidity. This was especially so in high functioning ASD children who were also most likely to be mainstreamed! Furthermore, by the time ASD children reach school age, their challenging behaviours are most problematic, affecting any inclusion process.

Applying specialist ASD programs in a mainstream setting can reduce that level of psychiatric co-

morbidity. Accordingly, greater academic achievement may come with the cost of greater depression and reduced self-concept. Inclusion itself does not provide benefit.

Factors that improve mainstreaming include specialised educational methods, smaller class sizes, clear leadership with positive attitudes, teacher attitude and training, and the development of individualized teaching procedures including functional assessment. Indeed, Wishart and Manning (1996) found only 6% of teachers felt qualified to deal with a child with SEN! Mainstream teachers were significantly less knowledgeable than special school teachers about ASD (Segall & Campbell, 2012). Lack of training leads to teacher stress and burnout. Training enables more realistic expectations, especially if it reduces expectations, and therefore a sense of failure. Conversely teacher knowledge improves child-teacher relationships, which is more important in ASD because of impoverished peer relationships. Improved teacher-child relationship improved inclusion in the classroom and reduced behavior problems.

Child attributes effect outcomes. For example, Asperger Syndrome is more likely to be mainstreamed and more likely to show increased problems as a result of placement! Better social and communication abilities and self–regulation (e.g., impulse inhibition) predict mainstream success, indicating that earlier emotional and social regulation skills in pre-school are important for mainstream success even in the context of high IQ.

Sensory processing problems are associated with poor mainstream success. Sensory problems associated with poor social competence negatively impact on social participation and conduct problems. Indeed, sensory problems contribute 50% of the variance of in academic performance in ASD. Externalizing behaviors and IQ correlate in mainstream settings, suggesting an underlying 'setting' cause.

One cannot conclude whether mainstreaming is good or bad for individuals with ASD. It is a complex issue but clearly requires a specialization of support in a mainstream setting. It certainly can be harmful if poorly managed. A 'rights-approach' may be another form of group discrimination. An economic rationale is a fallacy as appropriate approaches is expensive. A special commitment to ASD is needed in mainstream education, along with an individualized approach.

> *"While most parents want mainstreaming, as they believe it avoids the stigma of special schooling, evidence suggested that children suffer more from mainstreaming which leads to greater psychiatric co-morbidity."*

Conclusion

Reed (2016) provided a helpful, intelligent and authoritative overview of a complex subject with so much research from many international contributors. He clearly has considerable experience in ASD and its treatment, from an academic, clinical and educational perspective. One can get lost in the detail; however I found that the major recognised interventions have useful websites and examples of actual intervention on YouTube. It is really helpful to collect such a wide literature into a single resource which takes advantage of compiling the strength of evidence from multiple sources. What one realizes is how much research, replication, and funding is needed to be able to evaluate any novel treatment. Conversely there is considerable overlap in approach between the main interventions and in some ways the differences are important to evaluate. However, Reed provided a summary which most people interested in the best way to help a child with ASD will find essential reading.

Personal Views of the Book

I feel that one has to conclude that interventions do make an impact on ASD, but that change is slow, and requires an intensity in delivery and subsequently a pervasiveness of context. Most of the research evidence was about early intervention. The best results occurred the earlier the intervention began, especially prior to pre-school and with children whose IQ was over 50 who presumably had a greater capacity for intellectual recovery. Although professional therapy was more effective early, later parental skills were important to help parent-child attachment, and emotional and behavioural wellbeing. Yet the evidence suggested that specialist intervention needed to be maintained throughout school age, possibly

because school and peer relationships remain such a socially complex and challenging environment (less is known about adult needs).

I think that behavioral principles are important in early intervention and behavioral promotion of

basic recognition skills may enhance IQ, enabling language development and reducing externalising problems. There appears to be a point that pure behavioural approaches actually hinder social-emotional adaptive gains, which is because there is a stage that one needs to respect the emotional (and internal world) and attachment needs of the child.

