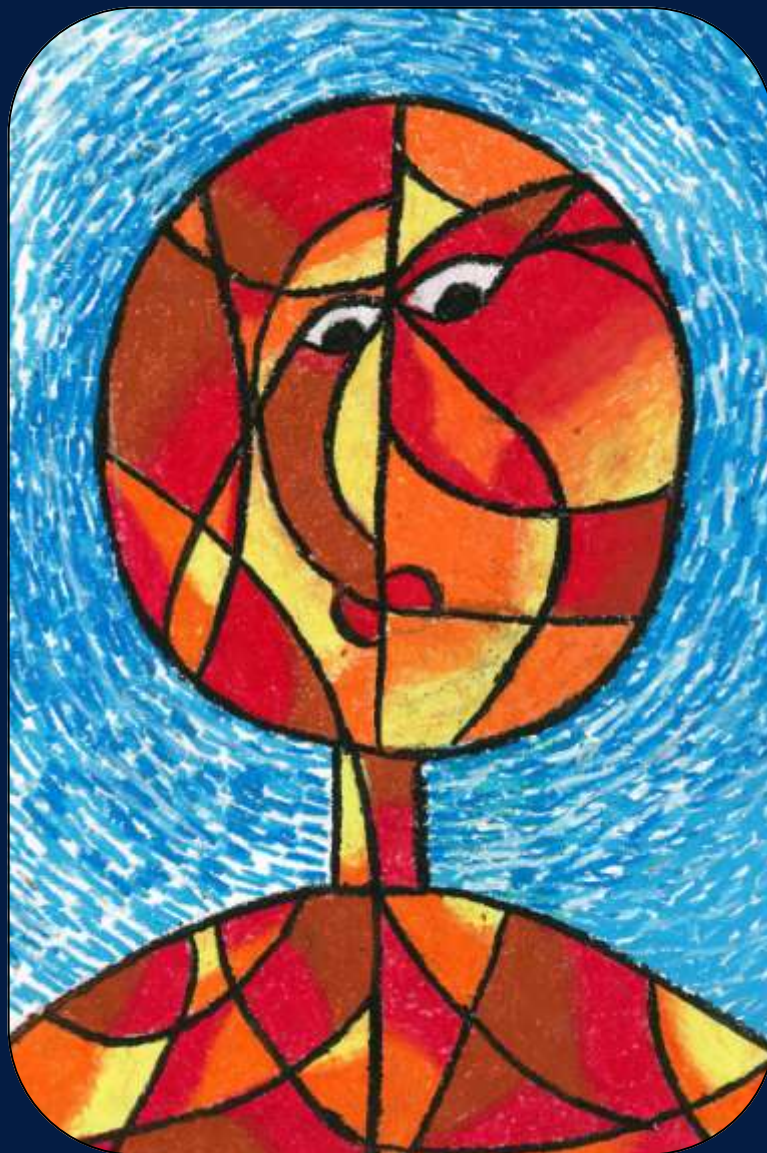


Journal of Mental Health for  
Children and Adolescents with  
Intellectual and Developmental  
Disabilities:  
*An Educational Resource*

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

## **Description and purpose**

*This journal is a modification of the previous newsletter; a vehicle of expertise about mental health information of children and adolescents with intellectual and developmental disability. As a product of CHW School-Link, this journal is supported by School-Link and a collaborative effort with a multi-agency editorial group from the Statewide Behaviour Intervention 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.*

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

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Terry Sarten

*CHW School-Link Coordinator  
The Children's Hospital at Westmead*

[www.schoollink.chw.edu.au](http://www.schoollink.chw.edu.au)

Welcome to the first edition for 2014. You will notice some changes to the CHW School-Link Journal content. The focus remains on articles we think are relevant to our readership across sectors but training and conference information will now be posted on the website so that it keeps pace with events. [www.schoollink.chw.edu.au](http://www.schoollink.chw.edu.au).

This edition covers a wide range of topics in the featured articles, the book and paper reviews alongside the regulars **such as the Medicine Cabinet, A Day in the life... and an** interview with one of those whose professional contribution has done much to improve the lives of children and their families.

As always we aim to provide a range of perspectives on mental health in children and young people with an intellectual disability with contributions from health, education and the disability sector.

There is huge change occurring across all sectors with major organisational restructuring and the NDIS rollout set to redefine the disability landscape. It is becoming evident that the shape of disability services will evolve and change

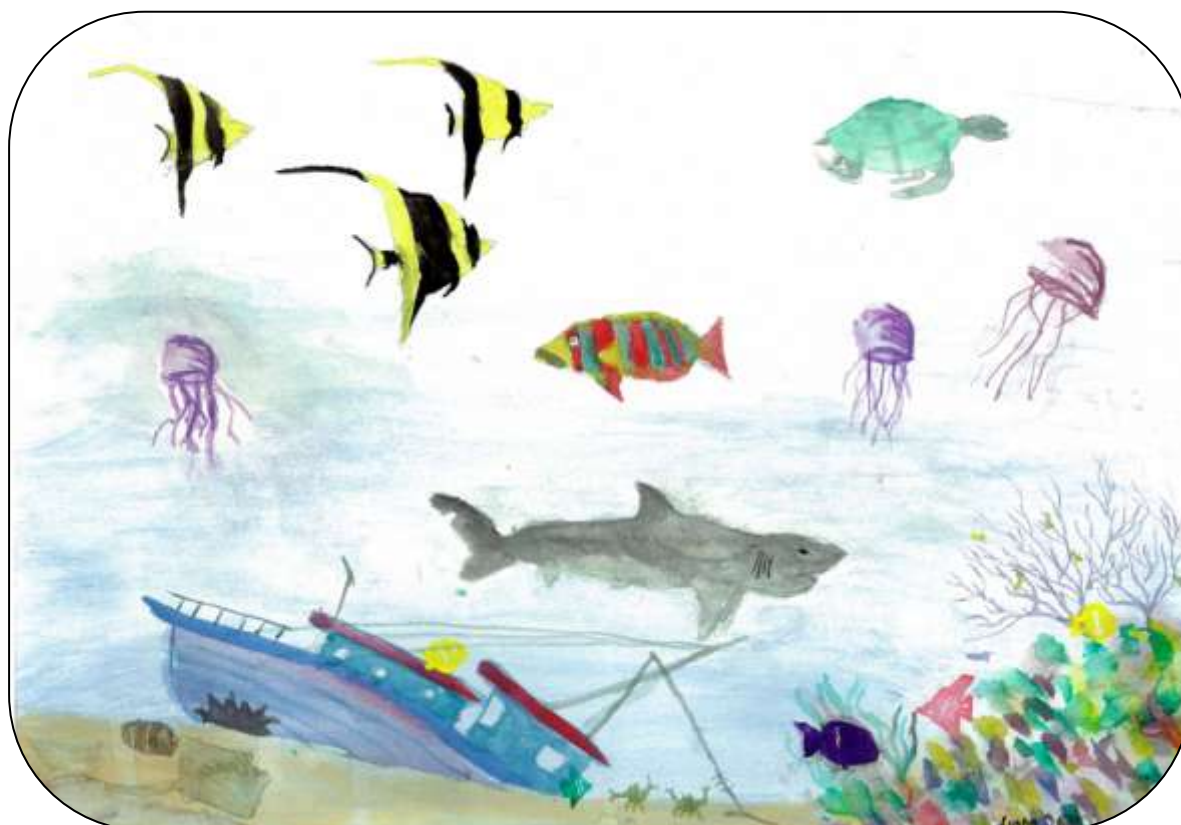
as a person centred model becomes established. It is an exciting time of change.

The Editorial Committee will be continuing its work in promoting the mental health of those with an intellectual disability. It is crucial that the collaborative alliances that have been built across sectors continue to grow, because promoting collective advocacy is so important for those less able to voice their own needs and concerns.

The team at CHW School-Link aim to provide a consistent connection between all the sectors as they navigate the new terrain by providing professional development opportunities, assisting readers to keep pace with events and news via our website and publishing this journal with feature articles on current research, projects, programmes and the people who make things happen.

Feedback is valuable so please let us know how the shift in focus works for you as a subscriber.

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# Diagnosis, Psychotropic Medication and Outcome in an audit of 150 Child and Adolescent Neuropsychiatric Patients.

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## Introduction

This report is a case series seen by a child psychiatrist with a special interest in children and adolescents with Intellectual Disability (ID) and/or ASD. In the absence of evidence-based consensus on diagnostic approaches, the clinician examined psychiatric diagnosis from a clinical descriptive approach, using both dimensional and categorical approaches to diagnosis to inform treatment. There are so few accounts of the reliability of psychiatric diagnosis in children and adolescents with ID (Einfeld *et al*, 2008; Lee *et al*, 2003), and none found in a literature search of cohorts of young people with Autism. In an Australian context, these patients often get poor access to mainstream services, despite severe levels of impairment secondary to their emotional or behavioural disturbance.

A brief history of the diagnosis of mental health problems is as follows. Traditionally, mental health problems were severely under-identified and their emotional and behavioural disturbance was attributed to their ID, thereby denying access to mental health services: what has been called **'diagnostic overshadowing'**. **Over the last 15 years both the Royal College of Psychiatrists (2001) and American Psychological Association with the National Association for the Dually Diagnosed (Fletcher *et al*, 2007) have brought out guidelines to enable a more consistent approach to people with ID, enabling them to have the same diagnoses that enable access to mental health services** as people with a normal range of intellect.

A brief comparison of cohort studies between UK and the USA illustrates quite different diagnostic practices, a lack of international agreement in the diagnoses found in people with ID, and possibly different schools of thought underlying these differences. These guidelines also raise areas in which there are difficulties in reliably eliciting psychiatric phenomena, but no guidance on how to resolve these problems (Dossetor, 2011 chapter 20).

In fact it is a regular experience of psychiatrists with special **skills and interest in people with an ID, that this 'same access' still means a significant under-recognition** of significant mental health problems. This is borne out by the research in the problems that mainstream doctors have in

recognising depression and anxiety, ADHD and ASD in this population (Hurley, 2008) and subspecialty research that shows the increased prevalence of these problems in people with ID.

Epidemiological longitudinal studies indicate 40% of children and adolescents have severe and persisting Mental Health Problems (Einfeld and Tonge, 2006) but behavioural questionnaires such as the Developmental Behaviour Checklist (DBC) or the ABC (Aberrant Behaviour Checklist **Manual; Aman, & Singh, 1986)** don't translate to psychiatric disorders. Further, there has been criticism that different **questionnaires don't agree with each other and find different dimensions of disturbance**. Further still, the additional impairment of a psychiatric disorder or behaviour disturbance versus that of ID alone has not been quantified in studies.

Disturbed behaviour may be described as due to Mental Illness, Mental Health Disorder, Developmental Disorder, Challenging Behaviour or Behaviour Problem. The labels a clinician uses is substantially a subjective determination affected by profession, employing agency and different theoretical models. Professional practice requires that competing theoretical models be considered and the value of each particular model considered in a particular clinical predicament. After all, both challenging behaviour and mental health disorder are both based on a bio-psycho-social model of poor social adaptation, and more often than not co-occur.

It is in the context of a lack of professional consensus of **standards of current practice that an individual clinician's practice can be of interest and illustrate practical approaches to assessment and management and may provide discussion on how to improve diagnostic accuracy.**

This is a presentation of a cohort of 150 more or less consecutive neuropsychiatric patients. They represent my practice in mental health and ID and ASD. A few cases that were of a more mainstream population with common psychiatric disorders, such as some of my telepsychiatry clients were not included. I work in a multidisciplinary developmental psychiatry team and work closely with clinicians in the disability services. We promote a developmental framework for

understanding behaviour. This provides a normative framework against which to consider disturbed behaviour and psychiatric diagnosis particularly in the context of abnormal and extreme behaviour or challenging behaviour (Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities: a framework for professional practice, 2011).

However the medical/psychiatric role is to focus on diagnosis and medication management of a particularly disturbed group. We provide tertiary consultations to developmental and behavioural paediatricians and child and adolescent mental health services.

## Methods

150 sequential neuropsychiatry files were audited and a database was created. From an examination of the files, the following information was recorded: age, category of ID (mild, moderate, severe, and profound), presence of ASD. The diagnoses as ascribed by the clinician were recorded based on DSMIV diagnostic criteria, but in addition the most common diagnoses were scored in a dimensional on a 0-3 scale of severity. These were: ASD, ADHD, Anxiety, Depression, Aggression and Self Injurious Behaviour (SIB). The other common diagnoses that were noted were Lability of Mood, Developmental Coordination Disorder, Sensory Sensitivity, and Sleep Disorder. The number and type of drugs given before referral and also those trialled but not continued were recorded. The drugs given at last attendance were separately recorded, based on the assumption that they constituted a stable drug regime. The Child Global Assessment Scale (CGAS) (Shaffer et al, 1986) was used to assess the level of impairment at presentation and where possible the score at follow up was also collected. The CGAS records a level of functioning on 1-100 scale, where 70-100 constitutes the normal range for mainstream population, below 50 is considered a severe degree of impairment, and lower levels imply progressively higher levels of dependency.

## Results

### Descriptive results of the cohort:

Average age was 12.8 years, standard deviation 3.7 years, range 4-23. Sex distribution was M:F 101:49. ID was present in 103/150 (68%). ASD was present in 119/150 (79%). Of those with normal intelligence 37/47 (79%) had ASD.

