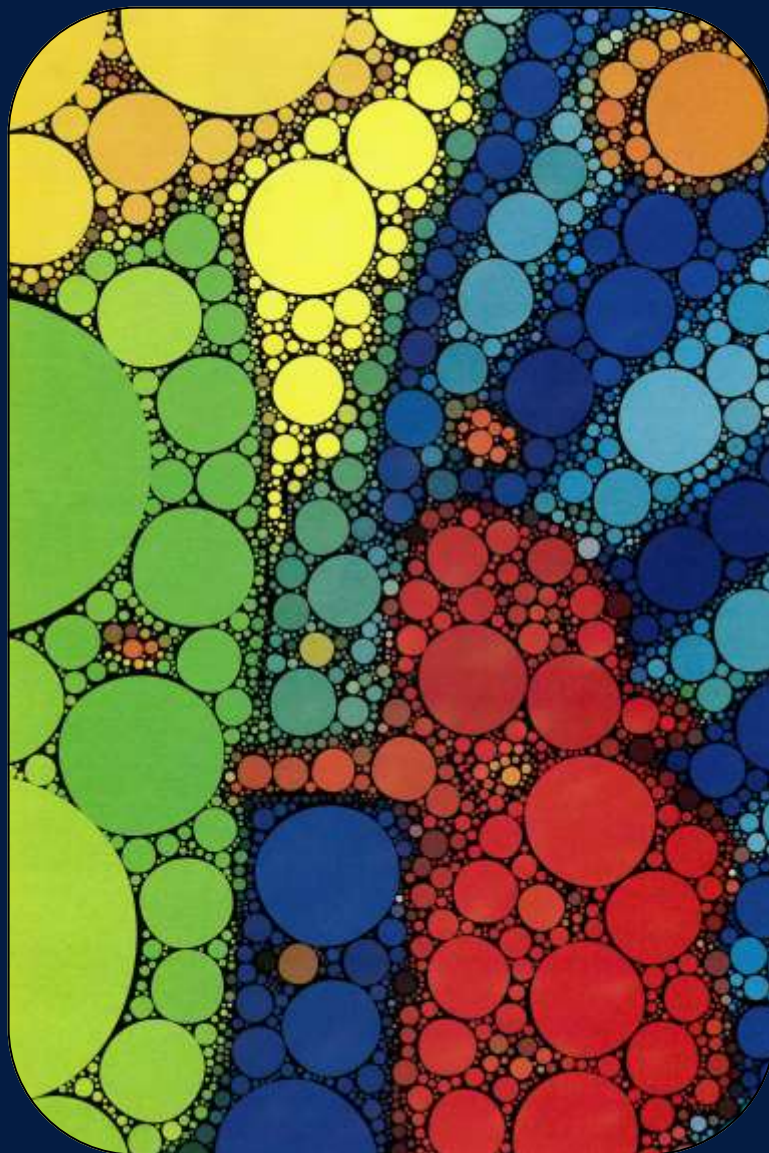


Journal of Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities: *An Educational Resource*

Volume Seven, Issue One, 2016. ISSN 2203-6687, SHPN CHW 160051



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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. We are extremely proud to present these ideas and invite you as authors to help develop this field and the knowledge base to help support children and adolescents.

On our Website:

www.schoollink.chw.edu.au

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

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

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Welcome to the first edition for 2016,

2015 was a busy year for School-Link as Hebah and I embarked on a journey around New South Wales to facilitate discussions on making adjustments to support the mental health of children and adolescents with an intellectual or developmental disability (IDD) in the classroom. Over 28 sessions were held from Broken Hill to Wagga Wagga to Tweed Heads and Ulladulla. Over 1200 registrations were received for this train the trainer workshop. We would like to thank the schools and School-Link coordinators who hosted us. 76% of participants said they would like to deliver the session back to staff. The Meet Jessica animation and accompanying resources will be uploaded onto our webpage by March 2016.

We hope you enjoy this edition of the journal. Highlights include:

- **Dr David Dossetor's article on aggression**-which is a fascinating insight into the complex nature of aggression, its function and possible management strategies that can be useful for parents and professionals alike.
- **Matthew's story is an honest and raw reflection** from Janine and Leonard, parents of a teenager who has experienced significant aggressive behaviours and how they are managing, despite the many challenges they are presented with.

- Deb Corfield and Lesley Whatson remind us that sexual development follows a typical sequence for everyone, with and without a disability, and that a proactive approach to sexuality education is paramount to promote health and safeguard against harm. The article suggests some excellent resources on the topic.
- An interview with Sue Foley as she begins a new **chapter as director of the children's court**. Sue reflects on her social work career and the important work that she lead under CAPTOS to help build and share mental health knowledge and services around the state.
- Judy Longworth presents the evidence on medications to treat anxiety in children with IDD when SSRI medications are not effective.

Enjoy reading this edition of the journal and please send any feedback or your own contributions to schoollink@chw.edu.au

Happy reading!

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Violence in children and adolescents with an intellectual disability and the importance of safety.

Associate Professor David Dossetor
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"It is easier to build strong children than to repair broken men."

— Frederick Douglass, 19th century American black social reformer.

Introduction

Family violence has benefitted from greater attention and has become not just a criminal but a public health issue with our Australian of the Year being recognised for her stand on domestic violence. In a civilized society, as our new prime minister says, we should have zero tolerance for violence whose roots come from a culture of failure to respect (women). Tackling this culture will no doubt help improve the mental health of many. Violence is defined as behaviour involving physical force intended to hurt, damage or kill someone. Aggression is a range of behaviours which can be physical, verbal, mental or emotional that can result in physical or psychological harm. Abuse is exploitative aggression in the context of an unequal relationship. Over half of adults and children with intellectual disability engage in aggression, although for only a minority is it frequent or severe (Benson *et al*, 2008; Matson *et al*, 2005).

Yet we live in the least violent time in history. As documented by Stephen Pinker (2011), this is due to the rise of democracy with the separation of law making, from legal process (courts) and law enforcement. It is also due to the rise of education and the greater empathy skills that arise from reading, leading to the decline in violent confrontation and the rise in collaboration and compromise where both parties benefit. These principals apply to the raising of children including those with intellectual disability.

Aggression is divided into impulsive or affective aggression, and instrumental or predatory aggression. The implication is that affective aggression is a failure of emotional or cognitive regulation whereas instrumental aggression has malice aforethought to cause hurt to another. The latter requires considerable mental development to have such awareness and insight of harm to another. In those with intellectual disability affective aggression is more common, and functional analysis subdivides affective aggression into the main subgroups of: attention demanding, task escape or avoidance, demand making, or for a sensory need. How-

ever for some this changes in different situations and in others no purpose can be identified. Aggression as a human attribute becomes as stable as intelligence by the age of 10. This is also confirmed in those with intellectual disability where longitudinal study shows that the presence of behaviour disturbance at 23years (mean age) is best predicted by the presence of behaviour disturbance at 12 (Einfeld *et al*, 2006), although it does decline a bit with time. But how can we understand aggression from the context of child development?

“affective aggression is a failure of emotional or cognitive regulation ”

Aggression and normal development

Did you know that toddlers are the most aggressive people on the planet (Pinker, 2011)? Of course they don't know it as initially they don't understand that their behaviour and feelings have impact on others. They are discovering their emotions, which progressively differentiate from an awareness of a level of arousal: too high to too low, where best human functioning is a calm alertness in the middle, to notions of internalising and externalising of affect: anxiety versus anger. These differences occur in the context of developing a theory of mind, whereby a child learns to match and compare emotions and thoughts with their primary attachment figure. Learning to compare and modulate feelings and thoughts in relation to others is at the heart of developing social skills. These social skills define us as a social animal and enable us to belong to families, communities and the human race. These skills are central to developing attachment, from which we learn the skills of making friends and contributing to creative reciprocity with others.

The normal pattern of behaviour development is that infants, as they grow older and develop motor skills, become increasingly active, exploratory, demanding and intrusive until the developmental age of 2-3years. At this age they develop their capacity of theory of mind, which has histori-



cally been described as the human spirit, involving the development of their internal world and awareness that others also have such consciousness. Their energy is then channeled internally into their imagination and their externalising **activities moderated. A parent's role is to teach them mutual respect, collaborative social skills and the benefits of positive attachments (love) with themselves and with others before they are too big and strong that their natural aggressive capacities become dangerous to others.**

Failure of this learning which Bruce Perry describes as types of parental empathy failure sometimes becomes engrained in the personality (Szalavitz & Perry, 2010). Psychopaths are amongst those who have miss-learned these skills and use violence to calm themselves or even for pleasure. Such clinical observations have contributed to the need for zero tolerance and the expanding of prisons to protect communities. Borderline Personality Disorders have problems in negotiating relationships with both problems of aggression and self-injury. They can benefit from long term specialised treatment approaches such as dialectical behaviour therapy. This evidenced-based treatment similarly involves negotiating safety and behaviour control, before focusing the therapeutic relationship on emotional wellbeing and relationships and problem solving.

Parenting skills especially for difficult children in difficult circumstances

Parenting skills are key to socialising aggression and learning to control and express anger in socially acceptable forms of thoughts and behaviour. The coercive pattern of parenting is a powerful explanatory model of the way in which parents allow their behaviour be determined by the intensity of affect from their child, when they give way to the distress or threat of aggression from their child and give them what they want (Patterson, 1982). This process reinforces the currency and power of aggression and intermittent reinforcement (by giving way sometimes), and teaches

the child that using emotional or physical threat is worth persisting with because it works. Parent training programs are dramatically helpful especially in preschoolers, before a child has a sense of permanence of self, as good or bad (Eldevik *et al*, 2009; Centre for Reviews, 2015). They both reward better, socially contributive behaviours, and inhibit aggressive or antagonistic behaviours accompanied with sufficient monitoring, for example knowing what the child is up to at all times. Structured activity and participation is another proven component to improving behaviour. After the age of 7 helping aggression takes a much more intensive and prolonged intervention as it involves changing established behavioural and emotional patterns, and changing self-concept and reputation (Mazzucchelli & Sanders, 2011; Scott *et al*, 2015). These processes for those with delayed development, are slower but the susceptibility to change also persists to an older age. Helping young people with delayed development requires greater understanding and skills such as Stepping Stones Triple P or the Incredible Years Program.

Where self-worth and family communication and relationships are vulnerable, there can be a recrudescence of aggression in adolescence which may be resolved by escape from troubled family relationships into independence. There is no doubt that hormones and brain immaturity contribute. This has been described as the maturation of the emotional circuitry in early teens before the higher functions of the frontal lobe control systems in the early 20s.

For those with an intellectual disability, rates of emotional and behavioural disturbance are related to their developmental age, much more than their chronological age. They remain in their developmental toddlerhood much longer, which influences both their capacity to learn emotional regulation and theory of mind, and are accordingly slower to improve. This applies to people with ASD where emotional understanding, theory of mind and social skills are specifi-

“the vast majority of people with serious psychiatric disorder are not violent”

cally delayed behind other developmental skills. However, in delayed development it is clearer that behavioural interventions to regulate behaviour and habits, and teach compliance, comes first before the development of an understanding of emotions and attachment.

Violence is not a psychiatric disorder

So often people link violence with psychiatric disorder. However the vast majority of people with serious psychiatric disorder are not violent. Depression and mania are associated with increased irritability and thoughts of harm to self or others. Occasionally someone with schizophrenia has delusional ideas that the world is against them, or that a hallucination tells them to do something awful. But as already stated, most violent people have an established pattern of this maladaptive behaviour. Is it maladaptive? Threats and violence are very powerful behaviours, which gets you what **you want in many ways, but at someone else's expense and associated loss of quality of relationship** (eg. fear and hate). In fact violent people often attract other violent people to **'sort them out'**. **Alternatively it is a route to a more restrictive environment**, whether this is prison, or a community residence with restrictions on freedom to protect others. It is also a cause of premature death especially from accidents, and, despite tending to ameliorate with time, also leads to increased rates of depression and other mental health problems later in life. In childhood and early school attendance, peers recognise aggressive children very quickly and reject them from their social circle, leaving aggressive kids to associate with other socially excluded kids (Patterson, 1982).