Many would argue that the development of emotional recognition and theory of mind skills occurs in the context of an attachment relationship. This contradicts Reed's assertion that, although most treatments rely on a notion of developmental theories of the development of the mind, the within-person theories of both theory of mind and emotional recognition become important at a later age/stage of development. That is, as the mind develops, measures of higher executive functions start to have a meaning and a reality.

Further there is evidence that the quality of parental wellbeing, and parenting impacts on the emotional and behavioural wellbeing of the child with ASD, yet intervention seldom takes account of this factor. Indeed the most intensive interventions sub-select for an atypical group of determined and self-efficacious parents. There are clearly individual factors that contribute to potential for improvement, such as IQ and language, but there may be many others, such as temperament, family wellbeing/motivation and genetic/other biological variance (such as hormones).

It is also evident that in most settings there is little awareness of psychiatric co-morbidity, which clearly is a whole additional complexity, for which one answer will not fit all. Clearly, sensory issues have an impact on prognosis, but there is too little research for us to have a coherent theory or approach(es) to intervention. The chapter on eclectic approaches illustrated a further problem, that is, that if you mix up treatment approaches, you are left with an omelet of inputs, and unless there is a further whole coherent approach to research of any particular mixture, you are left unsure what components are important in the omelet. This is a limitation of the competitive nature of academic research, in which success is the key to getting funding for the next research. Yet approaches in improving educational environments and intervention very appropriately investigate new contributions to promoting skills in ASD, but then embed them in the previously established specialist curriculum (Costley, Clarke, & Bruck, 2014). Thus this academic tome is essential to understand the scientific process of researching ASD, but we shall need different approaches to understand individual differences and how to individualise interventions.

"It is also evident that in most settings there is little awareness of psychiatric co-morbidity"

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De-mystifying the Mysterious: Reflections from a Fellowship Year in Intellectual Disability Mental Health

Dr Rebecca Koncz

In 2016, I was fortunate to receive a fulltime Fellowship to work with people with intellectual disability (ID) and their carers. Whilst I am now nearing the end of my training in psychiatry, no textbook could have prepared me for what I was about to encounter. It has no doubt been a year of challenges, interspersed with small victories for patients and their families which seems to make it all the worthwhile. The following is a short reflection on how my year working in ID mental health has helped to de-mystify what is too often an area cloaked in misconception.

I would like to begin by pointing out that, in Australia, training posts in ID mental health are rare. Therefore going into the year, I was not sure what to expect. My prior experience was extremely limited, as if ID medicine was shrouded in mystery and belonged somewhere in the far-off land of the disability sector. At a minimum, though, I did understand that the mental health needs of people with intellectual disability were not being met. People with intellectual disability have significantly higher rates of mental illness than the general population (reference needed). Whilst almost half of this population suffers from psychiatric co-morbidity, less than 10% of those are accessing adequate mental health care (Einfeld & Tonge, 1996). Thus, with naïve enthusiasm I plunged myself into the year, with posts in busy child and adolescent, and adult outpatient clinics across a number of public hospitals in Sydney.

I quickly experienced many of the challenges that are faced by people with ID and their carers on a daily basis. The current landscape of mental health services for people with ID is a desert, with a severe lack of services catering to their complex needs. For those few services that do exist, access to and navigation of the system is difficult, and they are often severely under-resourced. Waitlists are extensive. There is also a lack of access to in-house allied health staff or care-coordinators, who would ordinarily play a vital role in providing holistic care. I became acutely aware of the stigma surrounding people with ID; local mental health services and emergency departments frequently misattribute behavioural disturbance to a disability, instead of recognising the presence of a co-morbid mental illness. This is often through no fault of the professionals, owing to the aforementioned issue of inadequate training opportunities in ID mental health. In fact, I am only able to train in the area owing to a Fellowship grant provided by the NSW Department of Ageing Disability and Home Care (ADHC), administered through the NSW Institute of Psychiatry. I am extremely grateful for the opportunity, and only saddened to learn that ADHC (and presumably this Fellowship) will also cease to exist as a government service after 2018 due to the transition to the National Disability Insurance Scheme (NDIS).