**Average CGAS at presentation was 35 (range 20-55).** The average estimated **additional impairment from emotional behavioural disturbance on top of the level of ID was 30 CGAS points.** The **average CGAS gain from psychiatric intervention was 20 (range -5 to +30)** on 66 cases on which follow up information was available at the time of audit.

The number of patients receiving medication was 139/150 (92%). The average number of medications per patient was 2.2 (range 0-6).

**Table 1: Frequency of Diagnoses**

Diagnosis: Common Developmental Psychiatric Disorders	Frequency
ASD	106
ADHD	94
ODD (Aggression)	71
Anxiety	67
Depression	28
Lability of Mood	24
Self-Injurious Behaviour	18
Developmental Coordination Disorder	15
Sensory Sensitivity	9
Sleep Disorder	8
<b>Subtotal</b>	<b>440</b>
<i>Other Diagnoses- Number = 85</i>	
<i>Other Psychological Disorders: Recurrent Confusional State, Other Organic Disorder e.g. Catatonia, decline in skills; Pica, Specific Language Disorder, Separation Anxiety, PTSD, Dissociation, Somatic form symptoms, Episodic Dyscontrol, Sexualised Behaviour, Affect Related Voices, Hallucinations, Pseudohallucinations, Rigid/Obsessive +\- Obsessive Personality, Frontal Lobe Syndrome, Foetal Alcohol Spectrum Disorder, Blood Curdling Screaming, Offending Behaviour</i>	
<i>Physical Health Problems: Soiling/constipation, Reflux, Eneuresis, Neurological Disorder/Movement Disorder, including progressive decline, Epilepsy, TB meningitis, Traumatic brain injury, Hemispheric Pyrexia, Blind/Deaf, Obesity, weight loss, Immuno-defic, Eosinophilic Oesophagitis, Dental caries</i>	
<i>Genetic Disorder or Behavioural Phenotype e.g. VCFS, Klinefelters, SMS, CHARGE, Sanfilippo, 6-pyruvoyl-tetrahydropterin synthase deficiency, TS, Various Deletions e.g. 2p;</i>	
<i>Relevant environmental factors: Child Sex Abuse, Mother-Child Relationship problems, Xs Dependency, Parental Coercion/abuse, Lack of Limits, Domestic Violence.</i>	

The table above illustrates the frequency of the common disorders on the top section, most of which can be seen as developmental psychiatric disorders of which 440 diagnoses were made on the 150 patients. The other 85 diagnoses listed were categorised as other psychiatric diagnosis, physical health problems, genetic disorder or behavioural phenotype and disorder of the family environment. The average number of diagnoses per patient was 3.5.

In addition, in 27 cases there was pharmacological treatment of a parent for depression or anxiety disorder. 50 of the cases had other agencies actively involved in managing the cases, as a measure of the tertiary nature of the service. Twenty had disability services involved, of whom 10 had the

tertiary disability service involved (Statewide Behavioural Intervention Service) with whom my team has a service partnership, and 1 was involved with the Disability Criminal Justice Program. Ten had the welfare services (NSW Family and Community Services) of whom 4 were supported by their Intensive Support Service. 9 were in out of home care with a non-government organisation providing specialised accommodation services after parental relinquishment of care. Eleven were seen as part of our telepsychiatry service, which provides a tertiary consultation service to regional NSW CAMHS services. (Most of the telepsychiatry consultations were excluded from this cohort as they were mainstream child and adolescent psychiatry and not part of developmental neuropsychiatry practice.)

With such high frequencies of diagnosis, it was of clinical interest to examine any patterns of presentation. The correlation between the common psychiatric disorders and some other demographic information was examined with simple correlations, to look for patterns of associated comorbidity in this cohort.

Although both associated with maleness, I was surprised that in this cohort ASD and ADHD weren't associated to each other, but they are both associated with lower IQ. The associations listed of lower IQ are consistent with clinical experience: presentation CGAS, ASD, SIB, aggression, ADHD and number of medications used for current management. The correlation of ASD with Anxiety fits my clinical impression but ASD does not correlate with IQ or ADHD. The correlation of ADHD with Depression is an interesting suggestion. Anxiety correlates with depression but also aggression, SIB and DCD. The correlation of aggression with Sensory problems may be an interesting clinical finding as sensory problems are a clinical finding not a recognised psychiatric diagnosis. SIB is associated with the level of impairment, IQ, Depression and Anxiety and the number of cur-

rent medications possibly because of the pressure to achieve something in this difficult clinical predicament.

Current use of more medications is associated with the level of presentation CGAS impairment, ADHD, Aggression and SIB. Lability of Mood seems to stand on its own as clinical feature which surprised me, because it regularly seems to be clinically relevant to other problems.

A number of referrals to my practice are for assessment of a presumed psychotic illness. In the period of the study there were a few referred as having a psychotic disorder, presumed as schizophrenia and my diagnosis in these cases, supported by treatment effects was major depression, particularly in the context of ASD. There was one ASD boy with anxiety, ODD with an emotionally complex family, including excessive punitiveness, who on turning 18 had a violent episode which led to hospitalisation and a diagnosis of schizophrenia by a new treating team. The reliable diagnosis of schizophrenia in adolescence is often difficult and even more so in the context of ASD (Dossetor, 2007).

Table 3 lists the current medications prescribed on file at the time of the audit. The average number of psychotropic medications per patient is 2.2 with a range of 0-6. Although major tranquillisers are the most frequently used medication, but they are by preference a last choice because they can be seen as a stronger psychotropic with some side-effect cautions, especially if they are needed in the longer term.

I prefer to start with safer drugs like Night Sedation particularly clonidine or melatonin, to see if improving sleep patterns improves behaviour.

Stimulants are the most common psychotropic used in child psychiatry but have often been tried before a patient comes to my clinic. It has a place but has more failures and side-

## Correlations Between Diagnoses:

Male Gender correlates with:	ADHD*, ASD*
Lower IQ correlates with:	PreCGAS***, ASD***, SIB***, Agg**, ADHD*, NMeds*
ASD correlates with:	IQ***, Anx***, PreCGAS** (but not ADHD)
ADHD correlates	PreCGAS***, Dep***, Agg**, NMeds**
Anx correlates with:	Dep***, Agg*, SIB*, DCD*,
Agg correlates with:	PreCGAS**, ADHD**, Sensory**, IQ**, Dep*, NMeds**
Dep correlates with:	SIB***, Anx***,
SIB correlate with:	Pre-CGAS***, IQ***, Dep***, Anx*, NMeds**,
N of Meds correlates with:	PreCGAS***, ADHD**, Agg**, SIB**
Pre-CGAS correlates with:	IQ***, SIB***, NMeds***, ADHD***, ASD**, Agg**
Sensory correlates with:	Agg**
DCD correlates with:	Anx*
Labile Mood correlates with:	-

\*=p<.05; \*\*=p<.01; \*\*\*=p<.001

Table 2: Correlations between Diagnoses

## Medications in Current Use

No. of meds/pt=2.2 (range 0-6)

Night Sedation:	23pts	Clonidine 16, Melatonin 6, Chloral 4
Stimulants:	38pts	33 Rit, Concerta 7, Dex 2
Anxiolytics:	62pts	Clonidine 56, Propanolol 2, Naltrexone 2, Benzos 2
SSRIS:	48pts	Fluoxetine 35, Fluvox 9, Sertraline 3, Cipramil 1
Other Antidepressants:	47pts	Amitriptyline 39, Clomipramine 2, Strattera 3, Mirtazepine 2, Venlafaxine 1
Mood Stabilisers:	42pts	Carbamazepine 30, Epilim 11, Lithium 1
Major Tranquillisers:	64pts	Risperdal 34, Abilify 18, Seroquel 9, Olanzapine 3 Also trialled but not current: Lithium 4, Buspirone 3, Amisulpiride 1, Chlorpromazine 1, Lorazepam 1

Drugs tried before: Ave=3.4 Range 1-12 (sample of 79)

**Table 3: Medication in Current Use**

effects in this population. **Anxiolytics:** I think one of the reasons for this failure is the frequency of associated anxiety. Four-hourly daytime clonidine (starting dose 25micrograms) is a great anxiolytic especially in those still in earlier development. It is often helpful in anxiety driven self-harm or disruptive behaviour eg in the profoundly disabled. Propanolol has been remarkable in a couple of highly aggressive and self-injurious, agitated non-verbal autistics. Naltrexone is known for its therapeutic role in SIB but is also used in addictive behaviour. I have found it helpful in intense autistic hyperactivity and what I designated self-harming attention hunger. **SSRIs** have a role for suspected depression, where aggression is driven by stereotypic obsessions and for anxiety. However behavioural activation as a side effect has to be watched for carefully, particularly as the dose is increased.

**Other Antidepressants:** However, Amitriptyline is a well-established medication which I find very valuable for ADHD in the context of ID and or ASD, where the ADHD is often driving aggression but also with associated anxiety. Norepinephrine antidepressants are better for ADHD and impulsivity which can be a side effect of SSRIs. Strattera, although there is some studies supporting its benefit, I find helpful in exceptional cases, and I find prone to side effects in this population. **Mood Stabilisers:** Carbamazepine is the mood stabiliser that I was taught to use as a trainee in the mental health of children and adolescents with ID, and Steve Tyrer described it is the universal second line psychiatric treatment which has found an important role in bipolar disorders (along with other mood stabilisers eg Epilim). Major tranquilisers are the most frequent medication but should be kept as a 'treatment of last resort', although they are often started to manage acute disruption in the context of a chronic problem.

**Major Tranquilliser:** Risperidone has the best evidence of its value in the treatment of aggression of ASD, and it is a tertiary treatment for ADHD, anxiety and the aggression driven by stereotypic autistic thinking. My experience is that olanzapine is most powerful in the management of a recurrent violence for example where it is driven by stereotypic rigid thinking. I use aripiprazole (Abilify) and quetiapine (Seroquel) as second choice major tranquilisers especially where there is problems of weight gain on risperidone. They may be preferred where anxiety is the main driver of disturbed behaviour for example in ASD.

In 1992, I wrote an article entitled 'the hit and miss of magic bullets', describing how medication can be dramatically helpful, but our prediction as to which medication matched the client was poor (Dossetor, 1997). I wish to point out the number of medications of 3.4 per patient that have been tried (not necessarily by me) before the best combination is found. I feel by weighing up the significance of the different co-morbid diagnoses and trying the more established or commonly used treatments first that improves success rate. Different medications may be used to target different components of disorders or symptoms. Although aggressive behaviour is the most common presenting concern, in my view that it is seldom beneficial to make the aggression itself the target symptom for medication. The challenge of the psychiatrist is to identify co-morbid psychiatric disorder the treatment of which improves aggression. Aggression therefore needs to be considered from the context of a challenging behaviour as well as the association of psychiatric disorders, such as those commonly found in this cohort.

## Discussion

The most important observation from this study is that the presence of a co-morbid psychiatric disorder is as disabling as or even more disabling than the intellectual disability itself. One of the primary features of diagnosing a psychiatric disorder is the extent to which symptoms or a syndrome are impairing and disabling. In this cohort, on average, both the intellectual disability and the psychiatric disorder each contribute 20-30 points of impairment on the CGAS. However the psychiatric disorder is the reversible component of their disability.

It is a human rights/equity issue that mental health services cannot or do not consider this work core business and this should be a primary concern to disability service providers and funders. We need services with the capacity to provide multidisciplinary assessment and intervention for this group of severely behaviourally impaired children and adolescents with ID, which incorporates psychiatrists with subspecialty skills and interest. It should be the level of behavioural impairment that attracts the multidisciplinary service (Dossetor, 2011 chapter 25) and the assessment should examine the different theoretical models to understand and help the behaviour, rather than having these skills in different agencies, unable to work together collaboratively.

In practice, in NSW, Paediatricians are more likely to be involved, and are helpful for complex medical and developmental co-morbidities. Historically, child and adolescent mental health is provided by behavioural and developmental paediatricians, from whom most of my referrals come. However, there needs to be a more formalised and closer partnership between paediatricians and CAMHS and particularly with psychiatric support for the use of psychotropic medications. The National Roundtable on the Mental Health of People with intellectual disability (Dossetor, 2013) argued for the recognition of subspecialty expertise and the support to enable specialist mental health services for people with intellectual disability, as much of the success of such service provision is dependent on expertise not adequately represented by mainstream mental health services.

In 1993, our department at the Children's Hospital completed an audit on cases for whom medication was needed and given compared to those for which medication was not given.

**Table 4 of CGAS Measures before and after treatment in a department of child psychiatry, comparing patients who received medication vs those that did not, and the average number of points improvement (1993)**

Cases	Score before Rx	Score after Rx	Average improvement
Medicated:	39	60	21
Non medicated:	55	65	10

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**“the presence of a co-morbid psychiatric disorder is as disabling as or even more disabling than the intellectual disability itself...”**

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en and were treated through psychological treatments provided by allied health mental health clinicians. This had similar findings in relation to the CGAS measures used in this study. All children who are prescribed medication receive this within a multimodal intervention approach. However, those that required medication were significantly more impaired than those not receiving medication at the outset, had a greater benefit from treatment, but still remained more impaired at discharge.