I often explain that the neurotransmitter surges in rage are so great that if one attempted to block them in an attempt to prevent future recurrence, the client would be unconscious the rest of the time: like an anesthetic. The role of psychopharmacology in the management of aggression is dependent on finding an associated mental health disorder that can be modified with medication. For example treating **ADHD can have a dramatic effect on a young person's lack of emotional and behavioural regulation, and in turn their relationships**. What matters is whether the treatable psychiatric symptom is causally linked to the aggression. Sometimes traumatic, panic, obsessive or stereotypic driven anxiety can be treated and influence the frequency and severity of the anger and aggression. However, sometimes the anxiety is not related to the aggression. Indeed it is recognised that anxiety in a violent person is often a redeeming prognostic quality which may help them in moderating their aggression over time, possibly via engendering attachments, or encouraging people to persist in caring for them.

“He can't be naughty and be autistic”.

Why is there an epidemic of intensely violent autistic minors being brought to emergency departments? Emotional and behavioural regulation and wellbeing is one of the most important determinants for having a quality of life. Understanding and respecting the capacity every child has for autonomy and learning, despite their disabilities, is a crucial responsibility for every parent. All too often parents are permissive in their behavioural management, as they feel **victims of their child's developmental disadvantage, and feel sorry for and infantilise the child's competencies**. They often medicalise the explanation and therefore expect someone else to change the child they have failed to accept and respect. The increased recognition of this **developmental disorder has rightly led to parents' increased demand for skills and treatments for promoting development**, but has it also prevented parents for realising their primary responsibility for teaching emotional and behavioural regulation ie. learning to love?

Fetal Alcohol Spectrum Disorder (FASD)

Alcohol is a mutagen to the normal development of the brain in pregnancy. This is a critical piece of scientific knowledge for all binge drinking young women at risk of pregnancy. FASD children also often come from poor quality home environments, with abuse and neglect. Often by the time they are seen in child psychiatric services they are in better quality homes of foster care. They suffer a range of developmental disorders: ADHD, sensory processing disorders, coordination disorders, language and communication disorders, learning and memory difficulties, problems of executive function such as planning and sequencing skills, autistic spectrum disorders and particularly mood and behavioural regulation disorders. Part of their challenge is they often do not qualify as intellectually disabled (on IQ testing) and, despite the complexity and multiplicity of their disabilities, are not recognised for the level of support they need in a mainstream educational system. They often fail to **develop emotionally, socially and educationally and don't survive in school**. The rages of some of these young children seem to exceed most others I have been witness to. Helping them requires a combination of: understanding their domains of disability, providing the calm, persistence, warmth and encouragement of superlative parenting, support and intervention for them in the home, school and community, and determined pharmacological treatment of their ADHD, anxiety and mood lability. Providing all three requires loving families and a responsive health, mental health, welfare and disability system. I have seen caring families and their support services tested to the limit, but then witness the late development of a capacity in a young person for self-care, awareness of self and others and an interest in developing relationships that a year previously never seemed possible. This may be a lot to expect, but the costs of a dependent unemployed adult with a future of recurrent law breaking and substance abuse is likely to be considerably greater.

Challenging Behaviour versus Child Psychiatric Disorder

25 years ago the Training Resource Unit was set up by disability services to provide Applied Behaviour Analysis as the service solution to challenging behaviour, the then recog-

nised label of all severe emotional and behavioural disturbance in children and adolescents with intellectual disability. There is good evidence that behaviour intervention (ABA) including sensory intervention, relaxation skills, anxiety management skills, and emotional and cognitive behaviour therapy are effective interventions (Ali *et al*, 2015). Skill enhancement in self-help skills, communication, emotional understanding, monitoring and problem solving skills all contribute (See Dossetor *et al*, 2011). This requires a range of disability specific specialty professional skills. These interventions work to reduce the frequency and severity of aggression in a planned way but there is evidence that reactive management strategies also have a place in minimising the impact (Adams & Allen, 2001; Dossetor *et al*, 2011, Chapter 21). This also requires the monitoring of quality standards of practice to avoid excessive restraint and seclusion, which has been the blight of several public enquiries.

With the launching of the National Disability Insurance Scheme and closure of the State Disability Service we are at risk of losing the specialist therapeutic resource of skilled interdisciplinary positive behaviour support now provided by the Statewide Behaviour Intervention Service and Regional Behaviour Support Teams of the disability provision of NSW Family Services. They provide world class innovative treatment for the most complex cases in the state, such as play therapy, modified Trauma Focused CBT, Dialectical Behaviour Therapy, Systems Family Therapy and Parent Child Interaction Therapy for young people with intellectual disability, and then share their skills and train others around the needs of a challenging child. Is it possible that the NDIS will fund the non-government sector to provide this level of acute and multidisciplinary support?

I was recently confronted with the referral of a severely abused and neglected out of home care 12 year old, who started assaulting his case manager and carer as soon as I asked them to tell me what his problems were, (there being no one else to look after him). He had already seen 6 highly

regarded child psychiatrists and had so many established diagnoses: moderate intellectual disability, ASD, ADHD, attachment disorder, language problems, coordination disorder, oppositional defiant disorder, anxiety disorder, depression, possible bipolar disorder. Many treatments and psychotropic medications had been tried without significant benefit. If your development is so badly impaired and your aggressive behaviour traumatises both you and your carers, it is not clear that recognising these multiple psychiatric disorders in isolation to a specialist service system of care and welfare can possibly achieve much for someone who is a danger to others.

The Developmental Psychiatry Partnership (DPP) with Statewide Behaviour Intervention Disability Service

I have been privileged to be part of a tertiary interdisciplinary partnership between a small developmental psychiatry team, a small tertiary disability team and representatives from the Department of Education. Central to this partnership is conjoint work over cases of emotional and behavioural disturbance in young people with intellectual disability that have challenged their local multiagency health, disability and education services. Evaluation of some of these cases indicate that families valued the quality and sustained support that enabled them to keep on caring for a high needs and troubling disabled child. Other cases have relinquished care into long term respite. The traditional view of respite care is that respite is only part of a pathway to relinquishing care. What a simplistic view of families! We have had a number of children who have been relinquished for several months, but have then resumed family-based care (sometimes with a shared care arrangement), with ongoing support from developmental paediatrics and psychiatry, disability services, respite services and special education. All these cases involve high levels of aggression and violence in the context of a minor with intellectual disability.

One study in adults with intellectual disability showed treating 'challenging behaviour' with a major tranquilliser is not



effective (Tyrer *et al*, 2008). However to suggest all people with challenging behaviour and intellectual disability need the same treatment is facile. There is limited research available for drugs studies in children with intellectual disability and complex, often multiple, psychiatric disorders. Our clinical experience has demonstrated the importance of medications that treat ADHD, anxiety, depression, lability of mood, occasionally explosiveness, and excessively sexualised behaviour. These are the common psychiatric disorders associated with aggression. Often, adequate treatment of the comorbid psychiatric condition is necessary before other modalities or treatment can work.

Children that abuse their parents

Children are protected from abuse before the law, but parents are not protected from violence by their children. Human sensibility to the welfare of these parents still makes this a serious concern for others including professionals involved. It is distressing hearing the stories of a young person, often over 100kgm, hitting, kicking, throwing objects, leaving bruises and breaking bones of a parent. Police will intervene and take such a young person to hospital for review but most rages settle in a reasonable length of time and this is not the access route to an in depth assessment for what is usually an acute predicament in a chronic problem. Medical assessment will consider whether this is naughty/angry behaviour or a significant acute psychiatric disorder. Admission to hospital is reserved for high risk psychiatric disorders. It is a welfare issue when families feel **they can no longer tolerate their child's violence, with the breakdown of the family's capacity for care, custody and control.** There are concerns about Restrictive Practice Guidelines that sometimes lead to confusion over how to manage violence. These Guidelines are provided so that where restrictive practices are in the best interests of a minor, there are sufficient professional standards and monitoring to protect all involved.

These situations are complex: Parents have responsibility for the safety of their child with a disability and indeed the other siblings in the house. I regularly point out that parents have greater authority than police, doctors, courts or other support professionals for the care, custody and control of their children, at least till they are 16, and arguably until they have a capacity for informed decision making capacity (which may be even older). They can do anything in their powers to support and control their child, so long as they do not inflict hurt or harm. They are therefore seen as having all the power, but often it is the young person who may be as young as 7 who has the control over a parent by virtue of their strength and use of violence. In effect they have been

“Parents have responsibility for the safety of their child with a disability and indeed the other siblings in the house”



allowed to get away with terrorist-like tactics and to have an exaggerated control over their family.

Psychologically for a child, part of feeling safe is to know that your attachment figure (parent) is in charge. Feeling that your rage and loss of control is not under the control of a loving parent is an existential anxiety and threat. Swaddling an infant who is angry and thereby reassuring that such distress will pass is part of such security. Accordingly, those children, who have unsafe and unresponsive aggression, often respond to holding therapy. Holding therapy has been found helpful in ASD, as it teaches the parent that it is the child that lacks the skills of social engagement, and **helping them involves going into the child's social space** and teaching them human closeness which their autism makes them naturally avoid. I feel it is psychologically harmful for a child to be able to inflict harm to a parent. That a child is allowed to inflict distress, pain or injury is allowing them to establish an abusive pattern of behaviour. Sometimes this is fuelled by self-sacrificial attitude and behaviour from a parent. Conversely parental retaliation with hurtful punishment is not just harmful to the child, but sets an example of aggressive parental behaviour. Calm containment is needed for safety.

The key skill in parenting is not to allow aggression to influence a parent, and to contain and modify this behaviour without a show of anger oneself. It involves teaching alter-

native prosocial behaviours, with distraction or rewards (eg. differential reinforcement of incompatible behaviour). It involves teaching self-regulation skills (sometimes referred to as extinction of behaviour). Time sitting on the bottom stair, or time out in another room teaches the young person that only they are ultimately the only one in charge of their emotions and behaviours, and once they have re-established control, they are welcome to re-engage with others in the family for which they can be rewarded. Ultimately it teaches that aggression begets boredom, loss of influence and attention. (Where a child has regular predatory aggression, I feel that, with due family judicial process, a punishment of brief isolation is justifiable as parents can teach how the rules of our community work for crimes such as grievous bodily harm).

These approaches really do work with younger children, but older and larger minors may have well established patterns of behaviour. Frequently they are fuelled by an autistic misunderstanding of the world and sense of threat via any primary sensory modality, such as distress from seeing an obsessive fear, eg myna birds, or hearing a noise, or a temperature change, or some other stereotypic obsession. Often these provocations only make sense to someone with ASD. Nonetheless allowing a minor to inflict significant injury is harmful and can be dangerous. If such behaviour is not controlled in the home it tends to become generalised to other settings such as school.

The architecture of safety

In such situations, I feel parents have a responsibility to protect themselves by putting a strong door between themselves and an attacking child. It often helps to have a quiet room, sensory or chill out room. Often these extremely aggressive young people have major sensory sensitivities and the room needs to be adapted with personalised sensory experiences, such as a darkened atmosphere, cushions and mattresses for touch, pressure and proprioceptive experience, chewies, soothers, music, favourite visual entertainment etc. All of these sorts of contributions can be aided by a skilled occupational therapist and behaviour support therapist. Similar approaches have been shown to be effective with aggressive teenagers of normal intellect in mental health wards (Champayne *et al*, 2010). The principals include: creating a sense of safety, soothing through senses, distraction, stabilising through senses, creating positive associations, creating a sense of control, supporting appropriate expression and release, facilitating self-management (Sutton, 2011).

