

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

*Volume Twelve, Issue One, 2021. ISSN 1837-8803, SHPN CHW 210828*



# Contents

Article?	Author	Page
Are we nearly there? Caring for a child with intellectual or developmental disabilities: a roadmap from a developmental psychiatrist	David Dossetor	4
Resources	Editors	23
<b>An interview with Professor Emerita Patricia O'Brien</b>	Editors	24
The Medicine Cabinet: Storage of Medication at home and school	Judy Longworth	30
Reading List	Editors	33
The role of attachment in autism– a case study on attachment and its impact on behaviour	Dr Linda Tran	34

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

### **On our Website:**

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

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

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

# Editorial

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

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

All of us require good attachment for positive relationship development. During the ever-enduring worldwide lockdowns throughout the pandemic, we have seen the importance of this. We have all individually felt the need for positive engagement more than ever. Children and young people are still learning what attachment feels like and how it works. Children with autism or intellectual disability are the same, exploring attachment with a different set of tools available to them and a different pace. Dr Linda Tran, a psychiatrist at the **Children's Hospital at Westmead**, has given us an excellent insight into attachment through the use of the program Circle of Security, which is surely beneficial to us all. You can also view the related webinar on the School-Link website titled "**Banging my head; autism and the role of attachment based therapy (Circle of Security)**". View this webinar and more at <http://www.schoollink.chw.edu.au/mhid-hub-webinar-series/>

We have excellent articles for you this edition. Dr David Dossetor's article 'Are we nearly there; a roadmap from a developmental psychiatrist', an inspiring interview with Professor Emerita Patricia O'Brien from the University of Sydney. Dr Linda Tran discusses the role of attachment in autism including a case study on attachment and its impact on behaviour. Judy Longworth, our resident senior pharmacist discusses stor-

age of medications in both the home and school setting. We have included our regular reading list and bought back our resources page. There is an ever increasing number of resources which we hope to explore.

If you would like to contribute an article to our journal, please do not hesitate to contact us at SCHN School-Link. We would love to know about the work you are doing, and even if you would like to review a program or resource you have found useful that you would like to share with colleagues, we would welcome your input. Email us at:

[SCHN-CHW-SchoolLink@health.nsw.gov.au](mailto:SCHN-CHW-SchoolLink@health.nsw.gov.au)

Some important numbers to remember:

*Lifeline:* Call 131114 or  
*Lifeline Text:* 0477 13 11 14  
*Kids Helpline:* 1800 551 800  
*Headspace:* 1300 737 616  
*Reachout:* Reachout.com.au  
*Parent line:* 1300 1300 52

Enjoy reading this edition of the journal and please send us any feedback.

Jodie Caruana and Hebah Saleh  
School-Link Coordinators  
**The Children's Hospital at Westmead**  
[www.schoollink.chw.edu.au](http://www.schoollink.chw.edu.au)





# Are we nearly there? Caring for a child with intellectual or developmental disabilities: a roadmap from a developmental psychiatrist

Associate Professor David Dossetor

*The Children's Hospital at Westmead*

*Area Director for Mental Health*

*Child Psychiatrist with a Special interest in Intellectual Disability*

For convenience I shall refer to intellectual and developmental disabilities, which includes autism, as IDD. The title acknowledges what a bold and massive social change and experiment we have with the development the National Disability Insurance Scheme (NDIS) for children with IDD. I have chosen this topic to talk from the perspective of parents, partly because parents are our most important partners as a community that cares for children with IDD. I also think they are likely to have more influence on the politics of resolving the persisting weaknesses in our service systems.

**'He who studies medicine without books sails an uncharted sea, but he who studies medicine without patients does not go to sea at all'** (William Osler, 1849-1919, Canadian doctor).

William Osler's 19<sup>th</sup> century quote is one of the enduring truths of medicine. How does this apply to caring for a child? When I was training in child psychiatry, a paediatrician friend asked me what he should read to be a better parent. I was surprised at his question, feeling that parenting was best learned from the experience of the way your parents brought you up, **combined with life's wisdom, and as a respected friend** and paediatrician, I felt he should be giving me advice on good parenting. Besides psychiatrists are renowned for being experts on what goes wrong, not what to do right.