Considering the high prevalence of disorders, this study emphasises the importance of paying attention to anxiety and depression in those unable to describe their symptoms as these easily missed conditions can lead to valuable treatments. Recognising co-occurring anxiety is often the key to successful treatment of ADHD, aggression or SIB. The presence of significant or severe co-morbid anxious arousal has a range of valuable alternative treatments to consider as alternatives to SSRIs which have limited efficacy in this population and problematic side effects such as behavioural activation. A young person with ID who is deteriorating in skills, and may present with a range of bizarre symptoms, is more likely to have depression than psychosis, but it is more difficult to elicit the predominance of mood change.

Other results show that up to 50% of parents have depression, anxiety or burnout which warrants prompt treatment.

The use of more than one medication may be necessary because of the need to treat more than one condition, or because more than one medication may be more effective for a condition. Practitioners regularly focus on targeting a significant symptom with a medication, and sometimes a single medication may have effects on different symptoms or conditions. Hazell (2010) argued for the importance of recognising the role of different drugs in ADHD. He suggested that stimulants were the first line medication for ADHD, clonidine, atomoxetine and amitriptyline were second line medications and mood stabilisers and major tranquillisers were third line treatments. Sometimes intervention is proposed on the basis on a neurotransmitter theory of a problem. One example is the endorphin theory of SIB and stereotypic repetitive behaviour. It is observed that SIB induces endogenous endorphins, giving an 'opiate high' and naltrexone which blockades the effect of opiates can therefore lead to a reduction of SIB.

The common clinical diagnoses that are used in this study, may not be too different from the dimensions of behaviour that are derived from behavioural questionnaires. Accordingly, these epidemiological approaches to maladaptive behaviour in children and adolescent with ID provides some interesting comparisons. The table on page



9 lists the dimensions of the two main behaviour questionnaires, and the related dimensions that are also derived from their questionnaires. The first 3 dimensions (derived by factor analysis) fit with the clinical triad of symptoms associated with ASD. The observation that these factors are more highly correlated to low intelligence than chronological age, provides evidence to support a developmental model for understanding ASD. The same observation can be made of hyperactivity, anxiety and SIB, suggesting there are important developmental processes behind these areas of maladaptive behaviour. The only dimension that correlates with increased IQ is the Disruptive/Antisocial dimension, as active disruption to others requires an awareness of and intent to do harm to another.

Accordingly, these dimensions derived from epidemiological approaches to maladaptive behaviour in children and adolescents with ID support the notion that the common mental health diagnoses used in this study, are validated and probably have strong developmental or skill building components. I have argued that mental health (or losing your mind) will benefit greatly from understanding the processes of development of the mind, as we see in children with ID. This does not however mean that ADHD or ASD as a disorder loses its validity as a psychiatric disorder, even if there is limited research evidence to confirm or deny this.

For less frequent diagnoses such as psychosis or confusional states or frontal lobe syndrome, epidemiological approaches may not be a good way to substantiate these categories. It is in these disorders that psychiatrists may have a better experience, although by no means exclusively.

## Conclusion

In diagnosing mental health problems in ID and ASD the main diagnoses are common and co-occur. These mental health problems cause significant additional functional impairment and are likely to be predominantly due to biological factors and associated developmental processes. This study indicates that severely impairing emotional and behavioural disturbance, is the reversible component of their disability and the judicious use of medication is a critically important component of multimodal treatment. It is frequently observed that non-medical treatments cannot engage let alone treat these severely behaviourally impaired patients and medication is often a critical ingredient to gain sufficient improvement that other approaches can be used to enable a skill building approaches to long term recovery of function and participation.

Yet in those with ID and or ASD, medications may have lower rates of treatment success compared with a mainstream population and may have increased risk of side effects. However they are an essential part of treatment of these neurodevelopmental psychiatric disorders, which are central to helping a child or adolescent with mental health problems in ID and or ASD. Yet these disorders are general-

## The Dimensions of Behaviour Identified from Questionnaires eg Developmental Behaviour Checklist, Aberrant Behaviour Checklist are:

- |                           |                             |
|---------------------------|-----------------------------|
| 1. Self absorbed          | (x<Low IQ)<br>(stereotypic) |
| 2. Social relating        | (x<Low IQ) (empathy)        |
| 3. Abnormal communication | (x< Low IQ)                 |
| 4. Disruptive/Antisocial  | (x <High IQ)                |
| 5. Anxiety                | (<Low IQ)                   |
| 6. Hyperactivity          | (?<Low IQ)                  |
| 7. SIB                    | (x< Low IQ)                 |
| 8. ASD                    | (?< Low IQ)                 |
| 9. Depression             | (?<in Mild/N IQ)            |

*The factors of behaviour questionnaires contribute to validating the main diagnoses & validating a developmental understanding of behaviour*

*However for less frequent diagnoses epidemiology may be too broad an approach to validate less frequent diagnoses*

ly not considered to be part of mainstream adult mental health, but are an important part of the practice of adult psychiatrists with a special interest in ID.

Accordingly, psychotropic treatment is one component of any multimodal treatment plan that can improve the quality of life of young people with ID. Much of the knowledge of this subspecialty of psychiatry is dependent on expertise, because of the lack of funding to build the evidence base for this stigmatised, disadvantaged and neglected special need population. As my mentor and trainer in child psychiatry for those with an ID, who was a local hero to her patients, **used to say 30 years ago: "Any doctor worth his salt needs to be prepared to prescribe". Based on these clinical descriptions, in the Australian context, paediatricians and child psychiatrists need to collaborate for the sake of these children. Paediatricians should manage the highly prevalent developmental psychiatric disorders and child psychiatrists should provide psychopharmacological support and consult to the lower frequency disorders.**

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# Conference Review: The Good Childhood Conference, Melbourne

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The Good Childhood Conference was held at the Moonee Valley Racecourse in Melbourne on the 10<sup>th</sup> and 11<sup>th</sup> October 2013 hosted by Berry Street ([www.berrystreet.org.au](http://www.berrystreet.org.au)). **Berry Street's vision is that all children have a safe childhood, feel nurtured and have hope.** The primary focus of the conference was to ask: 'What sustains a good childhood? How can we best support those who have not experienced a good childhood?'

Hundreds of conference participants listened to keynote speakers from far and wide including England, the United States of America and Australia. The schedule of concurrent sessions was extensive and made choosing a challenge. Session streams included child welfare, out of home care, indigenous, therapy, family violence, wellbeing, language and communication, homelessness, disability and education.

**Maddie Witter's presentation "Foster Change by Building Hope" was particularly interesting.** As the co-founder of the Kipp Infinity Middle School in Harlem, New York, Maddie spoke about their success in working with disengaged youth in grades 5 to 8 who struggle academically. The key principle or take home messages were; 'hope is malleable and can be taught' and that 'hopeful people are successful people'. At the Kipp Infinity Middle School the focus is teaching and building upon students 'Hope, Persistence and Self Efficacy'. Maddie reports that these characteristics can be taught using the following four techniques;

## 1) Stamina

Maddie described stamina as a predictor of success. Stamina in this context refers to focus over time leading to achievement or expert status. At Kipp Infinity they work with the students to create periods of focus on tasks. They break down these periods into manageable and achievable time frames to build success in each individual. They work on strategies with the young person to assist them to re-focus when they lose focus or stamina.

## 2) Individualised Goals

Every student is supported to develop individual goals. They present their goals and progress towards them visually on any given day (e.g. through two comparison thermometers). The teachers also use this visual comparison as a modality for engaging the student in the act of reflection. Their pro-

gress that day is reviewed and if for example they are falling behind, the student is supported to understand what factors may be leading to this. Students are in essence, taught to build awareness of the factors that impact on their progress and to objectively explain why this may have occurred (e.g. "my court case is on tomorrow"). **This reduces the young person's tendency to internalise certain results as failures and therefore minimises the likelihood of them experiencing associated negative emotions.** It also allows them to learn about their barriers to goal attainment.

## 3) Cultivating Choice

The students are provided the opportunity to exercise choice and control throughout the school day and through person centred planning and tailored learning environments.

## 4) Calendars

Calendars are used to assist the student to map out their goals and the steps they need to take to achieve results. These are also used as a tool to engage the students in reflection and provide feedback.

Upon returning from the conference, I decided to Google Kipp Infinity Middle School and was greeted with the following striking statistics. The school currently has 358 children in attendance, 99% of the children are Hispanic or African American and 95% qualify for free or subsidised lunch. However, the most notable statistic is the student attendance rate of 97% for the teaching year 2012/13.

Maddie moved to Melbourne in 2011 and supported the development of a new school for incarcerated youth called Parkville College where she currently works. Maddie not only realised that so many of the children she was teaching were not attending school consistently or progressing academically due to overwhelming feelings of hopelessness, but went a step further to co-found a school based on an ethos of building hope, persistence and self efficacy within each student. This was an inspiring story of a professional woman whose vision and dedication has allowed these young people the opportunity to experience a better childhood.

# Review of Managing Madness: Mental Health and Complexity in Public Policy, Evidence Base.

Terry Sarten– School-Link Coordinator  
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Rosenberg, S. and Hickie, I. (2013). Issues 3. Journal of Australian and New Zealand School of Government. Brain and Mind Research Institute, University of Sydney

## Abstract

This paper explores the concept of collaborative care, particularly in relation to a range of new models of organisation and service that are emerging in response to one of the most problematic areas of public policy – mental health. These emerging models of coordinated mental health care are testing the limits of the evidence supporting coordinated care, and require critical evaluation. Myriad concepts of collaborative or coordinated care in health, including mental health, have created multiple definitions. Once definitional issues have been surmounted, however, the evidence for coordination of health care is reasonably strong. There is considerable research about which treatments and programs are best for people with a mental illness. There are few areas seemingly as complex as mental health, given that responsibility for policy and service lies across all three tiers of Australian government and across multiple jurisdictions. It also engages public, private and non-government sectors. Co-morbidities are commonplace, particularly drug and alcohol problems among younger people. Governments in Australia have traditionally taken responsibility for policy, programs and services, either as direct service providers or through contracting outputs from others. Yet the evidence indicates that for people with a mental illness, the best solutions are often not found in government but in the community and in organisations outside of government. New organisations and new structures are attempting more holistic management approaches, combining clinical care, community support, housing, employment and other services. This paper considers some of these new models in the light of existing evidence.

The key challenge facing continued reform in mental health is not uncertainty regarding programs or services, but rather how to drive coordinated care for consumers across departments, governments and providers. This review will highlight the key changes that must be made for the benefit of the millions of Australians with a mental illness. Such changes need to empower users of care systems to choose options that actively support coordinated and efficient care delivery systems.

**Review by Terry Sarten, CHW School-Link Coordinator**  
Sebastian Rosenberg and Ian Hickie from the University of Sydney provide a solid overview in this paper of the responses to mental health in Australia across the spectrum

of policy, provision and consumer experience. The authors acknowledge that services for those with mental illnesses **are a challenge for both government and NGO’s**. Joined up responses to counter the silo effect have long been advocated but this paper suggests that despite numerous reports, little has changed and that gaps in services remain where **“people get lost in the system, leaving themselves and their families vulnerable to significant health and social risk”**. It notes the many reports, policies and plans that have been produced over the last twenty years and the 50 separate statutory inquiries held between 2006 – 2012 and the recurring theme of policy and service silo’s.

***“While many agencies are engaged in the provision of services to people with a mental illness, public policy approaches are characterised by an ongoing concern for outputs such as occupied bed days and processes such as competitive tendering. This unintelligent approach leaves Australia largely outcome-blind with regard to the health, economic and social impact of mental health care (Crosbie 2009), and also generates a sense of unhealthy competition between service providers, rather than collaboration. A key finding of the Senate Select Committee of Inquiry into Mental Health in 2006 was that policy and service silos were preventing effective care”***.

***“Mental health is ideally suited to the development of a more integrated public policy approach because: it is complex and multi-factorial in causation; the knowledge and resources to deal with the issues are located across many sectors and do not lie exclusively within the public sector; there are a growing number of non-government agencies with shared goals in addressing the issue; and meeting multi-dimensional client needs will require the involvement of several agencies involved in service delivery, particularly for individuals with the most critical needs”***.

***“Governments and others are beginning to invest in a range of new models to deliver this flexible and integrated approach. This paper aims to present some of these models in the hope they are fully evaluated and add to our understanding about effective collaborative mental health care. Ending the enduring sense of crisis enveloping mental health in Australia depends on our capacity to develop new ways”***.

The paper discusses potential response that could fill these gaps focusing on case coordination and collaboration. Case coordination is cited as one area with an increasing body of supporting evidence. This is tempered by definitions and variations in the various models;

**“The challenge in relation to a review of care coordination is less about finding evidence of its effectiveness and more about actually pinning down a definition. While assumptions of common understanding are often made, the actual term used to describe care coordination in fact varies considerably and could include case management, collaborative care, inter-professional management, multidisciplinary care, shared care and team coordination, to mention just a few”.**

They note that the US Agency for Healthcare Research and Quality (McDonald et al. 2007) identified forty separate definitions of care coordination. The Agency was able to propose a considered summary definition based on its review.