In extreme situations the room may need to be adapted so the young person is protected from self-harm, such as unbreakable windows, soft furnishings, mattresses round the walls, and even rubber walls. It is remarkable how having such a chill out room can start by providing a capacity to protect caring parents, but becomes a favourite place for the young person to go and play and seek sensory stimulation. Sometimes metre-square cushions or portable gym mats can be used to present a soft façade to an aggressive teen, while preventing access to hurting an adult, and can be used to corral the teen to their chill out space. Case examples demonstrate that such a capacity to set limits and

protect from harm can bring about changes in violence and behaviour when every other psychological or pharmacological approach had failed. Critically, the parents need to make these architectural modifications themselves. We need to build a repertoire of architectural modifications and **sensory supports from different people's experience**; I regularly recommend a split or stable door, for young people with profound intellectual disability, to restrict access but maintain visual and verbal contact. It can be viewed as creating a specialised play pen for a 100kgm 15year old developmental toddler! Parents and carers may also need to learn aggression minimisation skills that include self-protective skills, which are now mandatory training for all mental health professionals, and for many disability, care and teaching staff with government policies of zero tolerance. It is just as important to protect parents as it is staff of the caring professions.

What is the alternative?

Parents often fail to appreciate what capacity they have for making a difference, possibly like other trauma victims they feel frozen from taking such initiatives. Yet they have the authority, responsibility, and the long term relationship and often the love and commitment. The only alternative is to give up and relinquish care which is not an easy thing to do. Many care providers will not take on difficult-to-care young people as it requires high levels of staffing and staff skills (and high levels of funding). Once dangerous violent behaviour is established, it can take years for skilled management and developmental maturity to improve it.

The legal context

Actual violence is an offence, but if the offender is intellectually disabled, and lacks capacity to understand the offence and legal process, then they are dismissed under a section 32 of the NSW Mental Health Act (2009), as it is inappropriate to punish such innocence. However the responsibility falls to the family and the community to provide for, protect and intervene to help such violent individuals. So often there is no service willing to help, and a lack of guidelines on what families can do, especially when they feel they are the victims of the situation. I hope this article provides some guidance for such families, with further support from the involved professionals.

Conclusion

Dealing with violence in young people with intellectual disability is a common but complex problem. Frederick Douglass' quote reminds us that early intervention is the best way to avoid these problems, but valuing all children including those with disability and acting to prevent emotional and behavioural problems is not a strong enough part of our culture. Part of that culture is the acceptance and inclusion of disabled children by the wider family and community, to share the additional burden of care and need for attention. Accordingly we need to consider what best practice for this serious problem is. In tackling violence, clients and parents/carers are regularly injured and occasionally die.

Safety intervention can have a role whether the extreme violence is predatory, affective, insightful or dissociative,

although differences in the type of violence may alter the way it is managed. When one considers 'state of the art' of intervention to help young people with intellectual disability and recurrent violence, such approaches to safety intervention is an under-researched and little documented area. These issues have been considered mostly in institutions or group homes for adults with intellectual disability. Very little has been written from the perspective of a family faced with this challenge. Every case needs to be tackled individually with a practice-based-evidence approach. Clinical experience shows that safety interventions, if implemented in these extreme cases, works quickly in preventing further injuries and is an important contribution to changing the pattern of behaviour for the young person with intellectual disability. This in turn can have long lasting effects to improving their quality of life, independence and freedoms.

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Matthew's Story

A case study of safety Intervention

By his parents Janine and Leonard

Our youngest son Matthew, is a 16 year old boy with a diagnosis of Autism, Moderate to Severe Intellectual Delay and Generalised Anxiety Disorder (with secondary depressive features). Matthew is a large boy in stature at 6 foot tall, weighing 100kgs and is totally non verbal.

During the early years, Matthew seemed similar to most other children with Autism – self injurious behaviour, non verbal, fussy eater, extremely rigid with routines and behaviourally, slightly more difficult to control than his peers in special needs pre-school and special needs primary school. Despite many years of regular Occupational Therapy and Speech Therapy, Matthew unfortunately remained non verbal and his behaviours were increasing.

By the age of 10, Matthew's high level of anxiety and behaviours including biting, kicking, scratching, head butting and lashing out at others, became a regular occurrence. In consultation with our Paediatrician, we decided it was time to commence medication to hopefully assist with his anxiety and behaviours. After trialling different medications and fine tuning doses, we noticed some improvement up until the onset of puberty.

Matthew's anxiety and violent, aggressive behaviours were becoming worse. We were referred by our Paediatrician to the Specialist Disability Health Team and the Department of Psychological Medicine at Westmead Children's Hospital for review. After a case conference with all involved in Matthew's care, we commenced a new regime of a range of medications. With the introduction of the new medications and increases in dosages, came continuing significant weight gain – **this was making coping with Matthew's increasingly violent, aggressive behaviours extremely difficult.** After repeated suspensions from his Special School, numerous calls to the police and ambulance for assistance, many admissions to hospital and further changes in medications, life for our family was extremely difficult. My husband had to leave work to be able to care for Matthew during the regular suspensions and also to transport Matthew to and from school, when his anxiety was too high to travel on School Assisted transport – this becoming a very regular situation.

In March 2014, Matthew aged 14, had a major meltdown at school. He injured staff and was physically restrained by 6 staff until an ambulance arrived and administered Midazolam to calm him. Matthew was once again admitted to hospital and received a 20 day long suspension from school which, added to the school holidays, ended up 6 weeks in total.



During this suspension time, Matthew's violent aggressive behaviours became a daily event, due to not following his normal routine and not being able to comprehend why he was not going to school. The day before Matthew was due to return to school at the end of the suspension period, **Matthew saw the "school visual" on his visual calendar and immediately launched into the most violent meltdown we had seen to date. He severely injured my husband's shoulder and our house suffered extreme property damage – far more than the normal hole punched in the wall.** As we were now physically unable to care for Matthew, he was placed in Emergency Respite. Our family was in crisis and we were at breaking point. After a Case Conference **with all departments involved in Matthew's care, we had to make the most heartbreaking decision for Matthew to remain in out of home care for a period of 6 months.** Matthew had no comprehension of why he was living somewhere else with constantly changing carers and we were suffering with loss, grief and depression. During the 6 months, we visited with Matthew regularly and unfortunately, **Matthew's violent, aggressive behaviours continued whilst in Respite Care.**

Matthew finally returned to school after the long suspension on very short hours. His anxiety was at extreme levels and the school suggested we apply for a transfer to another school with more appropriate facilities. We did this and had to apply to have Matthew exempted from school for a short while, until a place was finally granted at a new, purpose



built SSP with a room within the classroom, that could be used as a “calming room”. **Matthew slowly transitioned to the new school on short hours and utilised the “calming room” with success, to regulate his emotions.**

In preparation of Matthew’s return home, we decided as a family to have the best chance of a successful transition home, we needed to make some vast changes in our lives. I too, left my employment to assist and support my husband care for Matthew, we sold our car and purchased an 8 seater van to transport Matthew safely to and from school and that we too, would set up a dedicated “calming room” at home. The room was completely bare, except for a single ensemble bed. In addition, we were able to receive some ADHC funding to have a couple of Matthew’s regular respite carers assist with Matthew’s transition in the home.

On Matthew’s return home, at times of escalated behaviour, Matthew was taught to go to the “calming room” to self regulate his emotions alone. He did this, but not without smashing many holes in the walls and door of the “calming room” and proceeded to eat the debris. To try and eliminate further property damage and to make the room more safe and comfortable, we affixed foam rubber mats to the walls, placed foam mattresses on the floor with a couple of large heavy duty cushions, placed a sheet of Perspex in front of the glass window, a viewing panel in the door and installed an air conditioner to keep the room at a comfortable temperature. The initial assistance from the carers in the home for a few hours daily was crucial to the success of the transition home for Matthew - the patience, dedication and compassion these carers displayed to Matthew and our family was outstanding. Successful strategies were amended and implemented and we as a family, grew more and more confident in handling incidents of Matthew’s escalated behaviour.

Matthew now loves the “calming room” and visits the room quite a few times a day – sometimes it’s just a nice quiet,

comfortable spot to rest, listen to music, eat after school snacks and most importantly, to safely self regulate his emotions when his behaviour is escalated. When he has finished, he calmly walks out of the room and continues on with his day – an absolute turnaround to what we had to endure in the past during incidents of escalated behaviour. **The “calming room” concept is available to Matthew at home, school and at the Respite Centre he attends. This concept, along with slight tweaking of medication doses, has significantly reduced the frequency and severity of Matthew’s escalated behaviour and provided him a place to self regulate his emotions.**

Matthew has now been home for 10 months – Matthew continues to display escalated behaviours, albeit less frequently and the “calming room” strategy has proved hugely successful, ensuring Matthew’s safety and the safety of those who care for him. His transition home has been so successful that when a Supported Accommodation spot was recently offered for Matthew, we felt confident as a family to continue to care for Matthew at home and declined the offer.

Our family would not have been able to get to this point, without the multidisciplinary approach from all parties involved in Matthew’s care – Department of Education, School, Respite, ADHC and the Dept of Psychological Medicine at Westmead.

Our family will be forever grateful for this assistance that has ensured the successful restoration of our son home with his family.

Reading List

Bertelli, M.O., Munir, K., Harris, J. and Salvador-Carulla, L. (2016). Intellectual developmental disorders: reflections on the international consensus document for redefining 'mental retardation-intellectual disability' in ICD-11. *Advances in Mental Health and Intellectual Disabilities*. Volume 10, Issue 1, Pp. 36-58.

Defining intellectual disability as a health condition is central to retaining it in ICD with significant implications for health policy and access to health services.

Chaplin, R., Roach, S., Johnson, H. and Thompson, P. (2015). Inpatient Children and Adolescent Mental Health Services (CAMHS): outcomes of young people with and without intellectual disability. *Journal of Intellectual Disability Research*. Volume 59, Issue 11, Pp. 995-998.

This is a UK based study, which indicated that young people with intellectual disability and mental disorders significantly improve clinically when admitted to hospital.

Commonwealth of Australia. (2006). Disability Standards for Education 2005. <http://www.education.gov.au/disability-standards-education>. Accessed November 2015.

The Disability Standards for Education 2005 (the Standards) clarify the obligations of education and training providers and seek to ensure that students with disability can access and participate in education on the same basis as other students. The Standards were formulated under the Disability Discrimination Act 1992 and came into effect in August 2005. The website also includes the 2015 review. The standards are reviewed every 5 years.

Grefer, M., Flory, K., Cornish, K., Hatton, D. and Roberts, J. (2015). The emergence and stability of attention deficit hyperactivity disorder in boys with fragile X syndrome. *Journal of Intellectual Disability Research*. Epub ahead of print for 2016.

This is an interesting study correlating ADHD and Fragile X in boys. Impulsivity seems to be a key factor.

Munir, K. (2016). The co-occurrence of mental disorders in children and adolescents with intellectual disability/intellectual developmental disorder. *Current Opinion in Psychiatry*. Volume 29, Issue 2, Pp. 96-102.

This is an interesting article that discusses mental disorders and IDD in response to the change in the DSM-5 and the ICD-11. This review had several key points; interestingly, co-occurring mental disorders in children with IDD are more predictive of major restrictions at educational or vocational settings than the severity of the IDD.

Shashi, V., Harrell, W., Eack, S., Sanders, C., McConkie-Rosell, A., Keshavan, M.S., Bonner, M.J., Schoch, K. and Hooper, S.R. (2015). Social cognitive training in adolescents with chromosome 22q11.2 deletion syndrome: feasibility and preliminary effects of the intervention. Volume 59, Issue 10, Pp. 902-913.

This American study has used social cognition training to some positive benefit.

Wang, M. and Singer, G.H.S. (2016). *Supporting Families of Children with Developmental Disabilities. Evidence-based and Emerging Practices*. Oxford University Press.

We have not read this book yet, which is on our post-summer reading list. This book provides a review of evidence on interventions for families of individuals with developmental disabilities across the lifespan. We are keen to read more about the different resources.