Now at the end of a career of 40 years in child psychiatry, **I am aware we don't rely just on experience and wisdom**, but considerable scientific evidence about how to care for a child with IDD. In fact, the whole knowledge-base on how to care for a child with IDD has changed dramatically and, with that, the experience of growing up as a child with IDD has changed. Indeed, when I look back, my specialty of child psychiatry has changed almost beyond recognition. Albeit there is less research in the child psychiatry of children **with IDD, the role of the neurobiology of a child's de-**

velopment is recognised, not just the social hardship of families. However, I have learned so much from the families I have worked with and looked for scientific studies that provide evidence to make sense of their predicament. Accordingly, I now feel that parenting requires reading, learning and even training, as well as sharing experience with others in order to be a better parent. It is human to care enough to feel compelled to be a better parent than the previous generation and in every generation with the advance of understanding **that we can aim to do better. Accordingly, Osler's truth** is about the need to face the uncertainty of the future with a framework or established road of shared knowledge. I would argue that the prevention and promotion of mental health in families, schools and community is the most cost-effective health intervention and should generally have a higher priority in research and implementation (2013).

## 1. The scale of the challenge of C&A with IDD and of their emotional & behavioural/MH disturbance

I have been privileged to have researched family life for an adolescent with IDD and am still learning case by case from some remarkable individuals who care for these young people. In 1986-1990 I did a research study, interviewing 92 families with a child with high needs IDD (1991). This gave me a breadth of experience and showed me how much these families love their children with IDD. Their accounts challenged the professional orthodoxy that having a child with IDD was a persisting disappointment or grief for the dreamed of or anticipated child. However, the research also provided information and understanding of these families beyond my years.

Early in my training, in the 80s, I witnessed the closure of the last of the institutions and hospitals in which children with IDD had been abandoned and the slow development of community-based services. This was driven by the then new philosophy of normalisation, the primary but excessively simple tenet of which is

---

## “Parents are our most important partners as a community that cares for children with IDD...”

---

that without the institution these children would not be so handicapped and behaviourally disturbed. However, the first studies in the 1980s of groups of families with a Down syndrome child were showing that for 80%, having a child with Down syndrome was a rewarding experience. We now know that where that child with Down syndrome also has autism, that family life is much more challenging. In my own study it was only 30% that felt life was good enough for them and their high needs teen with IDD.

Against this we know that 40% of children with IDD have severe and persisting emotional and behavioural disturbance (Einfeld et al, 2006), and for those with autism this goes up to 70% with many additionally impaired by several disorders (Simonoff et al, 2008). Indeed, the research shows that the co-morbid emotional and behavioural disturbance has a greater impact on the burden of care than the developmental disability

(Hatton et al, 2007). Since the de-institutionalisation of young people with IDD, community-based mental health services have been unprepared and unskilled, and the subspecialty has been under funded. Understanding and managing the co-morbid mental disorders is a key part of improving the quality of life. My own tertiary clinic audit shows that mental health evaluation and treatment, particularly with medication can reduce that disability by an approximate average of 20% (2015).

There are additional well documented extra stresses: the increased chronic dependency of burden of care, (an average of 7 hours a day, 7 days a week), increased economic burden (\$15,000/year), parental burn out, stress, anxiety and depression (20%) and relationship challenges. There is no doubt that raising a disabled or different child can be a challenge, not that a neurotypical child is all easy. Having a baby always raises the risk that they may have difficulties, and up to 10% of babies have potentially disabling problems. It takes courage to face this risk. For those who have a child with a disability the process of acceptance and adjustment often takes a couple of **years but conversely the disability often isn't evident** for a few of years.

As we know the number of children being placed into



---

# “We need to understand what is involved in achieving a quality of life, social acceptance and resilience ...”

---

care is growing at a worrying rate, with approximately 15% of families placing a disabled child into care, and of adolescents in care, approximately 30% have a **significant disability**. Nankervis’ research (2011) showed that the main reasons for family breakdown varies with the age of the child:

1. The problems of acceptance in infancy,
2. The burden of care in childhood,
3. The behaviour disturbance in adolescence and
4. Family burnout and relationship breakdown in adulthood.