There is a significant disjunction between psychiatric, disability, government and non-government services that often left me feeling

helpless, and I could only imagine how people with ID and their families would have felt attempting to navigate this landscape themselves. With the transition to the National Disability Insurance Scheme, I have had to watch people wade through (or sometimes drown in) the complexities of the process, only to have their needs mis-identified and/or not addressed. I have therefore realised that the prescription pad, whilst central to my role, can be of secondary importance to my role in educating others and advocating for patients and families to have their needs met.

Having outlined a number of limitations, let me now turn to the sense of purpose I have developed in working with people with ID - the benefits of which certainly outweigh the systemic challenges. The Fellowship has provided me with an invaluable opportunity to develop clinical, academic and advocacy skills across the complex realms of intellectual disability and neuropsychiatry. This has been timely, particularly in view of the current paradigm shift towards the National Disability Insurance Scheme. Clinical presentations are highly varied and often extremely complex compared to general psychiatry, which lends itself to an unparalleled clinical experience. I feel I am now better able to provide clinical care for people with intellectual disability and their carers; as well as providing education and training to the health workforce at large. Collaboration with other medical specialties, allied health services and the non-government sector has been gratifying and vital for developing more comprehensive and integrated disability and health care services. In addition to clinical work, the Fellowship has enabled me to take part in conferences both nationally and internationally, and network with a cast of impressive, passionate researchers and clinicians to improve outcomes for people with ID. For registrars or psychiatrists interested in training in ID mental health, I would highly recommend pursuing the experience as a rich and rewarding field, both professionally and personally.

On a more personal level, I have been privy to the resilience of people with ID and their carers, which has been nothing short of awe-inspiring. The Fellowship has helped me to understand the complexities of ID mental health and so now it no longer feels as if it is an untouched enigma of a far-off land. However, I suspect the tireless commitment and compassion of families and carers will remain as one of life's greatest mysteries and inspirations to me.

As the training Fellowship draws to an end, I would like to express my sincere thanks to the NSW Department of Ageing Disability and Home Care and NSW Institute of Psychiatry for administering the funding. I am thankful to each of my supervisors for sharing their wisdom to develop my foundational knowledge and skills. I would especially like to thank my greatest teachers – that is, my patients, their families and carers, for allowing me to share in snapshots of their incredible resourcefulness. I will endeavour to continue to work across health and disability, in order to continue to improve the quality of access to and raise the standard of mental health services for people with intellectual disability.

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Project Air Strategy for Schools

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In 2016 the NSW School-Link Initiative joined in a new strategy **Project Air Strategy for Schools**; which is a collaborative project between NSW Ministry of Health and the NSW Department of Education and the Project Air Strategy for Personality Disorders at University of Wollongong. The program draws on the unique opportunity that schools provide for early intervention and prevention of mental illness among children and young people.

Project Air Strategy for Schools aims to provide education staff with information and tools to work effectively with young people that are experiencing a personality disorder or are presenting with emerging symptoms by offering an evidence –based approach that promotes early intervention within the school environment.

While primarily developed for use in schools **Project Air Strategy for Schools** can provide effective strategies for counsellors, health staff, youth and **welfare workers; as well as teachers, teachers' aids,** executive staff and school administrators. In **recognising that educators' are often well placed to notice changes in students' behaviour it aims to** provide those in the education environment with appropriate knowledge and skills to identify and respond to young people with emerging personality disorder symptoms and challenging behaviours including self-harm.

Project Air Strategy for Schools provides a comprehensive set of resources which have been developed to assist schools better recognise and respond to young people with complex mental health problems; it includes Guidelines, fact sheets, train the trainer resources and a short film 'Chloe's story'.