**“Care coordination is the deliberate organisation of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services. Organising care involves the marshalling of personnel and other resources needed to carry out all require patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care.**

(McDonald et al. 2007):

*From an Australian perspective, the Mental Health Coordinating Council of NSW (201) in a review of the literature lists a useful set of key guiding principles for service coordination, indicating it should be:*

- person directed driven and centred;
- inclusive of family, friends, peers and community;
- culturally safe and appropriate;
- recovery oriented;

- socially inclusive and seeking to address discrimination; and
- tailored and suited to individual needs, consistent with individual preferences.

*It is suggested that this list include “services must be relevant – the right service at the right time and in the right place”*

*The authors note that even though settling on a definition is difficult, “there is little problem finding evidence to demonstrate the benefits of care coordination, both for chronic conditions generally and in relation to mental health specifically.*

The following quotes from Shergold, Considine and Lewis are a good snapshot of the complex weave of the various agenda’s that this paper attempts to capture in a useful overview of the Australian response to mental health needs.

**“There are too many silos between central, line and operational agencies. Often they fail to recognize that no-one has a monopoly on experience or wisdom. There are too many ambiguities of role between jurisdictions in the crucial interstices of Commonwealth-State responsibilities for health, education, aged care, and disability support and infrastructure development. We focus on jurisdictional cost-shifting: citizens listen and hear only blame shifting”. Peter Shergold, 2005**

**“Given the enduring problems it faces in Australia, mental health is a perfect example of the need for public policy to build on what is proven about the benefits of collaborative care, so as to develop new approaches to drive even greater cooperation between service providers. Older style models of managing through either hierarchy or market forces do not seem capable of generating this collaboration”. (Considine and Lewis 2003).**

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# The Challenge of Challenging Behaviour



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The most frequent complaint of parents with children on the autism spectrum is that other people don't understand why their children do what they do. The disapproving glares in the supermarket, the mumbled comments about poor parenting or the child needing "a good smack" show that other people often don't understand why challenging behaviour happens and what to do about it. There are varying levels of understanding across the professional community too. This is why Positive Behaviour Support (PBS) professionals<sup>1,2</sup> are reviewing the understanding of behaviour and support and promoting a modern evidence-based description that aims to help families, services and even behaviour specialists themselves.

The Aspect PBS team were inspired to review our own definition of PBS. We have aimed for the definition to be relevant and easy to read, to address common questions that occur and to embody the key values and principles of PBS so that we can build empathy for individuals on the autism spectrum and promote a positive behaviour culture. As part of 'Aspect Practice' we are also sharing our evidence-informed work around Australia with people with ASD, their families, communities and organisations committed to improving the lives of people with autism. We wanted to start a discussion and we welcome any feedback from the PBS and autism communities.

## What is challenging behaviour?

Challenging behaviour is persistent behaviour that causes difficulties and limits a person's ability to have a good life. It's called 'challenging' because it challenges everyone who supports the person to understand why it is happening and to work together to find a solution.

## Challenging Behaviour – why does it happen?

Challenging behaviour is part of an *interaction* between three things (1) an individual, their current and past experiences and what they have been taught (2) the other people in their lives and (3) the environments, communities and cultures they live in. We want to encourage a new culture where there is a careful use of language around behaviours of concern. We encourage parents and professionals to recognise that the ownership of challenging behaviour is shared among all elements involved in the interaction not just the individual. For example, it is more accurate to say

*"there is challenging behaviour" than to say "he/she has challenging behaviour".*

Just as people who use a wheelchair have a right to everyday environments that meet their specific needs and allow them to access life freely and fully, people on the autism spectrum are the same. We know that providing a predictable day that allows for choice and control and gives access to preferred activities, using strategies to support communication, social and sensory needs, having well organised and structured environments and learning activities that build on a person's strengths are all part of autism-friendly environments. We wouldn't say that a person in a wheelchair has 'challenging behaviour' for not walking up the stairs. In a similar way we should focus on providing autism-friendly environments where there is challenging behaviour rather than labelling or blaming the person.

Challenging behaviour is sometimes viewed as a deliberate refusal to do what is asked and the punitive strategies that can be used in these situations may make the situation worse. It is important to remember that autism is a complex and varied condition. There may be many reasons why the person *can't* do what is asked, other than that the person deliberately *won't* do it. This can lead to misunderstanding about the causes of and solutions to challenging behaviour and those muttered comments in the supermarket.

## What is PBS?

There are some 'quick fix' approaches that aim to stop challenging behaviours – a student is stopped from hitting peers at school once they are expelled, a person cannot take food from others at a cafe if they are locked in their home and don't go out, or they can't scratch their arms if they are forced to wear gloves. Although these strategies do stop challenging behaviour, they do not explain why it was happening and can result in people with disabilities having poor quality of life - as well as their human rights denied. One goal for PBS is to improve the quality of life for all involved and to respect personal human rights. We understand that providing good quality support for people on the autism spectrum requires additional knowledge that is beyond everyday parenting or teaching, as well as a range of supports. Without this additional knowledge and support (and despite everyone's best efforts) it is possible for there to be a mismatch between a person's support needs and



what is being provided to them. This mismatch can increase the likelihood of challenging behaviour. Unfortunately, there **are often no long term 'quick fixes' for challenging behaviour** and PBS is an approach that requires commitment and time for results to be sustained.

PBS is based in the science of learning and there is strong evidence for PBS as an effective approach for challenging behaviour. PBS is both *positive* and *proactive*. Positive means increasing and strengthening helpful behaviours **through 'reinforcement' (not using punishment or negative consequences to reduce the challenge)**. Proactive means anticipating where things may go wrong and preventing them from happening rather than just reacting when things do go wrong.

Collaboration & coordination: A first step in PBS is to build collaboration and consultation with all of those involved. Each person has unique knowledge they can contribute to understanding the situation and the development and implementation of consistent strategies once these have been agreed on. PBS recognises that families are life-time supports and experts on their children and should be at the centre of all communication and decision-making.

Assessment: The Aspect team do an assessment of a **person's quality of life, individual strengths, abilities and support needs** and how well these are being met and can identify which services may be helpful in a particular situation. The team also completes an investigation into the challenging behaviour, often through observation and data collection. PBS understands that all challenging behaviour has a purpose **or reason (this is called the 'function')**; it is not random or meaningless. It is important to complete an assessment of the behaviour to work out *why* it is happening and then to teach an appropriate behaviour that replaces the challenging behaviour and gets the same identified need met. *It is essential to complete an assessment before agreeing on strategies.*

Intervention: Following the assessment PBS develops a support plan that has a number of parts. These include: developing an environment that minimises and removes the things that make challenging behaviour more likely to occur, as well as promoting positive behaviours; developing and reinforcing an appropriate behaviour that replaces the challenging one (this might be a new communication skill,

learning to wait or to manage anger appropriately); a plan to respond to the challenging behaviour and teaching other new skills as needed. The intervention plan needs to be implemented consistently across settings over time and its effectiveness reviewed and evaluated.

### Who can help?

A range of services and supports exist to help individuals on the autism spectrum, their parents, teachers and others to get the information and strategies they need. Ultimately, Positive Behaviour Support is done by the individual, their family members, carers and teachers and other staff who see the person every day; but there may also need to be specialist support. There are a range of types of services which can assist where there is challenging behaviour and this depends on each individual situation. Aspect has developed a series of resources and checklists to help families and support services to make the most of Positive Behaviour Support and these are available on the Aspect website. [www.aspect.org.au/pbs](http://www.aspect.org.au/pbs)

We hope this information helps with understanding challenging behaviour from a Positive Behaviour Support perspective and that parents/caregivers will be less concerned by looks and comments in the supermarket and other misunderstandings.

### Key messages

- PBS is a scientific approach that aims to protect a **person's rights and to promote quality of life for them** and their families
- Discipline is often interpreted as punishment. True **'discipline' is the hard work of PBS that is evidence based** and promotes positive learning.
- Challenging behaviour results from an interaction between a person, those who support them and the environments they live in. It is **no-one's 'fault' but often reflects a mismatch between a person's needs** and what is provided
- **All behaviour has a purpose or 'function'**. It is important to work out what this is
- PBS is different from general parenting approaches or popular behaviour management programs in that it is purely positive and carries out an individualised comprehensive assessment of the individual and the behaviour and closely matches the intervention to the assessment considering the function
- PBS means we work positively and proactively
- Team work and consultation is an important part of PBS
- It includes an investigation or assessment *before* working out our individual support plan
- We implement our support plan consistently across settings and over time.

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# The Medicine Cabinet: Adverse Reactions

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## Introduction

All medications and in fact anything taken into the body are foreign substances to the human body and thus may have wanted as well as unwanted effects. The desired effects are those with positive outcomes to the person taking them. The unwanted (adverse effects) are those that are described as side effects as per "A response to a drug which is noxious and unintended, and which occurs at doses normally used or tested in man for the prophylaxis, diagnosis, or therapy of disease, or for the modification of physiological function"<sup>1</sup>. There are also adverse events or mishaps associated with medication use and these are occurring also at an alarming rate – amongst the general population the incidence can be as much as 1-2% of all hospital admissions costing about 1% of total health care budget<sup>2</sup>. Adverse drug events are defined as any injuries resulting from medication use including physical harm, mental harm or loss of function<sup>3</sup>. Although some of these are avoidable these are not the reactions that will be covered in this article.

When assessing a new medication, there are many phases in the evaluation process. Prior to the beginning of the 20<sup>th</sup> century, the medical profession and associates relied on observation to identify herbs and therapies that were worthy. With the advancement of science, a scientific approach was developed by the Federal Drug Administration (USA) and other regulatory bodies for the clinical trials associated with new therapies and substances for human and animal use. These started with laboratory analysis followed by clinical study.

Then, as a result of the worldwide thalidomide disaster in the 1960s and other medications, there was increased testing and surveillance of clinical trials. Medications had to **have proof of safety as well as 'substantial evidence' of a drug's efficacy in the clinical trial setting**<sup>1</sup>. For more information about the history of clinical drug trials see [www.fda.gov/AboutFDA/WhatWeDo/History/Overviews](http://www.fda.gov/AboutFDA/WhatWeDo/History/Overviews)

Today pharmaceutical medications go through a thorough and rigorous investigation process which includes:

1. Preclinical testing – subject to extensive chemical, toxicological, and animal testing.
2. Clinical testing phase 1 – safety and pharmacological profiles determining actions and dosing, involves small number of healthy volunteers
3. Clinical testing phase 2 – pilot efficacy studies – controlled studies

4. Clinical testing phase 3 – extensive clinical trials - clinical trials by practicing physicians to patients with the actual targeted condition
5. Clinical testing phase 4 – post marketing surveillance<sup>2</sup>

Adverse reaction lists are then compiled from the phase 3 and phase 4 trials and this is part of pharmacovigilance or drug safety - collection, detection, assessment, monitoring, and prevention of adverse effects with pharmaceutical products<sup>8</sup>. Serious adverse events from phase 2 usually means that further investigations will be halted and going back to the drawing board. Most new drugs coming onto the market would have only approximately 1,500 patient exposures and only for a short period of time prior to the marketing of the medication ie after phase 3 trials. Phase 3 testing usually occurs in small homogenous populations and then once marketed the population experiencing the medication initially can be millions. However there are some drugs that cause very serious side effects but at very low frequencies. Phase 4 testing is usually the time when patients who would normally not fit into clinical trials ie have more than one clinical condition would use the medication. This would include the patient with intellectual disability and autistic spectrum disorders (ASD) and paediatric patients if the medication is not specifically designed to treat that condition.

Thus, it is important that adverse reactions to medications be reported as the rarer significant ones will only be picked up during post marketing surveillance. It is the responsibility of all to report the adverse drug reactions (ADRs) to help compile the list of known adverse effects. The post marketing surveillance is maintained by the Therapeutic Goods Administration (TGA) branch of the federal Department of Health through a 'blue card' system <http://www.tga.gov.au/consumers/problem.htm#medicine>. The pharmaceutical companies also have an obligation to report any adverse reaction reported to them to the TGA. Even if not previously reported this might be the first or not connected to the medication at all.

### *Identifying a causal relationship*

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**“It is the responsibility of all to report the adverse drug reactions (ADRs) to help compile the list of known adverse effects...”**

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A scale was developed – Naranjo scale for determining ADRs. This is a numerical scale of 10 questions to help determine the probability of an ADR<sup>5</sup>.

1. Are there previous conclusive reports on this reaction? Yes (+1) No (0) Do not know or not done (0)
2. Did the adverse events appear after the suspected drug was given? Yes (+2) No (-1) Do not know or not done (0)
3. Did the adverse reaction improve when the drug was discontinued or a specific antagonist was given? Yes (+1) No (0) Do not know or not done (0)
4. Did the adverse reaction appear when the drug was readministered? Yes (+2) No (-1) Do not know or not done (0)
5. Are there alternative causes that could have caused the reaction? Yes (-1) No (+2) Do not know or not done (0)
6. Did the reaction reappear when a placebo was given? Yes (-1) No (+1) Do not know or not done (0)
7. Was the drug detected in any body fluid in toxic concentrations? Yes (+1) No (0) Do not know or not done (0)
8. Was the reaction more severe when the dose was increased, or less severe when the dose was decreased? Yes (+1) No (0) Do not know or not done (0)
9. Did the patient have a similar reaction to the same or similar drugs in any previous exposure? Yes (+1) No (0) Do not know or not done (0)
10. Was the adverse event confirmed by any objective evidence? Yes (+1) No (0) Do not know or not done (0)

#### Scoring

- $\geq 9$  = definite ADR
- 5-8 = probable ADR
- 1-4 = possible ADR
- 0 = doubtful ADR

This can help in determining the probability of the reaction being medication related and thus needing to avoid the medication in future times especially if the reaction cannot be tolerated.