Although there is an apparent life cycle sequence to these problems, when a family breaks down, all 4 factors tend to co-occur. These 4 challenges are what any holistic and person-centred service for disabled children needs to tackle. This article aims to look for the answers.

In 2010 I wrote on “How much should we worry about the mental health needs of children and adolescents with or without intellectual disability?” and how the rates of abandoning children into care and the rates of psychiatric disorder in children were increasing, the western world over. Wilkinson and Pickett (2009) provided evidence that this may be best explained by the rising relative inequity in our society. The 2013 University of Sydney study, *Left Behind*, showed that while there had been improvements for people with an intellectual disability, in this time of rising prosperity the gap had widened between them and the mainstream. **We don’t yet know what impact the NDIS has had on rates of employment, marriage and inclusion, let alone mental health.**

An internal review looking at the factors associated with frequent attenders to our emergency department found similar factors of vulnerability predicted frequent attendances: moderate to severe intellectual disability, financial stress, compromised carer capacity and living in out of home care. Elsewhere I have argued that psychiatric vulnerability/disorder is a measure of a lack of social adaptability, but conversely, we need to understand what is involved in achieving a

quality of life, social acceptance and resilience and lastly community participation and contribution (Dossetor, 2012).

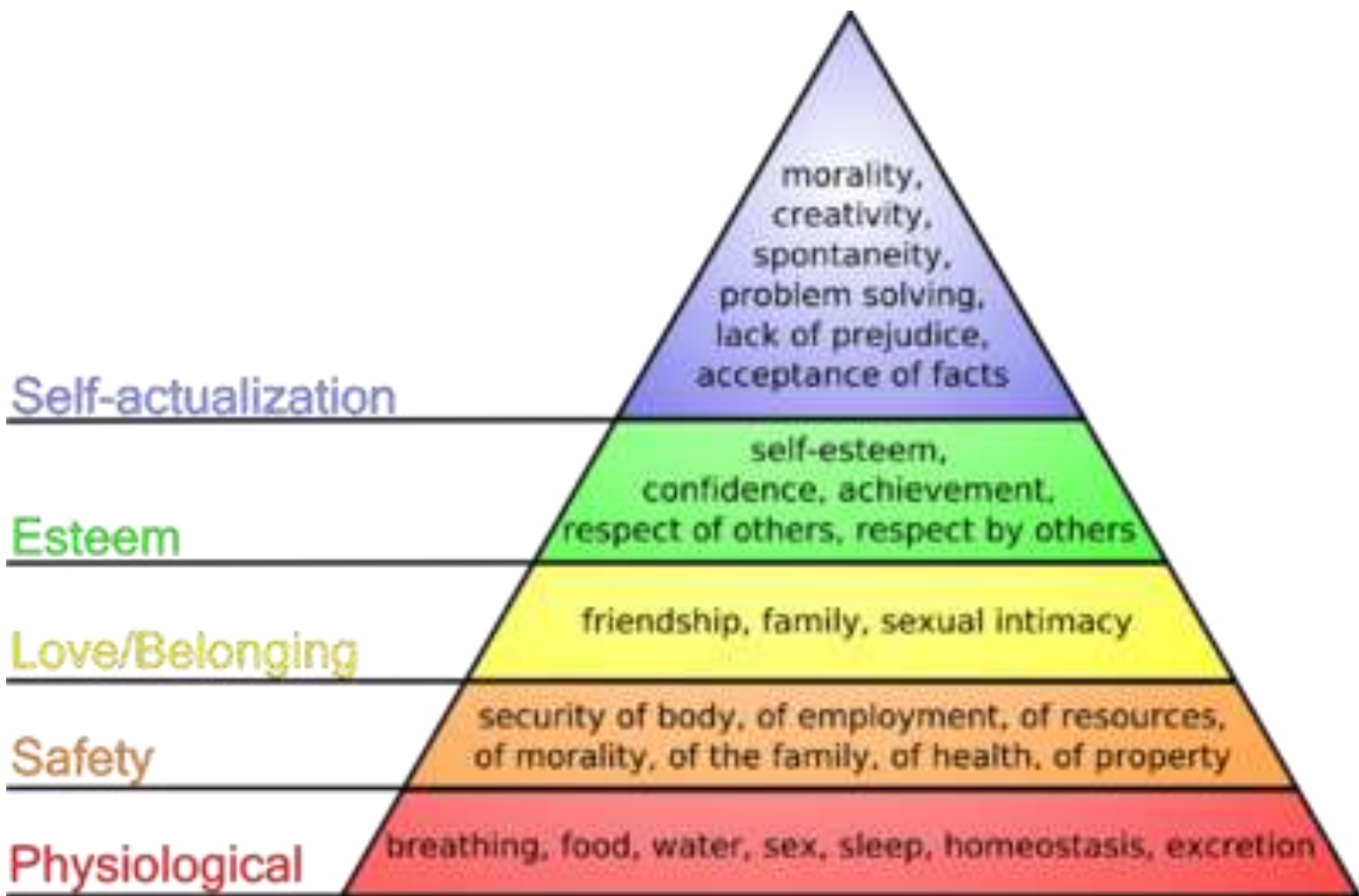
Arriving in Australia in 1991, with Ken Nunn our reforms in the department of Psychological Medicine at **the Children’s Hospital included giving children with IDD the same equity of access and respect as any other child for assessment and treatment**. This equity of access to health services for people with disability is now written into law for all health and mental health services (Disability Discrimination Act, 2010).