The Guideline (Grenyer et al, 2016) is divided into the following sections:
• Key principles for working with young people
• Understanding complex mental health problems
• Identifying and assessing risk
• Responding to crisis and self-harm situations

• Responding effectively to challenging behaviours
• Working to improve the school and social environment.
• Teacher wellbeing
• Working with parents with a personality disorder

The treatment principles are based on a "relational model" of intervention established by The Project Air Strategy for Personality Disorders and based on the **premise that "Relationships are at the core of our** mental health, particularly for a person with **personality disorder" (Grenyer, 2010: 8). Essentially** it concentrates on developing an empathic, non-judgemental, caring and respectful relationship. The aim being to establish trust, open communication and validation of the clients own experience. Thus it emphasises verbal communication.

The approach recognises that psychotherapy needs to be supplemented with brief interventions and structured therapies such as CBT or DBT. Furthermore it promotes collaborative care and planning where families, friends, carers and other professionals work together to offer comprehensive and consistent support (Grenyer, 2010).

Personality Disorder
Personality Disorder (PD) is a mental health disorder recognised by the International Classification of Diseases (ICD), and the Diagnostic and Statistical Guide for Mental Disorders (DSM). PD refers to personality traits that are maladaptive and pervasive in a number of contexts over an extended duration of time, causing significant distress and impairment.

Personality disorders are defined in American Psychiatric Association Diagnostic and Statistical Manual, 5th Edition, (DSM-5) as: An enduring pattern of inner experience and behaviour that deviates **markedly from the individual's culture. This pattern is** manifested in two (or more) of the following areas:
• Cognition (i.e. ways of perceiving and interpreting self, other people, and events)
• Affectivity (i.e. the range, intensity, lability, and

appropriateness of emotional response)
- Interpersonal functioning
- Impulse control

The fact sheet from **Project Air Strategy for Schools** estimates that PD occurs in around 7-11% of the Australian population (Grenyer et al, 2016). The exact cause of these problems is unknown but it is thought to arise due to a combination of factors including:
⇒ Biological factors – genetic or acquired
⇒ Drug and alcohol use
⇒ Early life experiences – abuse, neglect, death of parents, or other losses and trauma
⇒ Self-esteem and ways of thinking
⇒ Current social circumstances – financial, work, relationship or family stress.

Personality Disorder and Adolescence
Clinicians' attempting to diagnose an adolescent with PD will face multiple issues as clinical presentations are complicated by ongoing developmental changes, hormonal fluctuations, adolescent rebelliousness, peer influences and cognitive development in this age group. For this reason the developers of **Project Air Strategy for Schools have favoured the term 'emerging personality disorder' as a term that may be applied if a** young person does not meet full diagnostic criteria but is presenting with some personality disorder symptoms

(Grenyer et al, 2016).

Early warning signs of emerging personality disorder:
Unstable self-image
Frequent mood swings
Self-harming behaviour
Difficulty regulating emotions
Preoccupation with real or imagined abandonment
Excessive self-criticism
Disturbances in attention
Impulsivity or risk-taking
Abuse of drugs or alcohol
Thinking about death or suicide

> **"Clinicians' attempting to diagnose an adolescent with PD will face multiple issues as clinical presentations are complicated by ongoing developmental changes.."**

Young people who have an emerging PD can face a host of difficulties as they are most likely more emotional, less able to regulate their feelings, less resilient and more likely to engage in unhelpful behaviours. As such they can be misdiagnosed, for instance with a conduct disorder, especially as "the message that they are trying to send through their behaviour is often misinterpreted as manipulative, attention seeking or simply "bad" behaviour" (Grenyer et al, 2016).

> "Young people who have an emerging PD can face a host of difficulties as they are most likely more emotional, less able to regulate their feelings, less resilient and more likely to engage in unhelpful behaviours."

Project Air Strategy for Schools cautions against over diagnosing young people but also insists that clinicians be wary of "misattributing severe and debilitating distress as a "normal" part of adolescence". They suggest the young person's "whole style of functioning" be examined and that problems need to be severe and have endured for at least one year before warranting a diagnosis. There is mention that while it is common for young people to experience difficulties and take risks, attention should be paid to the frequency, duration and severity of these behaviours (Grenyer et al, 2016).