Wheeler, A.C., Raspa, M., Bishop, E., Bailey, D.B. (2015). Aggression in fragile X syndrome. *Journal of Intellectual and Disability Research*. Epub ahead of print for 2016.

Sensory issues and hyperactivity appear to be a predictor of aggression in this population. Both male and females were used in this study that was conducted by survey of caregivers.

We don't usually include fiction books so we decided to list a few works of fiction this time that deal with the world of developmental disabilities. If you have any favourites please send us an email to schoollink@chw.edu.au. *Of Mice and Men* John Steinbeck, *The Memory Keepers Daughter* Kim Edwards, *The Curious Incident of the Dog in the Night Time* Mark Haddon, *The Man who Loved Clowns* June Rae Wood, *Flowers for Algernon* Daniel Keyes, *The Rosie Project* Graeme Simsion.

Responding to Sexual Behaviours of Children and Young People with an Intellectual Disability

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Introduction

Children and young people with an intellectual disability have the same rights and similar goals, desires and feelings as their typically developing peers (United Nations, 1989; United Nations, 2006). This includes their aspirations relating to sexuality and relationships. Understanding healthy sexual development plays a key role in guiding how we shape and respond to sexual behaviours in children and young people with an intellectual disability. This is an area of practice that often raises a degree of apprehension and may leave clinicians wondering if there is something additional or different they should be providing. While some specialist knowledge is required, clinicians will have pre-existing knowledge and skills that can be applied to the presenting situation. They will also be influenced by their own values, beliefs and experiences. This article aims to provide scaffolds and resources to further help them in this work.

What is Sexuality?

“Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.”

Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed.

Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.”

(World Health Organisation, 2006)

Healthy Sexual Development

As with all forms of development, sexuality follows a fairly typical sequence. This is true for both people with and without an intellectual disability. An understanding of these developmental stages and milestones provides guidance in responding both proactively and reactively (Brennan & Gra-

ham, 2012; Family Planning Queensland, 2012; Johnson, 2015).

For example, toddlers are naturally immodest and openly **curious about their own and other people’s bodies and bodily functions**. By pre-school, children are more aware of gender differences and may engage in exploratory play, **taking the role of “doctor” or “nurse”**. Through their primary school years, children become increasingly aware of social rules and tend to be more modest, seeking privacy. It is also the time when the age old question of **“where do I come from”** is explored. In adolescence, young people experience puberty, sexual feelings and an interest in romantic relationships. The role of peers and body image also become more important as teens explore their self-identity. It is during this developmental stage, that young people reach the legal age of consent for sexual interactions, which is 16 years in New South Wales (Scott, 2014).

Throughout all life stages, healthy sexual exploration is a voluntary, spontaneous and playful information gathering process amongst equals. This means the children or young people involved are of similar age, size and ability level. Healthy sexual exploration is limited in the type and frequency of the behaviour(s) displayed. It is also easily redirected and balanced with interest in other aspects of life.

(Family Planning Queensland, 2012; Johnson, 2015)

A Proactive Approach to Sexuality

It is important to acknowledge that children and young people learn about sexuality in many ways. It is not *all* learnt at home or in the classroom, in the playground or online. Sexual knowledge, development and behaviour is shaped and influenced by a range of factors including the media (including social media), culture, living arrangements, the **child’s neighbourhood, the age of siblings, family norms, values and religion** (Johnson, 2015).

A proactive, educative approach is needed to promote healthy sexual development and provide safeguards against harm. This education can begin in early childhood with parents teaching the names of body parts, introducing the concepts of public and private places, setting bounda-

Framework	1	2	3	4
Domain	Sexuality	STIs/AIDS	Relationships	Health & hygiene
Possible sequence of topics (Figure one)	<ul style="list-style-type: none"> • Self-awareness and self-esteem • Body parts and functions • Puberty • Feelings • Sexual feelings • Being sexual <ul style="list-style-type: none"> ○ What does it mean? ○ Legal rights ○ Decision-making and assertiveness ○ Protective behaviour • STIs and HIV/AIDS • Pregnancy and contraception 	<ul style="list-style-type: none"> • Self-awareness and self-esteem • Sexuality • Sexual relationships, rights and responsibilities • Decision-making • Sexual health and diseases • HIV/AIDS • Signs of STIs • Transmission • Preventing diseases • Condoms: how to use and where to buy • Safe sex: practices and communication skills • Testing (STIs): rights and procedures • Treatment 	<ul style="list-style-type: none"> • Self-awareness and self-esteem • Feelings about others and choosing friends • Circle concept: different types of relationships <ul style="list-style-type: none"> ○ Communicating ○ Making friends ○ Maintaining relationships ○ Different things we do with friends ○ Appropriate behaviour • Sexual relationships • Consequences of being sexual • Caring for ourselves and our partner • Rights and responsibilities • Preventing STIs, including HIV • Problem Solving 	<ul style="list-style-type: none"> • Body parts and functions • Feelings: body awareness • Self-awareness and self-esteem • Nutrition and exercise • Feeling healthy and feeling ill • Health care • Contagious and communicable diseases • STIs and HIV/AIDS • Using medical practitioners and health services

ries for protective behaviours as well as preparing their children for puberty. Teachers and clinicians also play an important role in sexuality education, providing not only knowledge, but building skills and behaviour as well. Jones and Chivers (2011) proposed the following framework for sexuality education including a possible sequence of topics (See table).

There is a wide range of resources available to aid sexuality education. Some of these may be borrowed or purchased from *Family Planning NSW* (see http://www.fpnsw.org.au/disability_catalogue_2013_4.pdf). For organisations specialising in relationships and reproductive health in other states and territories please refer to the *Family Planning Alliance Australia* website (see <http://familyplanningallianceaustralia.org.au/services/>)

Special Considerations

When educating children and young people with an intellectual disability about sexuality it is important to consider their specific learning requirements and provide information in a way they can understand.

Special considerations may include:

- Building on their existing knowledge, skills and behaviours
- Providing additional time for them to process information and adjust to developmental changes: this may mean the same information is presented several times and in different ways

- Ensuring the clarity of language used (e.g., avoiding figurative language)
- Using visual supports to augment information
- Taking into account any sensory issues
- Ensuring significant time and focus is given to safety, protective behaviours and consent
- Helping to build the accompanying social skills, problem solving skills and decision making skills
- Providing information about social rules, boundaries and relationships (potentially through a Social Story™ format)
- Providing information and support to increase their ability to anticipate changes as well as potential consequences

(Hagiliassis, DiMarco, Gulbenkoglou, Iacono & Watson, 2006; Raising Children Network, 2013)

The *Raising Children* website (see <http://raisingchildren.net.au>) has further information and practical tips to assist parents, teachers and clinicians alike in their role of raising sexually healthy children. Family Planning NSW (2015) has also developed a tool to guide clinicians in supporting people with an intellectual disability (over the age of legal consent) to make their own decisions about their reproductive and sexual health. This is a useful companion to the **Capacity Toolkit (NSW Attorney General's Department, 2009)** when exploring an individual's capacity to consent.

When are Sexual Behaviours of Concern?

It is estimated that between 40 - 85 % of children will engage in some form of sexual behaviour before the age of 13 (Johnson, 2015). Despite this, many children and young people with an intellectual disability find their behaviour labelled as “deviant” or “problematic” even though it could indicate typical development.

“Children who are wrongly assessed as having problem sexual behaviour when they do not (a false positive) are at greater risk of being deprived other human rights.”

(Webster & Butcher, 2012)

As such it is imperative that clinicians seek to understand rather than label sexual behaviours. This requires a good understanding of child development and careful consideration of the social, cultural and family context within which the behaviour occurs.

Sometimes however, a child or young person’s sexual behaviours can be a source of concern – particularly if they are excessive, coercive, secretive, degrading or not among equals (Brennan & Graham, 2012; Evertsz & Miller, 2012; Family Planning Queensland, 2012; Johnson, 2014; Lamont, 2010; NSW Department of Health, 2005; Ryan, 1997; Pratt, Miller & Boyd, 2012).

- **Excessive** means it is occurring at a high frequency (or duration) to the detriment of the child’s interest and participation in other areas of life. E.g., a child spending most of their waking hours masturbating in their bedroom to the exclusion of other activities and time with family or friends.
- **Coercive** means a degree of pressure has been placed on the child to achieve compliance. E.g., the use of physical force, threats, manipulation, trickery or bribery.
- **Secretive** means the child has been encouraged to hide the behaviour and is prevented from talking about it. E.g., “you can never tell this will be our little secret.”
- **Degrading** means it causes humiliation to the child or loss of self-respect. E.g., naked selfies being emailed to classmates.
- **Inequality** means there is an imbalance of power, control and / or authority. E.g., sexual interactions involving a teacher and a student.

Overall, sexual behaviours tend to be considered a concern when they are developmentally inappropriate (i.e., reflecting sexual knowledge beyond their years), when they place the child or young person at risk of harm, when they cause offence to others, possibly because they break a social convention (i.e., occurring in the wrong place at the wrong time) or because they breaks the law (Evertsz & Miller, 2012; Family Planning Queensland, 2012; Johnson, 2014; La-

mont, 2010; NSW Department of Health, 2005; Ryan, 1997; Pratt, Miller & Boyd, 2012).

A Rights Centred Response Framework

Safety and the protection of children must be addressed as the priority. This may involve developing a safety plan (or incident prevention and response plan) whilst a more comprehensive assessment is undertaken. Consideration must also be given to child protection and mandatory reporting requirements. Clinicians are encouraged to consult the online Mandatory Reporter Guide (MRG) for more guidance (see www.keepthemsafe.nsw.gov.au). Promoting safety however, is only one part of a holistic response.

Webster and Butcher (2012) assert that a rights centred approach to sexual behaviours in children and young people involves three essential stages. Firstly, clinicians need to *recognise* the variation in normative sexual development in order to identify when sexual behaviours are of concern. Secondly, clinicians need to *reflect* on the information available through a sound clinical assessment process. Thirdly clinicians need to *respond* by putting interventions in place **which meet the child, young person and family’s bio-psycho-**



social needs while ensuring safety, dignity and rights are maintained.

The *Traffic Lights* framework is one tool which aims to guide practitioners through the process of identifying, assessing and responding to sexual behaviours (Family Planning Queensland, 2012). This resource uses the metaphor of traffic lights to describe the continuum of sexual behaviours as either:

Green = “normal” or healthy sexual behaviour and indicative of an opportunity to provide positive feedback and information.

Orange = “outside the norm” and signalling the need to take notice and gather information to assess and take action.

Red = “outside the norm” and requiring immediate action.

The Traffic Lights tool then provides a useful scaffold for identifying actions in response to the hypothesised function of the behaviour(s). For more information please see the *TRUE* (previously known as Family Planning Queensland) website (see http://www.fpq.com.au/publications/fsBrochures/Br_Sexual_Behaviours.php). A *Traffic Lights* App is also available via i-tunes (Family Planning Queensland, 2015).

Some Case Examples

Scenario One. Two kindergarten students were found giggling and showing each other their genitals in the school toilets. While the children were easily redirected by the teacher, she wanted to know what other action should be

“All work should be undertaken with the aim of promoting rights, maintaining dignity and building a sense of worth.”

taken. Using the Traffic Lights framework, the teacher, principal, and school counsellor hypothesised that the behaviour reflected “normal” curiosity in sexual development. With this in mind, the team determined that further education around protective behaviours, and public and private spaces would be beneficial. The children’s parents were also informed.

Scenario Two. The school received a phone call from a distressed mother. She informed the school that her daughter with Down syndrome had received texts from a classmate (who also had Down syndrome) pressuring her to send him naked selfies or else they would no longer be friends. Using the Traffic Lights framework to facilitate further discussion, the teacher, principal, parent, school counsellor and case worker determined that the behaviour was of significant concern given the coercive and threatening nature of the texts. It was hypothesised that the girl’s strong desire for friends and limited opportunities for social connections were increasing her vulnerability to such requests. In response the mother decided to continue closely monitoring the use of technology / social media, talk with her daughter about peer pressure and look into social activities such as joining a dance group. The teacher decided to develop lessons for the whole class around cyber bullying and peer pressure. This was an initiative that the principal hoped would then be rolled out school wide. The Traffic Lights framework was also used to develop a behaviour support strategy in relation to the other student involved.