Following on from my specialty training in the UK, I slowly found opportunities to try to help, one family at a time, with some of these most challenging difficulties, and in doing so I developed partnerships with other highly skilled clinicians in NSW, in paediatrics, psychological medicine and in disability. In a partnership between disability and psychological medicine clinicians we established the only multidisciplinary inter-agency (including SCHN School-Link and NSW Department of Education) **tertiary clinic in NSW ‘the Developmental Psychiatry Clinic’ which in 2014 had an external evaluation by the Centre of Disability Studies of University of Sydney which found that we provided world standard practice despite so little funding (2014)**. With the collaboration between some of the best clinicians in the state in mental health and intellectual disability in 2005 we received funding to establish a multidisciplinary evidence-based curriculum on helping some of the most difficult children with IDD and their families. In 2011 we published our textbook based on this curriculum, which will shortly be available free on our website (Dossetor et al, 2011), and since 2009 our School-Link liaison service for schools that cater for IDD has published this journal on the mental health of children and adolescents with IDD, free to access and available on-line ([www.schoollink.chw.edu.au](http://www.schoollink.chw.edu.au)). Although we were funded to provide interdisciplinary education and training, parents are the most important partners-and-advocates for children with IDD. We aim to write the journal in plain English, and be accessible to parents.

The elements of the curriculum for the MH of C&A with IDD were and still are:

- Aiming for a quality of life with the foundations of a shared evidence-based language and a bio-developmental-psycho-social-cultural framework of understanding a child and their context.
- Focus on families and carers
- Interventions that promote skill development
- Interventions to promote mental health
- Integration of service systems

We developed this curriculum from the evidence base,



what professionals thought was important, and have reviewed it in workshops at international conferences. I aim to signpost some valuable literature along the way.

This essay on 'what I would want to know and what I hope I might try to do if I had a child with IDD' but is based on our curriculum. It is also based on a partnership sharing many challenges with parents in making sense of a child with IDD and witnessing their love and skill to enable 'a good enough' quality of life for their child and family. The parents of children with IDD are some of our most amazing community heroes.

2. A framework of hope and aiming for a quality of life  
 The growth of a scientific literature on 'what makes a quality of life' is still recent but has some important lessons. One of which is that disability has little to do with quality of life and neither is money an important factor, so long as you have an adequacy. The history of mankind has shown and potentially can continue to be one of evolution and progress which involves valuing every person and their subjective experience of life, as part of acknowledging fundamental human rights. This advance of enlightenment is based on democracy, supported by science and the rule of law, and the hope for increasing prosperity. Accordingly, we should always be trying to build on the achievements of previ-

ous generations.