Personality Disorder and Intellectual Disability

Establishing a co-morbid diagnosis of PD for individuals with ID is exceptionally problematic and there is little research in this area. Most studies which directly tackle this topic focus on adult populations and "Questions remain regarding the etiology, as well as the prevalence and diagnostic validity, in intellectual disabled population" (Wink, 2010: 278). The research suggests that not only is there a lack of valid and reliable diagnostic criteria, but that the difficulties encountered when conducting assessments, due to cognitive and communication issues, could severely compromise outcome measures (Moreland et al 2008; Pridding & Proctor 2008; Wink 2010).

As Pridding and Proctor (2008) report "A review of literature on the diagnosis of PD by Alexander and Cooray (2003, p. 31) found 14 papers reporting prevalence rates from 1–91% in community settings and 22–92% in hospital. The authors comment that this difference is too great to be explained by real differences and question the clinical usefulness of the diagnosis. They conclude that: no accurate prevalence figures for PD in ID are available." (Pridding & Procter, 2008: 2813).

Difficulties in establishing psychiatric diagnoses in individuals with an ID is not limited to PD. It is a field where there is still much work to do and this is particularly relevant for children and young people (Dossetor, 2011). In making a diagnosis the type and severity of an individual's disability can also be a factor, as Tsiouris (2011)found with psychosis and depression which was over-diagnosed in persons with mild to moderate ID and under-diagnosed in persons with severe and profound ID (Tsiouris, 2011). Other studies simply do not include PD, concentrating instead on psychiatric disorders such as anxiety, depression, psychosis, bipolar and impulse control disorders (Dykens et al, 2015).

Difficulties with relationships and experiences of past trauma frequently underlie the development of PD (Grenyer et al, 2016). People with intellectual disability may be more frequently subject to such experiences but it is yet to be determined whether this then causes higher rates of PD. What is **important is that these "... experiences of rejection, failure experiences and social deprivation as they grow up," can lead to the development of unhelpful** personality traits (Roya, 2014:36).

> *"Difficulties with relationships and experiences of past trauma frequently underlie the development of PD ..... People with intellectual disability may be more frequently subject to such experiences but it is yet to be determined whether this then causes higher rates of PD"*

The authors of **Project Air Strategy for Schools** suggest that a co-occurring personality disorder should only be considered when a person with intellectual disability has mild to moderate cognitive and verbal impairments. They propose that the difficulties students with a moderate or severe ID have with communicating and describing internal experiences makes diagnosis unreliable (Grenyer et al, 2016).

Furthermore the Projects developers' point out that adolescents with a PD and those with ID often present with similar problems - including difficulties with communication, relationships, regulating emotions, coping with distress and engaging in challenging behaviours. As such it can be extremely difficult to determine if these behaviours are due to **a person's intellectual disability or a co-**occurring personality disorder.

Project Air Strategy for Schools and Intellectual Disability
Project Air Strategy for Schools ultimately leaves it to the discretion of individual schools to decide what materials are appropriate for whom. A fact

sheet "Intellectual Disability & Personality Disorder" offers some suggestion to assist staff working with students who have an Intellectual Disability (ID). These include presenting information in a visual format, using frequent repetition and simple language.

The program has some good resources and helpful advice for working with adolescents with complex mental health issues. The limitations of its effectiveness for students who have an ID will be partly determined by the type and degree of the disability individual students present with and the competency of the practitioner in working with these students.

Conclusion
Considering the high rates of mental health issues facing students with an ID (between 30 -50%) and the frequent placement of these students in mainstream schools it would appear that specialist resources to aid clinicians working with this population would be in high demand. Challenging behaviours and emotional dysregulation are often significant issues for this population of young **people and thus they could be considered 'core business' for counsellors working in educational** settings.

Modifying treatment approaches and providing appropriate resources can potentially address some of the problems clinicians will face when using **Project Air Strategy for Schools** with ID students but may need further adjustments for adolescents who have a moderate or severe disability.