Conclusion

Clinicians play a critical role in the promotion of healthy relationships for children and young people with an intellectual disability. While an understanding of typical sexual development should be used to guide responses to sexual behaviours, it is important to remember that each child, family and service system is unique and will require an individualised approach. All work should be undertaken with the aim of promoting rights, maintaining dignity and building a sense of worth. This includes initial safety responses to sexual behaviours and the design and delivery of interventions which meet underlying needs and promote well being. Clinicians are encouraged to apply their existing knowledge, skills and experience, the scaffold described here and the many resources available in both the mainstream and disability literature to inform their response to sexual behaviour in children and young people with an intellectual disability.

Acknowledgement

The authors would like to acknowledge Georgina Livingstone and Greg Elphinston from *TRUE Relationships and Reproductive Health* for sharing their expertise and peer reviewing this manuscript.

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The State of the Disability Sector Report

Centre for Applied Disability Research, National Disability Services

The State of the Disability Sector report includes a business confidence survey which shows that most disability service providers are cautiously optimistic and plan to grow in the next six months; but a high proportion think that government agencies are not working closely enough with the sector to implement the NDIS successfully.

As part of the survey, organisations with less than \$1M in turnover reported higher financial stress than large organisations and were more likely to see the NDIS as a risk rather than an opportunity.

The Report includes the first release of data from the largest analysis of the disability workforce ever conducted in Australia. NDS has collated data from 20,000 employees to provide a snapshot of the disability workforce. A key finding from the snapshot is that 38% of all disability workers are casuals, a relatively high rate which is likely to increase under the NDIS.

The NDS State of the Disability Sector Report 2015 also highlights the need to improve employment opportunities for people with disability and provides an analysis of the hot issues facing policy makers. It concludes with 20

things NDS would like to see accomplished in 2016 to ensure the successful implementation of the NDIS and more opportunities for people with disability to work, be educated and engage in community life.

NDS chief Executive Ken Baker commented: "The National Disability Insurance Scheme is the right destination. But poor access to market information; cumbersome NDIS systems and processes; insufficient financial reserves within organisations; and low prices are all barriers on the road to a sustainable and dynamic NDIS" said Dr Ken Baker, Chief Executive, National Disability Services

Ken Baker concluded: "The NDIS will double the funding for disability support, expand choice for people with disability and their families, invest in early intervention and replace a fragmented inequitable system with one that gives people across Australia access to reasonable and necessary support. But there are legitimate questions about how we get to this destination and at what pace; and how to turn the ambitious vision of the NDIS into reality.

Download a copy of the report at www.disabilitysectorreport.nds.org.au

Full transition to the NDIS:



What can we expect in...



Knowledge is Light: an interview with Sue Foley

Sue is a Senior Social Worker, team leader and CAPTOS Clinical Co-ordinator at the Children's Hospital at Westmead, Department of Psychological Medicine, moving to the Children's Court Clinic. Her areas of expertise include undertaking assessment of children, young people and their families in relation to physical and emotional abuse and neglect, and sexual abuse of children. She has presented research and discussions papers at a number of Australian and International conferences.



Your career to date; How did you get to where you are today?

Before I left school, I worked a lot with children, such as school holiday camps with the Anglican Church and the St John's Ambulance Brigade. I also have had a lot to do with music and working creatively. When I left school, I went to Canberra University to start a nursing course where I studied philosophy and ancient history which I partly read in French, because I love languages.

I left nursing after the 1st year, and applied to do medicine, but the application got 'lost in mail' and as fate would have it I started a Bachelor of Social Studies at Sydney University, majoring in anthropology. Anthropology gave me a strong interest in culture and social relationships. In addition I did a sub-major in psychology and major in Social Work practice. I was offered work at some of my placements, including at Sutherland Hospital and at the then Eastern Suburbs Child Guidance Clinic, as a 'social worker aide'. My final placement was in the then Catholic Family Welfare Service which looked after counselling, foster care and group homes.

My first employment combined both working for the Anglican Home Mission organisation, and the then Deaconess Institution, setting up and running group homes for young people in need of care, and working part time in St George Hospital as a Social Worker. In 1978, Neville Wran the Premier of NSW developed services for sexual assault vic-

tims. I established the sexual assault Service at St George Hospital in 1978, and was part of state-wide training for how to respond to adult and child sexual assault victims.

At St George Hospital I was a social worker at Pacific House Mental Health service, in the Emergency Department and various other wards, enjoying group work supporting children, family and young people and encouraging them to support each other so they were not completely depending on professionals.

In 1982, I moved from St George Hospital to Ryde and undertook family therapy and individual therapy at the Community Health Adolescent Unit, establishing strong interdisciplinary links between education and health services, through one of many journal clubs and education activities. The then Family and Community Services Department established a team of specialist professions – social workers and psychologists and I joined this program in about 1984 becoming an Area Child Protection specialist for Western Sydney. During this time I enjoyed a foray into legal settings as an acting legal officer for FACS and a specialist liaison person with health services.

After returning from maternity leave in 1988, I was assistant Manager of the Seven Hills Office and then acting Manager at St Marys and various other Western Sydney areas, before the upheavals in that department in 1990. I moved to be the Manager in the then CareForce Child and Family Services, looking after children's homes, the foster care program, group homes and establishing an innovative counselling service. I made an appearance at the Police Royal Commission at that time, giving information about the responses of churches and states to the needs of children and adults who have been sexually abused.

In 1998, I moved back to then DoCS and took part in setting up the DOCS Helpline. By this time I had two masters' degrees in Childhood Studies from the Faculty of Psychology at Macquarie University; and in Social Work from Sydney University and started a third one in Education at UTS.

In 2001 I moved to Nepean services as a consultant before moving to the Child Protection Unit at Children's Hospital at Westmead, in 2003. In 2004 I moved to the Department of Psychological Medicine as a Senior Social Worker and Non-medical team leader for Dr Kozlowska's team and shortly after became the Co-Ordinator for the CAPTOS Telemedi-

cine program in the Department of Psychological Medicine, eventually moving to be part of Dr David Dossetor's team.

What do you love about the Children's Hospital at Westmead? Can you tell us about one of your projects?

I love the environment of the Children's Hospital, I love the colours, I love all the artwork and I love its vibrancy. I have enjoyed the opportunity to be what I consider a social worker should be, that is, someone who implements our professional values of social justice, respect for persons, and promoting capacity and competence (of all). I enjoy work, as an educator, advocate, therapist, case manager, and consultant. With those principles in mind I take every opportunity to be creative, kind and encouraging.

Very early in my time at CHW I became involved in the Shaken Baby Prevention project. This important and innovative project aimed to provide an Australian version of what had been well respected education processes for all parents with children who are responsible for babies. We discovered that people do not really understand how vulnerable babies brains are. It is important that all parents and carers **understand that 25% of babies' deaths occur from various shaking injuries** and those that survive incidents of shaking have implications such as serious brain injury, communication difficulties or emotional/mental health problems. Some of these effects only become evident when the children are teenagers. This project is now in over 20 countries around the world and in over 20 languages and has been well received, particularly in countries where there were no resources before. It has been great to partner with the Kids Health staff, social workers at CHW and professionals and families in other parts of NSW Health and other national and international settings to distribute this program.

Since the start in 2002, there have been a number of different developments including tools such as postcards, posters and a video animation which is unique because A) it is short; B) very cute and C) the film is very engaging. Working with social work colleagues and many different students has enabled the project to continue and it is now internationally recognised.



What part does a social worker play in supporting children and young people with MH problems and intellectual and development disability?

I think social work can play a number of roles for children with MH and IDD. Social workers may work with schools to help them understand the meaning and function and **neurobiology of children's behaviour. My view is that parents and teachers are architects of children's brains through the children's experiences. I think the most important role social workers have is to enhance parental capacity, their understanding of their child and particularly to enhance their understanding of the kind of thing that might either inhibit or help the child's optimal development and optimal experience of the present.** For example, this might mean being an advocate at the school.

Our job as social workers and clinicians is to promote **children's resilience in the context of whatever disadvantage or whatever vulnerability they have.** This is particularly important when they have mental health problems or other developmental difficulties. It can be very hard for them to communicate their own stories or their own experiences.

As a social worker, I use many creative processes, keeping in mind what is important to that child. (Many of these are held and sold at the CHW Kids Health bookstore). Recently a young girl enrolled in a new school who had serious arousal problems. The school gave her the opportunity to jump on the trampoline for 15 minutes before class commenced - which was extremely beneficial. Social workers can help with advocating for these sorts of things. Parents sometimes think because they are not specialists they cannot be advocates for their child and are not allowed to challenge practices. Children with intellectual disability are very vulnerable so parents need a space to be curious about and review the interactions of their child with professionals.

Professionally and personally I like to challenge and change.

Question: The importance of professional development in allied health.



An innovative Trauma Think Tank is bringing together health professionals across NSW to discuss the impact of trauma on individuals, families and communities.

The Trauma Think Tank is facilitated through the Child and Adolescent Telemedicine Psychiatry Outreach Service (CAPTOS), a program established by The Children's Hospital at Westmead in 1996 to provide and promote child mental health services for regional and remote NSW.

Each week up to ten clinicians from a 1,000 kilometre radius teleconference to share knowledge and experiences relating to the impact of trauma. Even the most experienced clinicians appreciate the opportunity to consider new ideas and improve practice, especially in rural and remote areas where resources are limited.

Utilising this knowledge base of the impact of various types of trauma on the functioning of individuals, families and communities contributes to the confidence and capacity of clinicians in a variety of social work, mental health, juvenile justice and child protection practice settings.

Rural clinicians do not have the same ease of access to wider professional supervision groups or exposure to professional leaders in the field of psychology or therapy. Over the years CAPTOS has played a pivotal role in nurturing the skills and experience of rural clinicians, allowing them access to valued educational opportunities without the need to travel to city locations.

It is really important that we all keep on learning at a continuous rate; reading, listening to books on audio, and keeping up to date on the latest publications that might be helpful for parents and children. I really enjoy attending conferences so that I can hear an international perspective and staying up to date.

The CAPTOS *Trauma Think Tank* has helped relieve many professionals from feeling clinically isolated. In this process, professionals meet for half an hour on a Wednesday morning and watch various experts talking about their perspectives on the latest in neuroscience, family therapy or attachment. Participants then share their ideas with other clinicians around the state. They join from the Victorian border to the Queensland border and half way out to the west of NSW. Not only do they get to watch the experts, but the discussion helps them to construct new knowledge by interacting with each other and by challenging what they hear. This has practical implications enabling professionals to feel

empowered by their new knowledge and testing their new tools with their next family for positive effect.

University learning is great but knowledge is escalating, so accessing new information and knowledge is more important than it has ever been. We have to stay in touch not just by reading, but also by being part of a learning community.

Our middle brain (limbic system), that gets pressure from personal and professional contexts, can be calmed down **by our prefrontal cortex, our 'thinking' brain, when we feed it**. This is why I keep studying and learning; by keeping that part of my brain turned on, I am not relying on an intuitive or emotional response. It would be easy to become distressed with most of my clients, as many have tragic experiences and struggles; I need to stay well educated and well-resourced so as not to respond in an emotional way.

Please walk us through the history of CAPTOS on and how it has developed over time

When I came to CAPTOS in 2004, it had already been running since 1996. It was Dr David Dossetor and Dr Ken Nunn who in consultation with NSW Health proposed the setting up of a Telepsychiatry program. This included clinical video conferences, and rural visits, starting with Dubbo, Bourke and Broken Hill. It was established because of the difficulty for families in those areas to access Child Psychiatry services. As a result of the evaluation, it became a **permanent outreach service from the Children's Hospital at Westmead to the whole state of NSW**. From the evaluation process I was asked to establish more allied health clinical consultations and education for rural sites. All of the psychi-

“We have to stay in touch not just by reading, but also to be part of a learning community”

artists employed at the hospital were undertaking 4 hours telepsychiatry consultations a week and 1 to 2 rural visits a year. At one point, we had up to 100 people receiving clinical consultations through CAPTOS. That meant everyone in the Department of Psychological Medicine was very actively involved in CAPTOS services, and undertaking regular rural visits.