Once established there are many reasons why there is an adverse reaction. They can be due to the action of the medication on the body through other receptors such as the dry mouth and constipation association with amitriptyline (See Table overleaf).

As the collection of adverse reactions requires all to be vigilant and report, when using new medications or also medications that have been taken for a long period, adverse effects should be reported. More reports, with as much information as possible, the better the true picture of the incidence of adverse reactions in a given population – this is pharmacoepidemiology.

By reporting to an external authority one has the opportunity to add to other evidence and possibly prevent the event happening to someone else or a more serious event happening.<sup>8</sup>

By reporting to the Australian database, this is then reported to Uppsala Monitoring Centre which is the WHO international Collaborative Centre for Medicine Safety and contributing information to the worldwide surveillance system.

Reporting adverse reactions can be done by consumers through the Adverse Medicines Line at National Prescribing Service on **1300 134 237** during business hours and further information <http://www.nps.org.au/contact-us/adverse-medicines-events>

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Further reading

1. <http://www.who-umc.org/graphics/24753.pdf> WHO news-letter Pharmacovigilance: ensuring the safe use of medicines
2. <http://www.preskorn.com/columns/0311.html> Preskorn, S.H. Relating Clinical trials to Psychiatric practice: Part II. The gap between usual patient in registration trials and in practice. *Journal of Psychiatric Practice*. 2003: 455-61

Category	Definition	Examples
Allergy	Adverse reaction occurring in a susceptible patient involving an immunological mechanism	<ul style="list-style-type: none"> <li>• <i>Stevens- Johnson syndrome due to lamotrigine</i></li> </ul>
Side effect (predictable, dose related)	Any unintended effect of a pharmaceutical product, occurring at doses normally used and is related to the pharmacological properties of a drug	<ul style="list-style-type: none"> <li>• <i>Nausea from selective serotonin reuptake inhibitors antidepressants (SSRIs)</i></li> <li>• <i>Constipation from amitriptyline</i></li> <li>• <i>Hyperprolactinemia from risperidone and haloperidol</i></li> </ul>
Drug interaction	Interaction with another medication causing variation in its metabolism or pharmacological effect. May increase or decrease a medicine's effect	<ul style="list-style-type: none"> <li>• <i>Increased levels of aripiprazole with fluoxetine</i></li> <li>• <i>Lamotrigine and valproate</i></li> </ul>
Intolerance (unpredictable)	A lower threshold to normal pharmacologic action of a drug	
Toxicity/overdose (predictable, dose-related) Only unintentional overdoses are classified as ADRs ie due to error	Always dose related and usually occurs by the same mechanism as the therapeutic effect	<ul style="list-style-type: none"> <li>• <i>Renal failure due to lithium</i></li> </ul>
Idiosyncratic (unpredictable)	Adverse reaction occurring in susceptible patients. Mechanism usually unknown	<ul style="list-style-type: none"> <li>• <i>Interstitial nephritis with paliperidone</i></li> </ul>
Other	Pseudo-allergic reaction  (clinically resembling allergic reaction but mechanism NOT IMMUNOLOGICAL)	<ul style="list-style-type: none"> <li>• <i>Photosensitivity with chlorpromazine</i></li> </ul>
	Long-term drug effects <ul style="list-style-type: none"> <li>• Chronic use</li> <li>• Latent or delayed effects</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Tardive dyskinesia for typical antipsychotics</i></li> <li>• <i>Weight gain leading to metabolic syndrome from atypical antipsychotics</i></li> </ul>

# Interview with Paul Hutchins

## *Developmental Paediatrician The Children's Hospital at Westmead*

### **Paul Hutchins – Developmental Paediatrician.**

Paul has been with CHW for 34 years as a staff specialist. He trained in the UK. It was his experiences while training in the East End of London and the awareness of family adversity that led to a decision to work in developmental medicine. He came to Australia initially as part of an exchange programme and then took up a position with the CHW Child Protection team.

He describes the core of his work as the continued development of collaboration between health, education and families. This has included being involved in the establishment of the **Children's Hospital Education Resource Institute (CHERI)** and national and international work on ADHD and the NSW Stimulant Committee. He also has an interest in the development progress of 'gifted' children.

**Q: What are the biggest changes you have seen in the field of ID?**

**"The biggest changes in the field of intellectual disability** have come from an increasing awareness of the biological element of differences and their interaction with environment".

**"The science such as twin studies, has led to knowledge and responses in management that can result in an improved quality of life for those with an ID".**

**"This knowledge and understanding of the biological influences is critical – 50% of adult mental health has its roots in childhood developmental differences, which emphasises the importance of early intervention and also helps parents to understand that they do not need to blame themselves".** The field of genetics presents a constant flow of new knowledge emerging at incredible speed. The last two years have brought a huge change in what is known".

**Q: What do you see as cause for optimism and caution?**

**"The move towards seeing things as being on a spectrum,** rather than once size fits all, has lifted the potential for early intervention when at the milder end of the spectrum with better outcomes.

On the caution side – politicians and policy makers are still fixing labels- people are more than labels.

There is a critical need for more child psychiatrists to respond to the growing need".

**Q: What are the favourite aspects of work?**



**"Working with the world class team at the Child Development Unit at CHW that uses evidence based knowledge and is linked to professionals here and worldwide - and it is a public service ensuring access for all children and families. (I do not do private)**

**Q: Is the term intellectually disabled now the common word or are there international differences?**

**In the UK, the term used now is 'learning disability', which I think, is creating some confusion. In the US they have moved to drop the term 'retarded' which had very negative connotations".**

**Q: What are your views on the outlook for Mental Health & Intellectual Disability?**

We now know more about how to intervene early and improve quality of life but the competition for funding is problematic. The challenge is how to respond to an aging populations needs and those presenting in child health. If politicians and policymakers understand the value of early intervention, we can get better outcomes. The other aspect is that there are very few working in the field of ID & mental health so the skill resource is small.

**Q: Current projects**

I am heading to Vietnam in a week as part of supported professional exchange – which is a great way to be able to offer expertise that other countries cannot afford to access. It will be the first time to Vietnam but it is something I have done in a number of other countries.

# Trajectory: Changing the Direction

Terry Sarten  
CHW School-Link Coordinator

Health and Human Rights both provide leverage that can be applied to improving the life trajectory for the most vulnerable citizens. At a population based level, health can advocate for the provision of accessible services and act as ethical guardians. Human Rights advocacy provides a view that takes in the bigger picture that lies outside the influence of health. Both perspectives need to be harnessed to ensure the quality of life for those with an intellectual disability and mental illness. *“The recognition of human rights as a determinant of health opens up avenues for intervention in the pursuit of improved public health that may not have been realized in the past” (Exploring synergies between human rights and public health ethics: A whole greater than the sum of its parts. Stephanie Nixon<sup>12\*</sup> and Lisa Forman<sup>3</sup>. BMC International Health and Human Rights 2008, 8:2 doi:10.1186/1472-698X-8-2)*

All the papers listed below examine and report from different angles on the status of Australia’s response to those with an intellectual disability and mental health conditions and the potential for a more unified approach.

Like the Russian Matryoshka nesting dolls, these papers sit within one another, each an outcome within another place along a trajectory. All illustrate the critical need for sectors to work together on both the Human Rights and health fronts to improve the quality of life for those children and young people identified as being in this vulnerable section of the population. The final paper provides a picture of how the strengths of each can effectively reinforce the work of the other.

**UN – Convention on the Rights of Persons with Disabilities:** *concluding observations on the initial report of Australia, adopted by the Committee at its tenth session (2-13 Sept 2013)*

The perspective provided by the UN report captures both the positive steps and areas of concern for Australia. It acknowledges and commends the adoption of the National Disability Strategy 2010 – 2020 as a mechanism for implementation of the Convention across jurisdictions. It notes with approval the introduction of the national disability insurance and the Australian Law Reform Commission inquiry into matters of equal recognition before the law.

The report notes the Committee’s concerns around the degree of participation by those with disabilities and their representatives in the development of policy and legislation and the level of resourcing available to organisations that provide advocacy and support. It also recommends that the State strengthen the Disability Discrimination Act 1992 to more clearly cover the all those with a disability including

children, woman and children, indigenous, hearing impaired, deaf and those with psychosocial disabilities.

**Left Behind- Monitoring the social inclusion of young Australians with self-reported long term health conditions, impairments or disabilities:** 2001- 2009. Professor Gwynnyth Llewallyn, Professor Eric Emerson, Dr Anne Honey, Dr Maina Kariuka – Faculty of Sciences University of Sydney.

This report gathered and compared measures of social inclusion of those aged between 15 – 29 with and without disabilities over the years 2001- 2009. This showed significant differences. Disabled young people were less likely to be employed, engaged in education and more likely to be living in a jobless household, have low economic resources and experience financial stress/material hardship. They were also more likely to have mental health illness and poor overall health. Over the nine year time period young disabled people in Australia were up to five times more likely to have experienced multiple disadvantage and entrenched disadvantage. The report highlights the widening gap between the living conditions of disabled and their non-disabled peers. Although not specifically measured within the bigger picture presented in this report, the gap is sure to be even wider and the life trajectory for those with an intellectual disability and a mental health illness a much tougher one.

**Intellectual Disability and Mental Illness:** *The RANZCP paper Oct 2012*

The Royal Australian and New Zealand College of Psychiatrists take this further in the October 2012 position paper, Intellectual Disability and Mental Illness. It focuses attention on the relatively high prevalence of mental ill health (psychiatric and neurobehavioural disorders) in the population of those with an identified intellectual disability. This difference across all ages is 30 – 40%, a threefold increase in prevalence over the general population. They also add that there is further 1% with unidentified ID with even higher levels of mental health problems.

The RANZCP paper draws attention to particular sub-section of populations such as young people with autism. A proportion of them will have intellectual disability with clinically significant levels of psychopathology at times.

The high rates of mental ill health, poor general health and shorter life expectancy of those with an intellectual disability have been documented in the National Health and Hospitals Reform Commission report in 2009.

The paper includes reference to the many reports and studies that have consistently noted the lack of services and



training psychiatrists, mental health and general practice in assessing and meeting the needs of those with intellectual and developmental disorders. This is described as a form of **systemic discrimination**. To quote the RANZCP; “The lack of specialist services, barriers to accessing mainstream services and the lack of specific expertise results in poor standards of care and poor outcomes, such as individual suffering, indiscriminate chemical restraint, poor health outcomes, increased carer burden and costs to the community”. In 2010 the RANZCP set up a Special Interest Group in Intellectual and Developmental Disabilities to promote the study, research to advance understanding and improve the lives of those with intellectual/developmental disabilities and mental health problems. A focus of this group has been on advocating for specific training for health professionals and recommendations on health policy that advance the mental health needs of those with intellectual/developmental disabilities a priority.

**The Involuntary Detention of People with Intellectual Disabilities – Human Rights in Australia:** Human Rights in Australia Oct 30<sup>th</sup> 2012. Author: Bernadette Mc Sherry, Professor of Law and Director of the Centre for the Advancement of Law and Mental Health, Monash University.

A related publication is an article by Professor Bernadette McSherry in Human Rights in Australia. The Involuntary Detention of People with Intellectual Disabilities (published Oct 30<sup>th</sup> 2012) examines the laws in relation to detaining those with an intellectual disability in Australia. While all states have guardianship laws that enable decision making where the individual is considered unable to make their own decisions some states have other laws that mean a person with an intellectual disability can be held in a certain facility without their consent for indefinite periods of time. Section 32 of the Guardianship and Administration Act 1993 gives the Guardianship Board the power to order a person under guardianship to be detained in a specific place. This power is underlined in the statement that the **Guardianship Board may ‘authorises the persons from time to time involved in the care of the protected person to use such force as may be reasonably necessary for the purposes of ensuring the proper medical or dental treatment, day to day care and wellbeing of the person’.**

In both Victoria and Queensland there is legislation that enables the indefinite detention of individuals with an intel-

lectual disability who have been charged with or convicted of an offence punishable by imprisonment. (As a New Zealander I must acknowledge there is a similar piece of legislation there called the Intellectual Disability Compulsory Care and Rehabilitation Act)

Professor McSherry highlights in the article the human rights gap in state laws where a person may be placed in indefinite detention in a secure facility having been found ‘unfit to plea’ because of intellectual disability. She notes that at the time of publication (Oct 30<sup>th</sup> 2012) work had begun on a High Court challenge to the constitutional status of laws that allowed those with an intellectual disability, who have been found unfit to plea, to be held in prison indefinitely. She notes that Indigenous Australians with intellectual disabilities are over represented in this context. The variations across Australian States around this aspect of the law is an important issue in itself as presents a potential national abrogation of duty in terms of human rights.

**People with mental health disorders and cognitive impairment in the criminal justice system:** Cost-benefit analysis of early support and diversion. UNSW & PWC.

A perspective on the realities and systemic cost of this position is evident in a cost-benefit analysis of early support and diversion in a study done by UNSW and PwC. Titled ‘People with mental health disorders and cognitive impairment in the criminal justice system’ it outlines, using case examples, the human and financial benefits of effective early assessment, support and cross sectorial/ disciplinary work.