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Tips for Supporting a Person with Intellectual Disability and Emotional Difficulties

- People with intellectual disabilities sometimes use impulsive and challenging behaviours in an attempt to cope with overwhelming emotions. These behaviours can include aggression, self-harm and substance use. Therefore, it is important to develop a plan to ensure **every-one's safety in the event of a crisis.**

- All information needs to be simplified and presented at a level the person can understand. Try presenting information in visual (for instance pictures or charts) and practical ways, such as role-playing social skills or practicing coping strategies together when the person is calm.

- **It is important for everyone in the person's support network to** communicate and develop consistent boundaries and goals. This creates a predictable environment and helps the person feel safe.

- People with intellectual disability need opportunities to consolidate learning. Repeating skills and concepts over time can help the person remember the information and put it into practice.

- Providing tangible rewards for behavioural improvements can help to reinforce gains. A chart outlining progress towards goals and rewards can increase motivation and help keep everyone on-track.

- People with intellectual disabilities often find it difficult to understand abstract concepts. Therefore, try to focus on simple skills, such as reinforcing or role-playing how to ask for something and how to tell someone how I feel.

- Psychological therapy takes time. It is important to be patient and expect set-backs.

- **Working with and supporting a person's strengths increases their** confidence and sense of wellbeing. Activities that incorporate these strengths maintain interest and persistence. The use of humour and playful activities can also reinforce appropriate social skills.
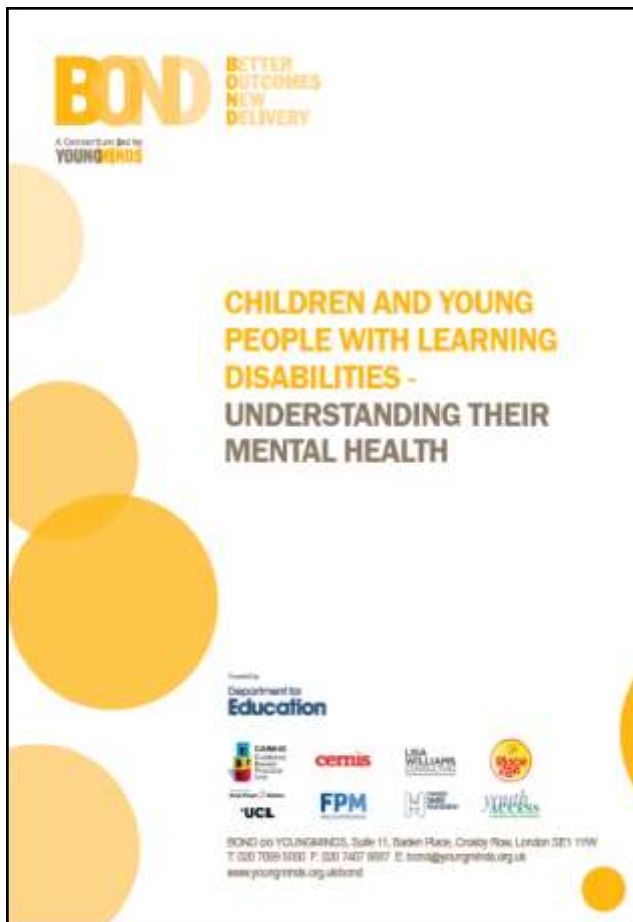
Children and Young People with Learning Disabilities

This UK report by YoungMinds (2014) provides background reading into mental health and intellectual disability (or learning disability as it is referred to in the UK). The report guides the reader through an understanding of positive mental health, wellbeing and resilience through to mental health problems specific to children with learning disabilities.

This resource specifically discusses how to identify mental health problems in children with learning disability and draws on information included in our Australian Intellectual Disability: Mental Health First Aid Manual (Pappas and Frize 2010). It also contains a 'what to do' section with practical tips on how to record concerns and raise these with parents.

This resource could be utilised by disability staff or a classroom teacher. The resource can be downloaded at: http://vox.mtcserver3.com/wp-content/uploads/2015/01/Children-Young-People-with-Learning-Disabilities.pdf

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

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