Educational services grew as technology developed. Now we can link up to more than 20 sites at a time. This changed the opportunities and allowed for regular education process.

My job as Co-ordinator was to ensure that we worked collaboratively clinically and administratively with all the rural areas, ensuring that it wasn't the Children's Hospital controlling the service. A network meeting was established with representatives from each Rural Health Area (Now called LHDs).

Future directions in your career

As I am in my mid-60's, I want to do what I enjoy and what I can make a contribution to. My career has always been about how I can contribute from what I have learnt. In my new role, I am the Director of the NSW Children's Court Clinic, based in Parramatta which moved to the Sydney Children's Hospital Network. It provides independent assessment of children and families before the Children's Court and seeks to assist the Court in making decisions about the needs, safety, welfare and future care of children. There are around 70 clinicians and a small team of staff who manage the Clinic's operations.

Favourite travel experiences

Hawaii is on the top of my relaxation list. I really like travelling to South America where my husband and I have done a few cruises. We have also been to Canada for a couple of conferences and we really enjoyed being amongst the Rockies. I am a bit of a fan of the Mountains and the sea and snow. When travelling, I never leave home without my ipad.

Favourite Books

1. **The Brain's way of Healing: Remarkable Discoveries and Recoveries** from the Frontiers of Neuroplasticity by Norman Doidge who provides an alternative model.
2. Emotional Intelligence by Daniel Goleman. He has also written one called Focus. Both these books are helpful for teachers and parents around helping children manage anxiety or their emotional responses to difficult situations. It is really about how social interaction can help children have a different intellectual and emotional functioning.
3. Bessel Van Der Kolk, *The Body Keeps the Score* and
4. Amy Cuddy, *Presence* - These latter two have been my most recent reads! Awesome!!

A Link to share:

Amy Cuddy TED talk: *Your body language shapes who you are*. Amy is an American social psychologist with a serious brain injury from a car accident at 19. She was told she



would never be an academic and that she would never recover her intellectual functioning. She is now an Associate Professor of Business Administration at the Harvard Business School and has made this presentation about Power Posing. Power Posing is about the non-verbal expression of power and strength and that nonverbal expression communicates to others but also communicates to us. Amy Cuddy says try a power pose and share the science.

Another video: *Just Breathe: children dealing with emotion*

Is there anything else you would like to add?

Sometimes in Australia we don't take on board what is happening around the world. Connecting internationally has been one of my great assets. I am on the board, as the Australian representative, for the International Society for the Prevention of Child Abuse and Neglect (ISPCAN) and I have **been involved since the early 80's. I am strongly committed to adding to and being part of an international community.** I have committed resources and time to what I believe in; my final addition is my motto - ***make the opportunity and take the opportunity.***

Thanks for letting me tell some of my story!!
Sue

The Medicine Cabinet: Anxiety treatment when SSRI's fail

Judy Longworth

Senior Clinical Pharmacist,
Department of Psychological Medicine,
The Children's Hospital at Westmead

In the latest National Youth mental health Survey – Young Minds Matter recently released the incidence of anxiety amongst the 4-17 year olds was for males 7% and females 6.8% with the majority experiencing mild symptoms of one of the anxiety disorders. This represents half of all people aged 4-17 years with a mental health diagnosis. The most common form of anxiety was separation anxiety representing 4.3% of the study participants. Overall 18.7% of children and adolescents with an anxiety disorder had a severe disorder whilst 25.9% had a moderate severity.

Whilst some of the SSRIs (e.g. sertraline and fluvoxamine) have a license for obsessive compulsive disorder in Australia there is evidence for their use in both OCD and other anxiety disorders in children and adolescents. This article will concentrate on what other medications can be used when SSRIs are not effective (MHCAIDD, V2, Iss 2).

There are no published clinical trials for use of any medications for treatment of severe anxiety symptoms in ASD. There have been some psychological trials with moderate anxiety in high functioning autism, although the numbers are small. Anxiety in the ASD population can present in many different ways such as impulsivity. Thus looking at the impulsivity literature the following medications have potential for use. These are also second or third line pharmacotherapies for ADHD. These have been discussed in previ-

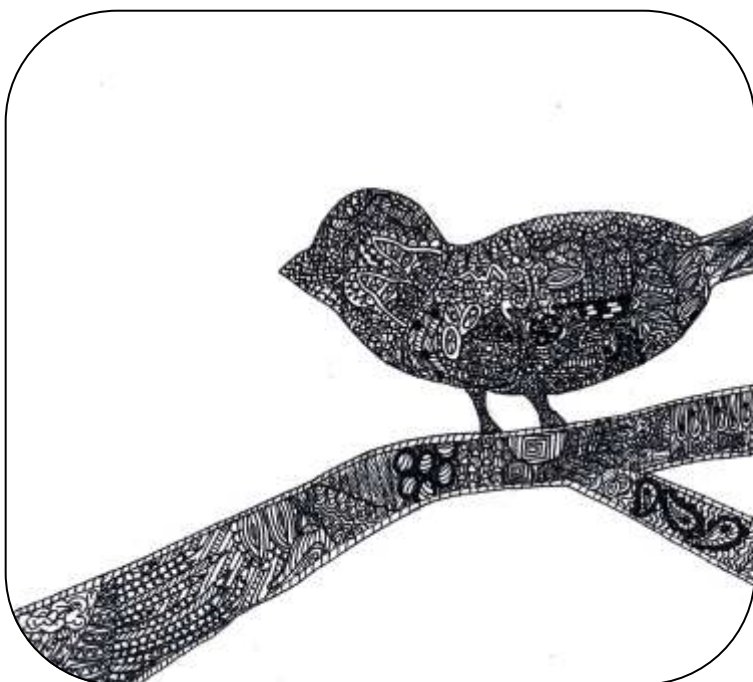
ous articles so refer to those on amitriptyline and clonidine (MHCAIDD, V4, Iss 3&4).

Other medications for anxiety include the use of propranolol (MHCAIDD, Vol 6, Iss 2) which has also been discussed earlier. Sometimes there is use of small doses of antipsychotics, typically either olanzapine or quetiapine (MHCAIDD, Vol 4, Iss 2) especially when the anxiety has a strong component of sleeplessness. As discussed, it is important to remember that these medications even at low doses can still contribute to significant weight increases so this should be monitored carefully as the long term implications can include diabetes and other metabolic conditions.

Naltrexone, a mu receptor antagonist used primarily to block the effect of opioid medications has been prescribed for alcohol dependence in the adult population. Naltrexone is used in autism for patients who experience significant self-injurious behaviour. The rationale behind this is to block the endogenous opioids generated by the self-injurious behaviour. There is some literature to suggest that the self-injurious behaviour is generated due to anxiety especially in the autistic population who have poor communication. Common adverse effects include nausea and vomiting as well as decreased appetite. Some experience sedation and worsening of the anxiety. As naltrexone blocks the opioid receptor, if having any planned surgery or needing strong pain relief with opioids, then the prescriber needs to be aware of the naltrexone, as the pain relief will be rendered ineffective.

Most paediatric studies in treatment of anxiety associated with obsessive compulsive disorder (OCD) have been with the SSRIs (fluoxetine, fluvoxamine, paroxetine, sertraline and citalopram). Trials for anxiety treatments for anxiety not associated with OCD are very limited and these include imipramine and venlafaxine XR. There is one small study (n=63, age 12-18 yrs) for use of imipramine with cognitive behavioural therapy for school refusal over an 8 week period but the results were poor and this is in a population who would be able to access the use of CBT.

Venlafaxine is a serotonin noradrenaline reuptake inhibitor but these effects are dose dependent thus at higher doses it is both a serotonin and a noradrenalin reuptake inhibitor. The venlafaxine XR trial had mixed results for a larger study (n=320, 6-17yrs) for generalised anxiety disorder. A short



term study showed positive results but this was unable to be replicated.

When venlafaxine is used there can be a withdrawal reaction due to the short half-life, this can be helped by the XR preparation but some patients will also need to be weaned slowly. It is important to note that overdose is dangerous. Most of the adverse effects are due to the lower dose serotonin blockade causing nausea, vomiting, headache, nervousness and insomnia. At higher doses the noradrenergic effects of blood pressure increase will occur due to inhibition of the noradrenergic receptors.

Compton and colleagues (2007) point out that one should weigh up if the condition in the child is sufficiently serious to warrant pharmacological intervention. Although much has been learned, many questions regarding the treatment of these paediatric anxiety disorders remain. Preferably, psychosocial interventions are usually combined with medication as these can augment each other, this provides the impetus to overcome anticipatory anxiety through initiating medication and then using the psychosocial interventions to consolidate any benefit from the medication. These studies were done in neurotypical patients which could apply to the autistic population, however more studies are needed.

There is a protocol to examine the evidence for other medications in the Cochrane library has only just been submitted (Livingstone et al, 2015). This protocol will look at other medications for irritability, self-injury and aggression in ASD besides the ones that have already been reported. These include risperidone for which there is some evidence for its effectiveness in irritability as well as aripiprazole.

In conclusion there is a paucity of any studies for medications other than fluoxetine for use in ASD population. More trials and studies of combination treatments of both psychological and pharmacotherapies are needed for one to say that one medication might be effective over another. Ongoing single trials for each individual patient will continue.

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“the incidence of anxiety amongst the 4-17 year olds was for males 7% and females 6.8% ”



The NDIS and MH & ID Services: Two Conference Reviews

Associate Professor David Dossetor

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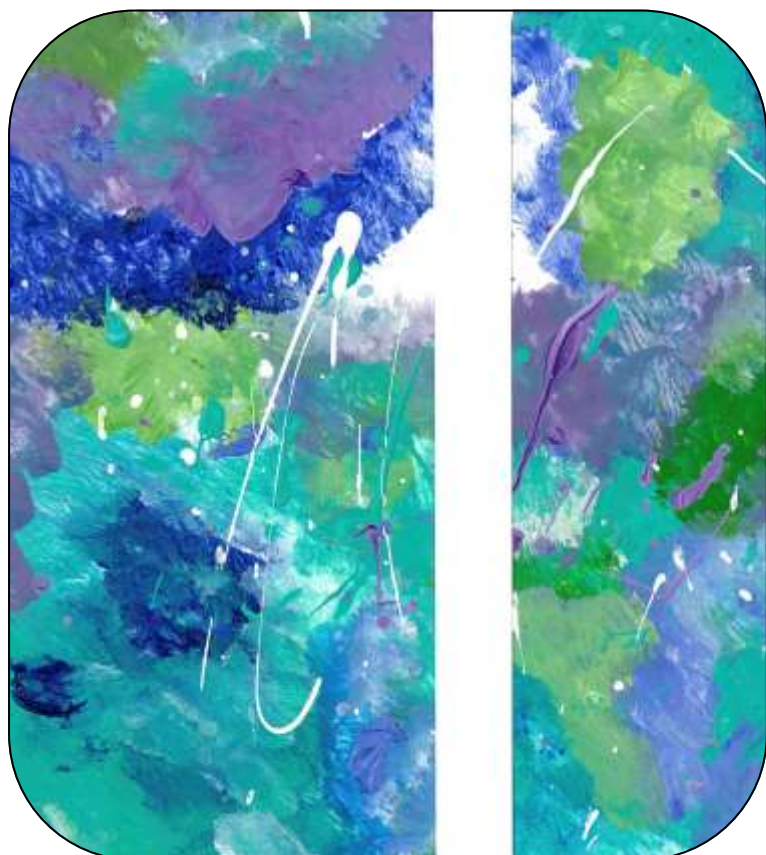
Area Director for Mental Health

Child Psychiatrist with a Special interest in Intellectual Disability

This report follows from my attendance at two recent conferences: (1) **“Designing & Delivering Mental Health Services within the NDIS”**, organised by Criterion Conferences 21-22/10/15 and (2) **“NDIS and Mental Health Services Forum”** organised by the Mental Health Commission of NSW, 5/11/15. My aim was to gain greater understanding of the implications for the client group of this journal: children and adolescents with intellectual and developmental disabilities. In fact the 2nd presentation represented a government/agency view, whereas the 1st represented an academic, clinician, mental health service manager, NGO and consumer perspective. The experience involves understanding a significant culture change of service provision and I think no one knows what the final impact will be, or what modifications to services for those with complex needs still need to be during the rollout.