Opening with statistics of the known prevalence of mental health conditions, psychotic disorders, intellectual disability and brain injury in both the general population in NSW and those in the criminal justice system, the differences are starkly apparent. Young people with mental health disorders and/or cognitive impairment are at least 6 times more likely to be in prison than their non-disabled peer group in the general NSW population. For Aboriginal young people, the potential for becoming a client of Juvenile Justice is 13.2% compared with 1.4% for non-Aboriginal.

The Justice system provides one of the few areas where relative costs can be calculated. Unlike other aspects of social intervention, legal consequences can be accurately counted. The cost of juvenile justice services, institutional stays and custodial time and engagement with health professionals can all be quantified with some accuracy. The case examples illustrate how the potential for intensive early intervention could have affected both the individual personal outcomes and the longer term costs. The trajectory traced by the case examples illustrate how earlier intervention had potential to make a huge difference. In a case study of a 20yr old, in the total combined cost of Police, Juvenile Justice, health and other agency involvement was calculated as \$5,515,293. These costs are shown to have fallen considerably with engagement at age 18yrs with NSW ADHC Community Justice Programme.

**The study’s authors propose this shows that if the young person’s intellectual disability and personality disorders**

had been identified as a key factor much earlier, it may have modified the history of involvement with the justice system, self-harm, physical abuse and trauma and the onset of other mental health illness.

The paper reinforces the need for policy makers to regard early intervention services for those with intellectual disability and mental health illnesses as an investment in future outcomes rather than a cost burden on the State.

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**“At the inter-sectorial level government departments need to continue building and implementing collaborative practice...”**

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**Exploring synergies between human rights and public health ethics: A whole greater than the sum of its parts.** Stephanie Nixon

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This paper argues that the interests of human rights and public health intersect and have a synergy that benefits both. **“The balance of this paper articulates how an approach that combines human rights and public health ethics can make a comprehensive contribution to the normative analysis of health issues than either approach made alone”.**

It sets the growing disparities in health and wealth within nations and internationally as a challenge for both fields. It quotes Jonathan Mann’s call for a collective approach to emerging health issues that encompasses medicine, public health ethics and human rights as a starting point for this paper. **“Mann’s thesis about the interconnectedness of health and human rights contributes to the understanding of what makes people healthy or ill [47]. This recognition that the protection of human rights is itself an important determinant of health is largely absent from the discourse on determinants”.**

The authors are very clear on the human rights obligations of states toward their citizens as a critical fulcrum. **“At a time when many developed country governments are reducing public expenditures on health, and after decades of structural adjustment programmes that have forced the same neoliberal reasoning on developing countries, a refocus on states’ legal obligations to progressively realize the right to health of all citizens offers added ammunition in both advocating for public health and, where necessary, litigating for specific health care services”.**

They note the current debates over what constitutes healthy public policy and the role of the private sector in delivering health care and the human rights doctrine that places responsibility for health with governments rather than the view **“:that health is a commodity that ought to be regulated by the market”.**

Although it does not specifically discuss disability, the focus in the paper on the issues around the right to health and public health ethics is very relevant to the particular concerns of those who work with mental health within the intellectually disabled child/adolescent population in Australia and internationally.

**The author’s sets out how public health ethics contributes to human rights by reinforcing the normative claims in international human rights law, which strengthen advocacy and the links between public health and human rights.** In the other direction the contribution of human rights comes from defining the right to health and the indivisibility of rights alongside the duty of states to respond to the health needs of population and the acknowledgement and inclusion of human rights as a determinant of health.

This last point is particularly relevant in countries where indigenous peoples and other vulnerable population groups health needs are being considered. The paper discusses the human rights lens as an effective viewpoint in addressing the health concerns of marginalized individuals and populations, with a reminder of the 10-90 gap. This refers to the 10% of global health research resources spent on **90% of the world’s health issues.** The influence of human rights is seen as crucial to encouraging public health to act on the **‘chronic neglect of issues facing the world’s most vulnerable populations.**

**Health as a ‘free-standing’ human right has been incorporated into various international treaties and regional human rights systems and these rights have become more than simply advocacy rhetoric but actual enforceable legal rights.** In their summary the authors see the **‘soft’ contribution of ethics as contributing and complementary to the ‘hard’ legal frameworks of human rights with both reinforcing what they describe as the untapped potential for collaboration between public health and human rights and the contribution rights and ethical standards can make to achieving more equitable outcomes across populations.**

**Summary:** All the above papers consider an aspect of the life trajectory for those with an intellectual disability and mental health problems. The issue of policy design across the ministries of welfare, justice, health and education is evident in all of them. Within the big national perspective there is a duty that comes with signing international protocols and building nationwide law reform that reinforces the rights of those with disabilities. At the inter-sectorial level government departments need to continue building and implementing collaborative practice. The communities of Australia need continued encouragement to support those with intellectual disability towards equal access to health services and social inclusion.

# Simon: A Very Special Olympian!

## Benefits of Exercise on Children and Adolescents with Intellectual and Developmental Disability

Jodie Caruana

*School-Link Coordinator  
The Children's Hospital at Westmead*



Recently I cheered on the Mens Basketball team at the 2013 Special Olympics Asia Pacific Games in Newcastle. The determination of the athletes was equally matched by family and friends watching and wildly cheering them on from the stands. All players had a talent and contributed something unique to the team. After the winning match the players were elated and posed beside their proud mothers and other relatives for a photoshoot akin to the professional league.

For those who haven't heard, the Special Olympics strives to create a better world by fostering the acceptance and inclusion of all people especially those with an intellectual disability. According to the Special Olympics, sports participation can shift the focus from disability to ability, from isolation to involvement. Special Olympics offer regional, state, national and international participation and competition in an array of sports.

Simon is a special Olympics Ambassador and has been competing in the Special Olympics for five years. He was selected to represent Australia in the Asia Pacific Games for basketball and his team won bronze. The highlight of Simon's involvement is the social contact. "The best parts of representing Australia were meeting people from different countries and meeting new people from different parts of Australia. Also walking into the Hunter Stadium wearing the Australian Uniform and winning the bronze medal for Australia". Simon trains twice a week, once golf and once basketball. He participates in quarterly regional competitions.

Simon's mother and carer Annie reports "My intention was for Simon to have fun and be involved in something other than reading and watching television. At first I did think 'how was he to cope?', as he is not very athletic, but I was proved wrong. His golf is exceptional for someone who has not received professional training and his height is an added bonus when he competes in basketball". "The socialisation for mums is very therapeutic. We meet for lunch or breakfast and compare giggles. As parents we do a lot of brainstorming when we meet, we catch up on the latest news for carers. For example there were some grants being offered recently which I heard about through networking with other parents which enabled me to apply".

I quizzed Simon and Annie about the benefits of participation in sport. Simon had positive things to say about meeting new friends and being excited when competitions were close. Annie reported "Physically his extraordinary transformation in body shape, he has really filled out in the upper body even though he only trains twice a week. At first the coach and I were very concerned as he would go bright red in the face and tire very early through lack of oxygen which would bring on his asthma. But now he can stay on court for hours and hardly gets tired at all".

Annie highlights the sense of community that is a result of Simon's involvement in the Special Olympics. "As far as a sense of community is concerned the Special Olympics has contributed so much to Simon's life. There are discos, birthdays and fundraisers." Annie hasn't noticed any differences in sleep patterns or moods since participating in exercise but his self esteem was noted- "Simon is not a competitive person at all and if he loses a game he always says 'at least I gave it a go'. But when he wins, he talks about it for days. He once said to me 'Mum I never thought I would ever be an Olympian!' - that's our benefit!"

### Benefits of Exercise on Children and Adolescents with Intellectual and Developmental Disability

The Special Olympics caused me to reflect about sport and exercise and its relationship to health, mental health and wellbeing. We have all heard about the physical and mental benefits of exercise: expends energy, improves fitness and circulation, lowers heart disease, clears the mind, alleviates



stress, mild depression and anxiety but what about the benefits for children and adolescents with developmental and/or intellectual disabilities. I wanted to find the evidence. Like a hunter I hunted, my eyes scanning the written text whereby I swiftly realised the need for more large scale evidence.

Children and adolescents with developmental and intellectual disabilities experience greater rates of obesity than the general population. De, Small and Baur (2008) reported that in their study of 95 2-18 year olds visiting a developmental assessment clinic, 24% were overweight and 15% obese (a total of 40% combined). De et al note that compared to a study of school aged children the same year a total of only 23% were obese or overweight. De et al reported no significant differences across ages, sexes or level of intellectual disability or global development delay.

De, Small and Baur 2008 report that childhood obesity is associated with a number of health problems, including diabetes, hypertension, sleep-disordered breathing, orthopaedic complications, abnormal lipid profiles, stigmatisation, bullying, future risks of heart disease and cancer. They note that children with developmental disabilities have predisposing factors for obesity including co-existence of certain genetic conditions for obesity, use of anti-epileptic and anti psychotic medications that can cause weight gain combined with reduced levels of physical activity.

Lotan et al (2004) from Israel suggest that lack of physical fitness in those with an intellectual disability may lead to rapid ageing. In their study within a special school, they investigated a short term daily treadmill intervention. Children presenting with poor physical fitness demonstrated significant improvement. 15 children aged 5-10 years (4 mod ID, 8 severe, 3 profound) exercised daily over 2 months for an average of almost 20 mins per day. The children were test-

ed 2 months prior to, at the start and end of the intervention. Prior to the intervention the children walked for an average of 6.7 minutes, by the end of the program this had increased to 28.8 minutes. Speed also increased from 1.7 kph to 2.7kph, rates improved significantly for rest and during effort during the intervention. The researchers also found a correlation between functional ability and improved cardiovascular fitness.

Lack of physical activity by children with developmental and intellectual disabilities is not only an individual problem but lies within our social structures. Johnson (2009) reports that people with disabilities are less likely to be engaged in physical activity due to lack of access and lack of information on appropriate activities, lack of support from community and nature of disabilities. Johnson describes that this can lead to decreased circulation, poor self concept and decreased independence. In their meta-analysis documented benefits include: improvements in aerobic capacity, gross motor function and high levels of participant and parent satisfaction. Johnson notes that outcome measures should include assessment of social benefits, self esteem and body image.

A meta-analysis looking at 16 studies on exercise involving 133 children and adults with ASD by Sowa and Meulenbroek (2012) concluded that exercise does benefit motor and social skills with an overall improvement score of 37.5% across all studies.

Running in particular has a small evidence base that it may reduce aggression, self stimulation, and disruptive behaviour. Four case studies indicating the benefits of running **were reported in Sowa and Meulenbroek's (2012) meta-analysis**. One case study did report the significant reduction of aggressive behaviour of a 24 year old male as reported by staff members after a 20 minute daily running program (Allison et al 1991). Another study by Celiberti et al 1997 reported that physical self stimulation decreased and a 50% reduction in disruptive behaviour after three 6 minute jogs per week by a 5 year old, whereas walking had no effect. In a third study by Nicholson et al four 9 year olds with **ASD (2 high functioning ASD 2 Asperger's) jogged for 12 minutes three times per week for 2 weeks** and academic engagement time increased. In a fourth study by Rosenthal -Malek and Mitchell (1997) 5 males aged 14-15 years jogged for 20 minutes, self stimulatory behaviour reduced and work related performance increased (correct academic responding and number of completed tasks).

Oriel et al 2011 examined the effects of aerobic exercise on academic engagement in younger children with 9 ASD (3-6 years). They found that after 15 minutes of running 7 of the 9 students improved in correct responding. 5 of the 9 improved in on task time- however results were not statistically significant. Improvements were observed to continue for 30 minutes after exercise. Kern et al noted this threshold as being 90 mins.

McMahon and Gross 1987 found that self concept and physical fitness improved in a study involving 54 boys with a learning disability aged 7-12 after participating in aerobic



activity (distance running, aerobic dance and variants of soccer) for 25 mins, 5 days a week for 20 weeks when compared with a control group. No changes in academic achievement were observed.

Gabler-Halle, Halle and Chung 1993 describe several studies in their critical review on the effects of aerobic exercise on psychological and behavioural variables of individuals with developmental disabilities. In one study by Allen 1980, 12 1<sup>st</sup> – 5<sup>th</sup> grade boys participated in a 5-10 minute aerobic period (walking jogging or running) 3 days per week for 6 weeks reduced number of disruptive classroom behaviours by half for boys with behavioural and/or perceptual disorders. The greatest reduction in behaviours was noted the hour immediately following exercise. In a second study outlined by Gabler-Halle et al (1986) involved 25 teenagers with mild or moderate ID who were assigned to a 10 week Special Olympics swim training program or control group. They found a significant increase in self concept (Piers and Harris Self Concept Scale) and cardiovascular endurance. Gabler-Halle et al 1983 conclude that there are varying degrees of relationship between aerobic exercise and positive changes in intellectual functioning, behaviour and self concept in children and adults with ID and the need for more research as existing studies are correlational only. They suggest that a higher intensity in aerobic workout seemed to show the greatest effect. They also highlight the importance of choice for individual in participation.

In my search there were no studies that looked at the benefits of exercise on anxiety, depression, stress, self esteem, hostility /anger in children and teenagers with intellectual and/or developmental disabilities, as with non disabled peers. The effects of social team sports such as basketball, netball, soccer or cricket need investigating with larger sample sizes.