Janet Schorer, (2) Executive Director of the NDIS Reform Group of NSW Department of Premier and Cabinet Office described this as the greatest social reform since the introduction of Medicare: **‘its about the human right of choice’ and ‘will shape the future of helping people’**. In NSW 140,000 will access help (funding packages) which is an increase of 45,000 from current service provision. It will

create 25,000 jobs and in 2018/19 will rise to \$6.4 billion with a 2 year roll out starting on July 1016. Current ADHC clients will be the first to receive assessments. It is a provision based on need and not rationed or capped. The NDIA has to develop/provide the implementation. NDIS Act 2013 **provides a framework for ‘reasonable and necessary support’, with rules of support. It will be based on what might be a novel question for many of ‘what is your goal (in life)’**. She predicted that market forces will move clients away from specialist services to more generic services eg from hydro therapy to joining a gym. Further, earlier intervention will prevent more complex problems developing. Support does need to consider value for money and the responsible role of families. The Disability Inclusion Act 2014 will drive Disability Inclusion Action Plans of all mainstream services to be more inclusive. James Dunne (2) Director of Social Policy Implementation, Government Relations Branch, described the changes in terms of a growth of the deinstitutionalisation/rehabilitation model of mental health and talked about the cluster group meetings of Family and Community Services (FACS), Education, Transport, Housing and Health organised by the Department of Premier and Cabinet Office to coordinate this partnership between NDIS and the cross government services. He reported that the Department of Health will be monitoring and evaluating the framework being introduced. The main distinction is between health and NDIS: health is based on the diagnosis and treatment of a medical condition, whereas NDIS is **based on a person's functional impairment. Some of the interface issues include: when is allied health intervention disability support and when is it a health intervention? In NDIS, therapy has a role in maintaining function. But what if a health intervention is needed because of a disability, such as cerebral palsy surgery for contractures, or psychotropic medication to minimise chronic psychosocial disability? When is a goal reasonable and should you be allowed to choose an intervention that isn't evidence based? Will health and the justice system be the provider of last resort?** Tracy Wright and Monika Koetzke Macdonald (2) from FACS talked about the impact on 450 people with intellectual disability in large residential homes (institutions) in the Hunter New England. Success depends on partnership with mainstream services eg GPs, but these people will still need access to day programs. Some have readapted well. There are 69 with complex needs often with a criminal justice background which will require access to mental health and other specialist skills. There are currently 12 who are struggling and under their client monitoring and review process: 4 with behaviours of concern or MH problems, 2 because of



placement problems, 1 where no provider can be identified and 1 with problems of continuity of care.

The strengths of large residential care provision is: skilled and knowledgeable staff, strong management and clinical leadership, skilled multidisciplinary teams, access to specialists, consistent staff, early intervention for problems and coordinated integrated management plans. Can any of this be reproduced under the NDIS? How do you transit to the NDIS a 15 year old, graduate of the criminal justice system, with mental health problems, intellectual disability, self-harm, aggression to staff who has already had 15 placement breakdowns? They are looking to develop an intensive support framework with 18 key initiatives which will also need to build capacity in the health sector. There needs to be an agreement not to allow the blocking of beds in acute care in health or mental health or in the criminal justice program. We look forward to hearing more details on service development for those with complex needs. This account brings to mind that the closure of institutions of people with intellectual disability in UK in the 90s was balanced by the maintaining some of the funding for building of specialised ID psychiatry services. I see this as an essential part of any modern model of community care for people with ID.

Leanne Johnson (2) General Manager gave a general mental health perspective on lessons learned from the Hunter Trial Site. It has taken significant time to clarify the confusion between what is NDIS and what is Mental Health. The benefits have been increased funding and range of services, new models of accommodation, increased flexibility of support, resulting in staying well for longer and shorter MH admissions. An advocate to support the application to access NDIS has a higher success rate, and the average length of time preparing for and applying is 60 hours of professional time.

However 76 long term patients have been accepted into the community. Challenges remain with: clinical governance, guidelines and procedures for staff, barriers for the most complex, vulnerable patients, access to safe, secure, affordable housing, not knowing the NDIS status of a patient, minimal service for non-NDIS consumers and a lack of data. New services have needed mental health training and education and should that be at the cost of the mental health services? Monitoring and safeguards of complex vulnerable clients; Health is part of the cost of support; increased need for the public guardian in decision making; the service capacity of NGO sector; ensuring choice and control for consumers. Progress has required: clear health governance, documentation of disability and disadvantage, a centralised database, appointment of NDIS champions, project manag-

“It has taken significant time to clarify the confusion between what is NDIS and what is Mental Health”

ers and access coordinators, active engagement with the NDIS, regular interface with NDIA, and organising the coordination of the NGOs. The NDIS website is a font of developing information.

Conversely Conference (1) was not attended by a NDIS/NDIA representative. The response to an invitation was: the NDIS does not provide services, just provides an economic **market place in which NGOs provide the services. ‘Market failure’ is the term used to describe the failure to provide services to those in need: this particularly focuses on those in ‘small markets’, such as regional and remote populations,** clients with complex care needs and clients with high levels of mental health issues.

Sarah Pollock (1) from Mind described the NDIS is a transfer of power from the government to the individual, recognising the citizenship of individuals despite their disability, **but also how ‘choice’ can be used to limit entitlement, if there are no options. Many people struggle with ‘outing themselves’ and declaring their disability. The NDIS gives a business imperative to make a service that is meaningful to people.** Judy Harper (1) from NSW Council of Intellectual Disability spoke directly to my concerns when she talked of the problems of mental health problems in people with an intellectual disability. In Australia 120,000 of the 400,000 people with an intellectual disability have a mental health problem. However diagnosis is challenging and she cited a case where 5 different psychiatrists said there was no problem until they saw a specialist psychiatrist in intellectual disability, which led to treatment that kept the person out of prison. How does the NDIS work to support access to the **expertise? The concept and label of ‘challenging behaviour’** prevents recognition of a mental health diagnosis. Both GPs and general psychiatrists are under-skilled and we are a long way behind the development of a subspecialty compared to the UK. We need multidisciplinary approaches for challenging behaviour, looking at the behaviour through **‘multiple lenses’.** Sometimes medication for behaviour is inappropriate and sometimes it is essential.

The National Canberra Roundtable on MH & ID established consensus for the need for subspecialty mental health skills. However the \$115million for the NSW Mental Health Strategy provides no money for intellectual disability. Prevention of these mental health problems needs attention such as with skilled parenting programs such as Stepping Stones. She cited the needs for: inclusion into mental health services, equity of access, prevention, specialist ID MH services, collaborative models, workforce development and data to address the multiplicity of disadvantage. Tier 2 NDIS services need linkage engagement and the \$140million allocated will not be sufficient. How does NDIS support access to mainstream services? We will not survive the loss of the ADHC specialist services. It remains unacceptable that the NDIS has not even considered the assessment of the combined disability of Intellectual Disability and Mental Health Problems.

Leanne Dowse (1) Chair of Intellectual Disability Behaviour Support, UNSW, a speech therapist by background, talked about her 10 year life course research study on those with

“At a minimum, a case like Natalie needs intra & inter agency collaboration, which is proactive, not reactive, with comprehensive case management, specialist MH and prescribing, and trauma focus”

complex needs in the criminal justice system with 2700 in the study, most of whom don't have the personal capacity to access NDIS. An example case was a woman called 'Natalie' in her 20s with multiple psychiatric disorders, substance abuse and asthma. Her psychiatric diagnoses included ADHD, Dissocial, Schizoid and Histrionic Personality Disorders, and Psychosis in the context of substance abuse. She was subject to child abuse, had problems at school at 12, a brother with mental health problems, 22 contacts with the police by the age of 15 including 7 periods of custody, multiple out of home care home and residential placements which broke down because of her behaviour. She had minimal therapy of little impact; had 3 high risk pregnancies by the age of 22 who were all taken into care. She had charges for malicious damage to property, was a victim of domestic violence, had multiple AVOs against her and was under the Guardianship Board, yet no one identified her intellectual disability or psychosocial needs. The cost for her support and surveillance and control has already cost the state \$960,000 without considering her personal and the community costs. Complex support involves the relationship between simultaneous, intense and multiple needs in health, disability, social disadvantage, risk, justice and legal issues including decision making capacity. Domains of intervention change over time. Her individual needs have both a breadth and depth which are interconnected. Her environment lacks natural or informal supports to meet her needs. The services lacked a unity of capacity to provide support, often providing no service response because of service gaps and silos. Complexity theory, like a symphony orchestra, determines the input is greater than the sum of its parts. Access to NDIS may be a human right, but care is deferred to the criminal justice system. NDIA also requires voluntary engagement, proving eligibility, needing support for planning, gathering information and making decisions. Natalie will be deemed ineligible because NDIS is only about the ID, not the rest of her psychosocial disability.

How can those with the most complex needs not be eligible?

1. NDIA will fail to reach its target audience because of the lack of and access to documented information.
2. How could she take up voluntary engagement with her history of trauma and lack of trust of professionals? This also needs a self-awareness of need.
3. Eligibility gets altered based on cost control and advocacy.
4. Support Planning requires the planners to identify both the ID and the mental health disability but then

what products are available to purchase to support such complex needs?

5. Getting the information and making the decision involves: need, interest, literacy, transport to attend an appointment, and a capacity to think of goals and aspirations.

At a minimum, a case like Natalie needs intra & inter agency collaboration, which is proactive, not reactive, with comprehensive case management, specialist MH and prescribing, and trauma focus. It also requires mainstream support, which has a focus on inclusion not their lack of capacity. Key ingredients include: best practice guidelines, services with training, supervision and mentoring. It takes time and leadership. **'Market failure' is a failure to address the needs of an individual.** Building market capacity may take 20-30 years, as found in UK. Market deregulation led to competition from large scale overseas providers such as Serco with a profit motive that can kill competition, diversity, and niche capacity and connection. Leanne suggested the NDIA is retreating from complexity. There is no ID working group in NDIS. Self-determination is a middle class idea for those with supportive families. In complexity theory small steps all help, e.g. starting with a visit to the dentist, but most of the **work needed will not be 'billable'**. **Legally the state government still has responsibility for the welfare of its population and mainstream service provision.**

Two mental health consumers Simon Swinson and Erika Gelzinnis talked of their experience of the Hunter Pilot Study: the problems of meeting the criteria of need; the need for advocacy skills, the need for professional assistance in application and skills in describing problems. Erica described the bureaucracy failures of documents lost, misinformation between agencies, lack of direct communication and the lack of MH expertise in Assessors. Her aim was to get out of poverty. Her exceptional GP helped guide her through the maze dysfunctional services and helped her believe she had a right to a quality of life. It was frustrating that she had money allocated but no functional service to provide for her needs. She felt that the NDIS is incompatible with a recovery model of support. **She concluded: "I would like to be able to contribute to society but will probably always need support"**. **Simon summed the dilemma as "you need to present yourself in your worst state and with the assumption that diagnosis is permanent"**. Ben Mathews, a NDIS transition manager with a lived experience, also talked of the problems of helping customers apply, quoting Bob who needed 5 hours of meetings to get him to even consider an application. He also talked of the loss of MH Rehab funding reducing supported employment capacity. Michelle Massey, Team Manager of Mental Health Services for the Salvos in the South Australia Pilot, talked of the problems of changing their service structure from block funding to NDIS funded fee for service and the business processes that have to be set in place. They can only provide what NDIS has funded, not what the clinician feels is needed. Despite tailoring their service they are running at a loss at the current support fee of \$45/hour, with increased client loads and less time to give. In fact the financial loss had to be subsidised by the National Salvos organisation.



They risk the loss of collaboration with MH services, because as NDIS providers they are not allowed access to **clinical information including client risk profiles**. Paul O'Halloran, Director of Mental Health International Networks for Developing Services, presented on the growing evidence on Recovery models of intervention in MH and its overlap with the Psychosocial Disability Models of NDIS.

Debbie Hamilton, a doctor with the lived experience, talked of how you need an advocate to get a package, and without such support you will fail. You may have the name of a service, but it is difficult working out what it does. It is difficult to articulate what your goals for life are, especially if you **have been 'in a difficult place'**. **Up till now NDIS has not** been proficient in substitute decision making. David Meldrum from Mental Illness Fellowship Australia talked of the epidemiology of NDIS for people with mental illness. 4 million Australians have a mental illness a year. The NDIS is designed to provide assistance for 56,000 with mental illness and complex needs requiring support from multiple agencies. But there are 103,000 with persisting severe mental illness (SMI) and 321,000 with episodic mental illness. Peer workers are skilled in recognising who will become long term care cases. The National Mental Health Service Planning Framework identified 65,000 who had SMI, with severe psychosocial disability requiring assistance or severe disability in 2 or more dimensions. This 2 year project and report has been ignored by NDIS. He is concerned that many of the most needy will miss out. In actuarial terms it is predicted that 80% of those with disability will have an NDIS package by 2020, but that for those with Mental Health Psychosocial disability, this will be only 20%. He is concerned that to provide funding for 56,000 mental health NDIS packages, the states will transfer funding to NDIS which would otherwise have provided for the other 80% with SMI but receiving no NDIS package. He ad-

vocated that for the better good of people with SMI that it would be preferable to fund NDIS MH packages for a fewer number eg 40,000 so that the states funded NGOs could still provide services to the other 200,000 with SMI not receiving a NDIS package. Such a mixed model of funding is the only way to get a balance. The 5th MH Plan also focuses on Prevention, Promotion and Early Intervention, Suicide Prevention, Primary Care, Hospital Admission Avoidance, and Research. Vanessa Kirk, Lead Case worker from Mission Australia talked of some Hunter Valley MH Cases, such as **'Amber' a 28 year old with intellectual disability, schizophrenia and challenging behaviour**, who was considered too hard for any NGO to provide a service, and therefore none was given, even though she had a package.

Peter Gianfrancesco, NSW State manager for Neami National talked of his experiences in UK of developing the business model, mechanisms, jargon and hype of NGO Insurance service provision: focusing on the 5 Cs: Cultural competence (who are we here for), Customer service (90% is your relational and engagement skills, only 10% is technical skills: **'have we wowed you?'**), **Capability (often to do** with hidden skills and what distinguishes you from your rivals), Capacity (not to be overcome by demand, work out debt recovery and cash flow systems), and Costs (need to know own costs and flexibility in cost for service provision). The idea is that NDIS should be disruptive in the market place with innovation, like Uber has been in taxi provision. They extended their service provision into schools, public services and private companies. Each employee needs 26 billable hours per week. But financial viability is support fees of \$75/hour to enable 20% profit for growth and enhancement, (a commentator at conference (2) described this as market making). The primary survival motive of services is profit.

“There is a real risk of disintegration of service provision with privatisation and privacy destroying collaboration and the sharing of clinical information and expertise”

Jane Henty and Jonathan Harms from MH Carers ARAFMI Australia presented a carer's perspective: Australia has 2.7million carers with increased rates of health, mental health and disability themselves. For example carers of people with a personality disorder have the same rates of PTSD as Afghanistan veterans. Holistic assessment should **take account of the carer's needs, for example providing** respite. NDIS should take some pressure off carers, but they are often expected to manage the packages. The Information, Linkages and Capacity Building (ILC) is the new term for Tier 2 of NDIS and a Framework that is planned to lead to a new organisation (probably another NGO) designed to guide carers and clients where to go for services, that will publish (name and shame) the services that do not provide appropriate inclusive services, as a governance process of linkage between the NDIS to other government and non-government services http://www.ndis.gov.au/sites/default/files/documents/ILC%20Policy%20Framework_0.pdf.

In conclusion there is a diversity of information, experience and concerns. There will no doubt be winners in this reform, but the challenge is how many losers will there be and how

big the losses. In fact, prompt action can still prevent such an **important social reform 'inadvertently' causing such** losses. Some people involved in the pilot studies are aware of the concern about the mental health needs of children and adolescents with intellectual and developmental disabilities. There is a real risk of disintegration of service provision with privatisation and privacy destroying collaboration and the sharing of clinical information and expertise. Who will manage the children and adolescents who find themselves abandoned into the care of health and the justice system? Business novelty and hype is a limited substitute for interdisciplinary expertise. With these seismic social changes the maintenance of the essential centralised roles of ADHC remains critical: practice guidelines and policy, interdisciplinary practice leadership, workforce development especially in Positive Behaviour Support and MH (including the MH fellowships in ID), tertiary interdisciplinary expertise and treatment partnerships (Statewide Behaviour Intervention, Integrated Services Program and the Community Justice Program), innovation through research and partnership (including the University Chairs of Intellectual Disability Mental Health and Positive Behaviour Support) and complex client monitoring and review (clinical governance including Restrictive Practice Authorisation). We still need a special focus on those with additional disadvantage such as Indigenous and CALD populations, and those with multiple sensory disabilities, behavioural phenotypes and FASD.

A current review needs to resolve this by July 2016. May be this ADHC resource is what could provide the impetus/funding to enhance specialist ID MH and 1st world health/MH practice and remodel the hub and spokes of interdisciplinary expertise based from health? There are also significant funding concerns about the maintenance of services for those with severe mental illness who will not qualify for an NDIS package.



Current models of health service delivery for people with intellectual disability

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For the NSW Agency for Clinical Innovation (ACI) Intellectual Disability Health Network

Executive Summary: The Social Policy Research Centre (SPRC), UNSW Australia, conducted a literature on current models of health service delivery for people with intellectual disability. The review was commissioned by the New South Wales Agency for Clinical Innovation (ACI) Intellectual Disability Health Network as part of the *Blueprint* that ACI is developing to deliver improved health services for people with intellectual disability in NSW. This document reports the findings of the literature review.

The review focused on publications in English language from January 2011 to January 2015. Keyword searches were undertaken in four databases: PsycINFO, Social Science Citation Index, Medline and CINAHL; in these latter two databases relevant keywords were searched only as MeSH (Medical Subject Headings) terms. The review identified nine models of health service delivery for people with intellectual disability, seven from the UK and two from Australia. All the models identified in the literature review stress the need for interagency collaboration. It seems to be increasingly accepted that generic models of health care are not resourced sufficiently to appropriately meet the needs of people with intellectual disability. Integration of the expertise from specialist services within mainstream services is often presented as potentially the most advantageous approach. This approach entails a way of delivering services based on co-operation and integration between generic and specialist teams.

The models were categorised along two main conceptual axes: the type of interagency framework they propose, whether multidisciplinary or interdisciplinary, and their approach to serving people in remote locations, whether based on central hubs or including outreach services. In particular, multidisciplinary frameworks are described as teams of professionals from different disciplines who approach the client from their own perspective and then meet **to review the clients' needs in 'case conferences' which are usually undertaken in the absence of the client.** Interdisciplinary frameworks consists of multi-professional teams whereby practitioners from different professions often meet the client at once, integrating their disciplinary approaches into a single consultation and more often involving clients in any discussions regarding their condition, prognosis and the plans about their care.

The majority of models addressed the wider health service needs of all people with intellectual disability. Four models focused on the interactions between health services in specific life passages: post-school transitions, hospitalisation,

and end of life care. Five of the reviewed models were multidisciplinary and centralised: the Community Intellectual Disability Services (UK), the Tertiary specialist services (UK), and the Learning Disability Liaison Nurses (UK), person-centred planning, and the model for partnership practice between specialist palliative care and intellectual disability services. Two of the reviewed models were multidisciplinary and decentralised: the Hub-and-Spoke model (Australia) and the Birmingham Social Policy Research Centre 2015 2

Assessment and Treatment Service (UK) and two were **interdisciplinary, decentralised models: the 'Fair Horizons' model (UK) and the 'wobbly hub and double spokes' (Australia).** The review did not find any interdisciplinary, centralised models. None of the literature met the systematic review standards of high research quality, because it did not include rigorous evaluations.

Giuntoli, G, Newton, B., Fisher, K.R. (2015). *Current models of health service delivery for people with intellectual disability: Literature review* (SPRC Report 12/2015). Sydney: Social Policy Research Centre, UNSW Australia. The Social Policy Research Centre is based in the Faculty of Arts & Social Sciences at UNSW Australia. This report is an output of research funded by the New South Wales Agency for Clinical Innovation (ACI) Intellectual Disability Health Network.

To read the whole document please visit <https://www.sprc.unsw.edu.au/newsroom/articles/current-models-of-health-service-delivery-for-people-with-intellectual-disability-literature-review/>



The launch of two professional frameworks for supporting people with intellectual disability

Two outstanding resources from the Statewide Behaviour Intervention Service of the Clinical Innovation and Governance directorate, Ageing Disability and Home Care (ADHC), Family and Community Services (FACS) were launched at the State Library of New South Wales on Thursday November 26, 2015. These were the Taking Time Framework and the Practice Improvement Framework. Both resources aim to assist the disability sector to deliver high quality support to people with disabilities, their families and those in their support networks. A variety of interesting speakers addressed the attendees including the Deputy Secretary of FACS - Jim Longley; Psychiatrist - Dr Bruce Chenoweth; **Berry Street's Take Two Director Annette Jackson and Manager of Take Two's Practice Development and Training Team, Sarah Waters.** Doug Payne presented on behalf of Daryl Neal, State Clinical Services Practitioner for Life Without Barriers, as did the Director of Clinical Innovation and Governance, ADHC, David Coyne.

The Taking Time - Framework: A trauma-informed framework for supporting people with intellectual disability. Deputy Secretary Jim Longley (pictured right), spoke at the launch about how the FACS recognises the potential for trauma to impact on the lives of people with intellectual disability and the need for a trauma-informed approach to promote healing and recovery and prevent re-traumatisation. Annette Jackson and Sarah Waters from **Berry Street's Take Two Program in Victoria who were the lead authors of the resources** spoke about the importance of thinking about trauma informed practice through a holistic lens.

The Framework and its accompanying literature review can be downloaded here:
http://dadhcintranet.nsw.gov.au/client_services/clinical_innovation/statewide_behaviour_intervention_service/sbis_publications

The Practice Improvement Framework for behaviour support

The Practice Improvement Framework is a guide for the delivery and evaluation of training, work practice support, supervision, knowledge and skills acquisition and professional development for staff across behaviour support services in the disability sector. Deputy Secretary Jim Longley noted the importance of this resource given there are no tertiary qualifications or peak professional bodies in behaviour support.

The Practice Improvement Framework is a multi-modal learning experience utilising e-Learning modules, web based resources, videos, face to face workshops and work practice support/ supervision. The resource targets professionals in the disability sector at the entry level right through to the advanced practitioner.

The Practice Improvement Framework is available to government and non-government staff and can be accessed online at <http://pif.learnflex.com.au/>. Over 900 people have registered since its release in June 2015.



The beautiful artworks in this journal are taken from the participants of the **Operation Art project** at the Children's Hospital at Westmead. You can find out more at <https://www.artsunit.nsw.edu.au/visual-arts/operation-art-2014>

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