What does the existing research mean for teachers, parents and other professional staff? Where possible it is best to encourage choice in exercise, ideally the more intense the better- however any time spent less sedentary is a start. Classroom teachers could aim to introduce sport before a challenging academic task. Parents can look for opportunities in their community such as the Special Olympics to get their child more active and as Special Olympics Australia describe to give “continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community.”

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# A Day in the Life of a Music Therapist

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Humans have used music as a tool for improving health for a long time and Music Therapists now work in many health care and education settings.

As an overview to music therapy the Australian Music Therapy Association (AMTA) uses the following definition:

*Music therapy is a research-based practice and profession in which music is used to actively support people as they strive to improve their health, functioning and wellbeing.*

Music engages so many areas of our brains and bodies, from memories to heart rate, personal preferences and emotions. While people have been playing, listening to and enjoying music for centuries, the more recent development and availability of scans (such as functional neuroimaging) for research purposes, has provided increasing knowledge about what is actually happening when we engage with music. Research has found that music can release neurochemicals in our brains including endorphins and dopamine which are linked to pleasure, oxytocin associated with trust, and when engaging with sad music, prolactin which has a consoling effect. The stress hormone cortisol has also been found to decrease in response to music and engaging in musical activities (Bartlett, 1993; Nakayama, 2009).



*An oncology patient enjoying music therapy with her family.*

While music is considered to be abstract sounds, it has an ability to communicate different emotions. This is partly because music can mimic our physiological responses to different emotional states- for example, slow and heavy sounding music is usually interpreted as very sad which reflects physical symptoms of fatigue and lack of excite-

ment. Compare this to faster and bouncy music reflecting **an elevated heart rate and 'bounce in your step' when excited. The differences in musical keys between major ('happy sounding') and minor ('sad sounding') have also been** shown to reflect how we speak when happy or sad. Music can be used to match emotional states and slowly alter to a more positive state. When we are not able to comprehend our emotional state or use words to communicate, the music we play expresses our physiological responses to how we are feeling. This ability to express and play our emotions allows a release of emotional energy, for example banging on a drum when feeling stressed provides a therapeutic release (Carr et. al., 2011; Winkelman, 2003). Song writing is another method used for self-expression as some people find it easier to express themselves through music and song lyrics.

**A music therapist's day starts with assessing who they will be seeing and the aims for that client.** There are a wide range of potential aims a music therapist works towards **from increasing the fluidity and speed of a client's walk to** having a client say their own name in a learnt hello song, a relaxation session or providing an opportunity for self-expression. One session may focus on one particular aim or the therapist may have multiple aims which are being worked towards. As an allied health professional, the music therapist often works as part of a multidisciplinary team and will regularly collaborate with other professionals (such as Occupational Therapists) in setting goals and undertaking therapy.

The music therapist then determines the best methods for achieving the aims. Music Therapists conduct both individual and group sessions, depending on the needs of the clients, and the goals of therapy. Generally having people playing instruments and singing no matter the level of skill, enhances the positive effects and engagement to the brain. Simply listening to music is also beneficial especially for relaxation. The type of music is also important with preferred and familiar music being of most therapeutic benefit. The adaptive nature of music is great as it allows the therapist to manipulate a familiar piece of music to be either faster or slower or change other elements to achieve the desired aim. For example: In a music therapy session with **an Autism class at a Special School, the song 'We Will Rock You' was used as a basis for a group song writing activity.**

The process of composing new lyrics as a group addresses goals of self-expression and communication. The performance of the song, with its strong, steady rhythm, promotes active participation, engagement, and emotional expression. A day would finish with assessing how the day had gone and planning as well and cleaning and maintaining instruments and equipment as needed.



(Image acquired from: <http://www.studydiscussions.com/music-and-music-therapy-courses-in-new-zealand/>. 20/2/2014)

### Case Studies

Erin\* is a 10 year old girl with Autism Spectrum Disorder who attended weekly individual music therapy sessions. The goals of therapy were to promote social and communication skills, provide an avenue for self-expression, and improve fine and gross motor skills. Interventions used to address these goals included a structured session that allowed for some elements of choice, call and response musical activities, exploration and improvisation on a wide range of musical instruments (such as drums, chime bars, boomwhackers, and percussion), song writing, movement to music, combining music with other artistic expression such as drawing, and teaching skills on piano including reading musical notation. Outcomes of music therapy included Erin displaying enhanced verbal, non-verbal and musical communicative skills, improved self-regulatory ability, longer attention span and engagement in activities, increased confidence in self-expression, and improved coordination of both fine and gross motor skills.

Oliver\* is a 5 year old boy with moderate to severe developmental delay. He is non-verbal, is in a wheelchair, and has limited movement and fine motor control in his limbs. Oliver attends weekly music therapy group sessions with four other students in his class. Goals for all students in this session include opportunity for emotional and self-expression through music, promoting purposeful independent movement and physical rehabilitation, and encouraging social communication and shared experiences with each other. A specific goal for Oliver was self-expression and improved self-esteem through vocal expression. In working towards this goal, the music therapist used songs that addressed each student individually in a turn-taking exercise, inviting responses either verbally or non-verbally. The use of anticipatory pausing, and repetitive phrases in these songs provided impetus for Oliver to vocalise (often in time and/or

pitch), often resulting in him smiling widely. Oliver would continue his vocalisations for extended times showing increased attention span and engagement.

\* Names have been changed

The following websites contain further information about Music Therapy:

<http://www.austmta.org.au/>

Website for the Australian Music Therapy Association, including a listing of Australian Registered Music Therapists.

<http://www.nordoff-robbins.com.au/>

A form of music therapy working predominantly with intellectual and developmental disability and mental health clients.

<http://daniellevitin.com/levitinlab/LabWebsite/about.htm>

The Levitin Lab with research conducted by musician, neuroscientist and author of *This Is Your Brain On Music*, Dr Daniel Levitin and colleagues.

<http://www.loc.gov/podcasts/musicandthebrain/>

Library of Congress podcast series on 'Music and the brain'.

### References

Bartlett, D., Kaufman, D., & Smekekop, R. (1993). The effects of music listening and perceived sensory experiences on the immune system as measured by interleukin-1 and cortisol. *Journal of Music Therapy*. Vol 7, Pp. 10-16.

Carr, C., D'Ardenne, P., Sloboda, A., Scott, C., Wang D. and Priebe, S. (2011) Group music therapy for patients with persistent post-traumatic stress disorder – an exploratory randomized controlled trial with mixed methods evaluation. *Psychology and Psychotherapy: Theory, Research and Practice*. Vol 85, Iss 2.

Nakayama, H; Kikuta, F; and Takeda, H. (2009) A Pilot Study on Effectiveness of Music Therapy in Hospice in Japan. *Journal of Music Therapy*. Vol 46, Iss 2, Pp. 160-72.

Winkelman, Michael. (2003) Complementary Therapy for Addiction: "Drumming Out Drugs". *American Journal of Public Health*. Vol 93, Iss 4, Pp. 647-651.



christine bigby & patsie frawley

social work practice and intellectual disability



# Book Review: Social Work Practice and Intellectual Disability

Christine Bigby & Patsie Frawley – BASW

*Practical Social Work 2010. Palgrave MacMillan, UK.*

*Reviewed by Terry Sarten – CHW School-Link Coordinator*

This book was chosen for review as it highlights both the importance of the social work role in work with intellectual disability and the continued need for professional development across all disciplines in response to new knowledge. Part of a British Association of Social Workers series edited by Jo Camping, this book is aimed at both students and those already in the profession who are looking to refresh and increase their understanding of this aspect of social work practice.

The forward, by Lesley Chepoweth, Professor Social Work at Griffith University notes the book is the first to focus on ID within disability despite the long history in the UK of social work involvement in this field and that, like social work, the disability perspective is grounded in human rights, self-determination, participation and choice. The book opens with a reminder that those with an ID are People First and are as diverse and individual as those around them. Although the focus is very much on the UK it does include **reference to Australia’s development of ID services.**

It is divided into 7 chapters: Understanding Intellectual Disability, The Social Problems of Intellectual Disability, Services to Support people with ID, Working with individuals to assess and plan support: initial steps, Planning, dilemmas and decision making, activism, advocacy and self-advocacy and Implementation policies for social inclusion.

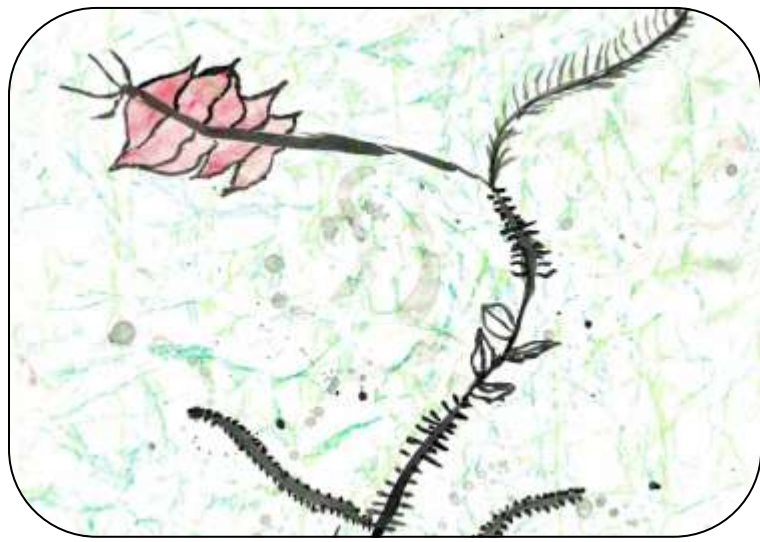
The book does not have a specific chapter on mental health and ID but does note this as another level of disadvantage amongst the key indicators of employment and income, appropriate housing and support and social inclusion. It tracks the changes in perspectives on ID and notes the Australian changes in understanding, quoting from a 1931 **edition of the Medical Journal of Australia: “There is no need in a journal such as this to refer to the great army of**

mental defectives in the community, their association with habitual drunkenness, prostitution, venereal disease and **crime, to their prolificacy; nor to the economic aspect”.** **The authors cover the 1970’s – 1980’s emphasis on normalization and human rights as a significant shift in ideas and in particular the contribution of Social workers such as Gill Pierce in Melbourne who played an important role in improving services for those with ID in Australia.** The small number of psychiatrists with specialist training is mentioned as a particular current feature of the health system in Australia.

There is a brief section in the book that makes direct reference to mental health and ID, the higher level of incidence and the difficulties of getting access to good diagnosis and treatment within generic mental health services. The issue of diagnostic overshadowing is discussed and the labelling of problems as behavioural linked to ID rather than mental health and the importance of psychiatric assessment is emphasised as a crucial path towards access, engagement and treatment of mental illness. Challenging behaviour is also emphasised as a point when a comprehensive **functional assessment “that includes all bio-psycho-social aspects of a person and their situation as well as the analysis of the behaviour can support the development of a multi-faceted support plan”.** **The authors note this is where the social worker advocacy role for a comprehensive assessment can potentially break a cycle of reactive responses that can in turn led to restrictive options.** The analysis stage of assessment is described as the key to reflective social work practice that considers the reasoning and values around decisions, with these being open to scrutiny.

Of particular relevance to social work with mental health and intellectual disability is a section that looks at advocacy. It describes a close fit between the aims of disability advocacy and social work.





## Reading List

**“While encompassing the social change agenda, advocacy also actively strives for equality of access to existing services and lobbies for additional and more appropriate services for individuals and groups.” (p.157)**

The authors suggest that the recent consultative approach has drawn advocacy into a formal process and they cite research that proposes this change has weakened the effect of advocacy in the disability sector. (Goodley 2001; Goodley & Ramcharan 2005) **The shift from the politicised approach in the 1980’s to institutionalise in the 1990’s has led to marginalisation in the current phase with the inference that consultation with government can mean a dilution of influence.**

The book provides a perspective on systemic advocacy and shared knowledge shaped into a collective concept as an effective vehicle for influence and sees strength in supporting self-advocacy as a means to inform and influence policy and service delivery. Although it is not explicitly stated, the **author’s position seems to be one of support for system activism as part of good social work practice in the disability sector.**

### Summary

The issue of mental illness in the ID population is not dealt with in any detail although it is noted as an under-resourced speciality. The section on advocacy offers a perspective on how the Social Work profession can be active in creating change but references research that indicates consultation with government can mean a dilution of influence.

As a NZ Registered Social Worker and ANZASW member, I understand the value of standards and ethics. They can provide a solid framework for the social work profession and promote the reflective practice needed around the complexity of working with those who have an intellectual disability.

The book’s focus is on creating a greater understanding of what constitutes good social work practice when working with people with an intellectual disability and it does this very well, being comprehensive, with relevance to the Australian context.

Bouck, E.C. (2014). The postschool outcomes of students with mild intellectual disability: does it get better with time? *Journal of Intellectual Disability Research*. Vol 58, Iss 6, Pp. 534-548.

**An American study that includes in-school experiences and data across 8 years.**

Chadwick, O., Kusel, Y., Cuddy, M. and Taylor, E. (2005). Psychiatric diagnoses and behaviour problems from childhood to early adolescence in young people with severe intellectual disabilities. *Psychological Medicine*. Vol 35, Pp. 751-760.

**An interesting read about the persistence of behaviour problems from childhood to adolescence.**

Gilmore, L., Campbell, m., Shochet, I., Roberts, C. (2013). Resiliency profiles of children with intellectual disability and their typically developing peers. *Psychology in the Schools*. Vol 50, Iss 10, Pp. 1032-1043.

**A positive outlook for children with ID with the use of the right supporting factors.**

Haysom, L., Indig, D., Moore, E., Gaskin, C. (2014). Intellectual Disability in young people in custody in New South Wales-Australia- prevalence and markers. *Journal of Intellectual Disability Research*. Jan 2014, No Pagination Specified.

**A good insight to a local issue.**

Holmes, L.G., Himle, M.B., Sewell, K.K., Carbone, P.S., Strassberg, D.S., Murphy, N.A. (2014). Addressing sexuality in youth with autism spectrum disorders: current paediatric practices and barriers. *Journal of Developmental and Behavioral Pediatrics*. Vol 35, Pp. 172-178.

**Great to read about the recommendations for this issue which seems to be an oft forgotten topic.**

Lecavalier, L., Kaat, A.J. and Stratis, E.A. Mental health disorders in young children with Autism Spectrum disorders. In, Tarbox, J., Dixon, D.R., Sturmey, P., and Matson, J.L. Eds. (2014). *Handbook of Early Intervention for Autism Spectrum Disorders: Research, Policy, Practice*. Springer, New York.

**A very useful handbook that is guides from research to practice.**

Tomlinson, M., Yasamy, M.T., Emerson, E., Officer, A., Richler, D. and Saxena, S. (2014). Setting global research priorities for developmental disabilities, including intellectual disabilities and autism. *Journal of Intellectual Disability Research*. Published online ahead of print. [10.1111/jir.12106](https://doi.org/10.1111/jir.12106)

**A great way forward in research.**

# Conference Report: The Second Annual ACI Intellectual Disability Health Network Forum

Associate Professor David Dossetor  
*The Children's Hospital at Westmead*

The Disability Network of the NSW Agency of Clinical Innovation (Dossetor, 2013) has been established for 2 years and the second Annual Disability Health Forum was held on 7.3.14. This was a valuable coming together of a range of interested parties and significant partners concerned for the health and welfare of people with Intellectual Disability (PWID).

To achieve better health outcomes for PWID, who usually have complex and chronic health needs, improvements in equity of access to health services, is vital. The pressing challenge is for mainstream services to have greater understanding of these health needs. This was illustrated by the recent **Rare Disease Day: as Steve Waugh said "400,000 people have rare diseases but few people know about them". Maria Heaton, Co-Chair of the Disability Network Executive and parent of a child with Lissencephaly reminded us that "PWID come as a package with their carers"**. This was a passionate forum with a strong sense of the inequity that PWID face both in the health and disability service systems in NSW. This report is not intended to provide **a comprehensive summary of the day's presentations**, which are available on the ACI website (<http://www.aci.health.nsw.gov.au/networks/intellectual-disability/id-forum-2014>). However presentations from key invited speakers expanded our horizons.

Kerri Lawrence, Manager of the Mental Health Strategy and Policy unit for the NSW Mental Health Commission, presented on behalf of John Feneley, the Commissioner. The Mental Health Commission was founded as an independent statutory body in July 2012 as agent of change and person centred reform in mental health to **'improve the mental health of all people in NSW'**. **At least one deputy commissioner must have 'lived experience of mental illness'**. There is also an advisory council of 16 members representing a diversity of the community. The question remains of how can the commission have an impact on PWID when there is no new funding for mental health services. There remains a disconnect for the mental health of PWID with the transition to NDIS, as much of the mental health problems are related to a lack of services and a lack of recognition of their needs.

Mary Hawkins, Branch Manager of National Disability Insurance Scheme presented on the rapidly adapting structure of the NDIS pilots which were launched 1.7.13. The aim of the NDIS is to limit cost but achieve good outcomes: by investing in things that help early, giving choice and control of services, demand driven not funding restricted, delivered

locally working to national coverage. The brokering will be through individual plans through setting goals, defining other supports and NDIS funded support. The provision of **'reasonable and necessary support'** has to show a reduction in disability and increased functionality, particularly through employment, which in turn reduces a need for support. Practitioners will have to demonstrate change, and the NDIS will be developing an algorithm of the evidence and effectiveness of different interventions. There will be different funding package levels for different levels of disability, using supported and substituted decision making for a child. The Hunter New England pilot already employs 76 staff, including 32 planners, 8 coordinators, 13 regional support officers and 22 support staff. There are 55 registered disability Non-Government Organisations, 357 registered service providers, and another 1500 eligible. 1221 plans have been completed. The scheme has been described as building a plane while flying it, emphasising the continuing modifications, including establishing an evidence base.

While the NSW Disability Services provided by ADHC will cease to exist as this funding is transferred to the NDIS between 2015-18, a range of functions provided will need to be provided within an NDIS context. This was a key message of the presentation from David Coyne, Executive Director of the Clinical Innovation and Governance Directorate of ADHC (CIG). This includes certain discrete services: the Integrated Services Program for people with a range of complex support needs and challenging behaviour, the Community Justice Program as a substitute provision to imprisonment, Regional Behaviour Intervention Teams, and Tertiary Behaviour Support as provided by the Statewide Behaviour Intervention Service. There will still be a requirement for policy development, practice leadership in the disability professional skills of occupational therapy, dietetics, speech therapy, physiotherapy, psychology and behaviour support. There will still be a need for practice development and research, adapting interventions for PWID, such as interventions (Dialectical Behaviour Therapy) for Borderline Personality, and Complex Management Review Panels for cases that are failing to progress. In Queensland and Victoria there are equivalent functions and some similarities of service as found in CIG in NSW.

Further the CIG has also funded some specific mental health initiatives such as the Chair of Developmental Neuropsychiatry and the Chair of Positive Behaviour Support at University of NSW, advanced training fellowships in MH&ID, and the memorandum of understanding between health/

mental health and ADHC. Negotiation with NDIS/A will need to occur in order to ensure these important initiatives continue to support the disability sector. David has summarised 6 key functions which are required in a new NDIS environment: Safeguarding; Practice Leadership, research and development; Innovation; Access to specialist tertiary consultation and support; Workforce capability and development; and monitoring and review. One proposed solution is that consideration be given to the establishment of **'centres of excellence' or hubs which have regional capacity** to deliver and contribute to tertiary clinical consultation, capability development and practice leadership. The NDIA could build on the exiting work in CIG but also in Queensland via the Chief Practitioners Office.

Kathryn McKenzie, Director of Systems Reviews at the **Ombudsman's Office (OO) presented on their role in disability**, such as the review of deaths of PWID in care (100/year) who die on average 30 years younger than the average population. The OO is concerned about access to medical treatment: behavioural problems prevent access for routine checks of blood pressure, teeth, eyes or breast cancer. There are problems of informed care and consent, a **dislike of hospitals, an aversion to touch or a fear they wouldn't cope** leading to missing out or refusing examination or treatment. PWID need special support for admission and discharge arrangements and planned and coordinated transfer of care from hospital back to their home. The OO hear of easily avoided system failures. They have problems of lack of access to community care for chronic ill-health and referrals to specialists to prevent recurrent acute admissions with chronic lung disease or diabetes. They also need greater support over lifestyle risks from obesity, reduced activity and smoking. They need coordination between Medicare Locals and mainstream services. Disability Reform is placing greater pressure for mainstream services to meet the needs of PWID. The NSW Disability Inclusion Bill 2014 has given the OO increased powers and they will be working to ensure appropriate and minimum safeguards over health provision, working in conjunction with the Australian Human Rights Disability Discrimination Commissioner, to resolve complaints.

Melissa Clements, Director of Disability Learning and Support in NSW Department of Education and Communities (DEC), presented on the education reforms of the last 5 years. The medical model has had a big impact on identifying and defining disability, but there is a need to move to measures of functional need, rather than diagnosis. The increased recognition of disability has required education to look at improving teacher skills to support special needs in a mainstream setting. Gonski will provide additional school funding based on the measures of disability. At present there is no national dataset but 24 different disability datasets. The legal framework requires DEC to treat all students with disability on the same basis as their peers, making reasonable adjustments, in consultation with parents and carers. Of 740,000 students, 12% (90,000) have additional learning needs, of which 80% are supported within regular mainstream classrooms.

Barbara Lewis and Jackie Small (Co-Chairs of the Network's Access and Equity subcommittee) presented on the mapping process of access to NSW Health for PWID. This provided evidence on the need for Local Health Districts to improve processes to enable greater equity of access for PWID. For example, most LHDs lack a specific point of contact for PWID or provide specific information or supports for them. There are few mainstream staff trained in the special health needs or routine processes to support PWID. The Forum saw snapshots of the videos developed by the Network to raise awareness and hear from clinicians about the health of PWID. There is little doubt that the 3 pilot Tier 4 Intellectual Disability Health teams have had a big impact both in specialist provision but equally through building awareness, partnerships and pathways into mainstream health services. With the attention on the NDIS in Hunter New England, there is an opportunity to enable the specialist health services for PWID at Stockton Residential Centre Clinic to be funded and remodelled as a Tier 4 Specialist ID Health Service,

Chris Shipway Director Primary Care and Chronic Services Agency for Clinical Innovation described the ACI methods of supporting consumer and clinician led change based on the **experience of the patient's journey, to enable LHDs to respond to best practice models of care**, using the skills of the health economics team and enhanced evaluation and research capacity. The Intellectual Disability Health Network needs to articulate a single approach to enable improvements across the whole spectrum of health from primary and community care to specialised and in-patient care. Not only is there a constraint on new funding for health, but more can be gained through building capacity and skills in mainstream services to improve access and quality of health services for PWID. Les White Co-Chair of the Network and the Chief Paediatrician for NSW led the discussion that promoted the notion that LHDs be required to show **'reasonable adjustment' for PWID which would pull together** much of the work done by the Network to improve the awareness and special processes that need to be considered for PWID.

## Reference

Dossetor D. 2013, Better Health Services for People with Intellectual Disability in NSW: the Agency of Clinical Innovation Disability Network. CHW School Link Newsletter Volume 4, Issue 1 Pp. 2-5, [www.schoollink.chw.edu.au](http://www.schoollink.chw.edu.au).



# Communication Passports in the United Kingdom and New Zealand

The National Autistic Society in the UK is promoting a new Passport to assist communication for those with autism.

**The autism 'passport' document explains the communication, sensory and support needs of the individual passport holder.**

Developed to assist higher functioning adults on the autistic spectrum who may be living independently and have learned to mask their autistic traits - which may mean they are not obvious to others - who might fail to recognise or understand the difficulties, especially in situations where health, welfare or employment needs are being evaluated. Although it was designed for adults to carry and use when it is difficult to explain their needs in stressful situations, it is a concept that could be extended to children and young people to ensure appropriate responses in emergencies or when presenting at health or social services.

The National Autistic Society website describes it as simple document; **"The passport can be filled in easily and can be presented in any situation, to social, health or employment professionals. Reading it will inform the recipient of the specific needs of the individual and help them to make the necessary adjustments to deliver a tailored and effective service".** To download a copy of the autism passport go to: [www.autism.org.uk/~media/nas/documents/publications/passport-to-individual-autism-support.ashx](http://www.autism.org.uk/~media/nas/documents/publications/passport-to-individual-autism-support.ashx)

The concept of a health passport has also been picked up in New Zealand where the Health and Disability Commissioner is working with District Health Boards (DHBs) throughout New Zealand to introduce the Health Passport into hospitals. This comes in the form of a booklet which can be used to provide details of a patient's communication and specific support needs. This can then be presented

when attending hospital or other disability services to ensure effective communication no matter whether that is local or in another part of the country.

The format covers many of the factors that relate to the communication needs of those with an intellectual disability and autism with the aim of assisting staff to gain some immediate understanding of that individual wherever the present. The passports have already been integrated into a number of health districts around New Zealand and the Health and Disability Commission supports the introduction of the passports to all hospitals and is working with relevant community organisations to facilitate distribution of passports to consumers on a nationwide basis. The following link will take you to the health passport site.

[www.hdc.org.nz/about-us/disability/health-passport/download-your-health-passport](http://www.hdc.org.nz/about-us/disability/health-passport/download-your-health-passport)

Here in Australia the Red Book was introduced by the NSW Department of Health to assist carers and health service providers with easy access to relevant health information and reduce the need for the client/patient to repeat their medical history when attending services. It is being used by some clinicians for patients with an intellectual disability or those with chronic conditions but has been limited in its take up by health professionals as it is considered difficult to capture all the relevant information in the current format, particularly around complex conditions.

*(Accommodation Policy and Development Directorate Ageing, Disability and Home Care,*

*Department of Family and Community Services NSW March 2007, amended September 2010, April 2012)*

[www.adhc.nsw.gov.au/\\_\\_data/assets/file/0007/228094/Health\\_Care\\_Policy\\_and\\_Procedures\\_April\\_2012.pdf](http://www.adhc.nsw.gov.au/__data/assets/file/0007/228094/Health_Care_Policy_and_Procedures_April_2012.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 [http://www.pau.nsw.edu.au/Visual\\_arts/Operation\\_Art/index.htm](http://www.pau.nsw.edu.au/Visual_arts/Operation_Art/index.htm)

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