Maslow described a hierarchy of human motivation and well-being, divided into healthy physiology, safety in life, love and belonging, self-esteem and self-actualisation, or physical needs, psychological needs and self fulfillment. Maslow's Hierarchy (Above)

Human advancement therefore involves the growth of well-being in our community. I am struck with the similarity that this has with the domains that contribute to quality of life. No one has a perfect quality of life or complete self-actualisation, but we can all aim for a 'good enough' quality of life. 'Good enough' parenting is a phrase that the paediatrician Donald Winnicott (1973) coined, implying that one cannot aim for perfection, as it is always balanced by our empathy for others. For example, Robert Cummins (2012) has done considerable research on quality of life, including for adults with intellectual disability and finds that the key determinants are:

- adequate standard of living
- safety and shelter
- health and nutrition
- belonging and having valued relationships
- being linked to the community
- having a purpose and making a contribution to community, and
- having a hope for the future.

The components described create aims for us or a young person with IDD to achieve ‘a good enough’ quality of life. Indeed, he talks eloquently that the duty of politicians and government is to provide the mechanisms for much of this: a safety net for all, with access to housing, safety, nutrition, health services; to reduce discrimination against difference to build self-worth, and enable community valuing and participation, including a valued employment contribution. He backs this up with rigorous community-based research.



*Quality of Life by Robert Cummins (2012)*

Babies are not small adults, but what is so wonderful and fascinating is in children we witness the growth of consciousness, self-awareness and intersubjectivity. In those with IDD, we see the differentiation of this process happening more slowly. This includes developing skills in:

- identification of self and non-self
- motor regulation, coordination and sensory modulation
- selective attention and attention switching
- communication skills and theory of mind
- mood regulation and empathy
- self-concept and self-esteem
- reciprocal social interaction and relationship building, and
- reality testing, perspective taking and other executive function skills

These skills are best evidenced by the capacity of a young person to make new good quality peer attach-

ments. The most important skills are the development of attention and concentration, a pre-requisite for learning, and the development of theory of mind: the capacity to appreciate that others have separate thoughts and feelings to your own which is the central deficit of autism. It is this developmentally determined understanding of child development that explains what is needed to foster optimal development as the child grows (Image on page 9).

These models of the advance of man, the elements of quality of life and the components of child psychological development are a valuable guide for understanding children. It is the components of child development which predetermines the type of relationship capacity seen in childhood and determines what is most helpful to counter the challenges of disability that I shall come back to during the course of this article.

### Family reports of hope

In 2001 I wrote an article “Parenting a child with intellectual disability: the chosen and those that chose”. This literature review (Stainton & Besser, 1998) described that despite the additional adversities that some parents reported there were some advantages of caring for a child with a disability, such as:

- The child is a source of happiness and joy, marveling at events and sequential small achievements in the life of their child.
- Parents report an increased sense of purpose and in giving priority to the elements of love, affection, caring, and simplifying life.
- Some parents reported expanded personal and social networks and community involvement due to their disabled child, and added meaning to various relationships, such as learning who your real friends are and experiencing involvement in a caring community.
- Some parents reported their child provided a source of increased spirituality and faith in humanity.
- Some reported bringing a family closer together; sometimes their child was a make or break experience.
- There was increased tolerance and understanding, not just for the parents but also for the siblings, not just for disability but for all human differences
- Having a child with a disability was a source of personal growth and strength, persistence, bringing out the best in themselves.
- Lastly this experience enabled them to have a positive impact on others, the community and professionals, who were handicapped by their own pre-convictions or prejudices.

This thematic literature on the difference of disability



illustrates the fundamentals of what is needed to cope with any adversity and to build a caring community for children. The implication being that mainstream families often live life in the fast lane and may miss out on some of these more personal and intimate experiences which are found when you face the reality of a child with IDD. It is important for professionals to appreciate such potentials and work to enable such positive adaptation. Most people who work in disability generally come with positive and altruistic intent.

### 3. Acceptance and primary MH prevention through parent training

Acceptance should be modelled by health professionals from the time of the birth. This modelling of acceptance of the wonder of new life is moderated with the acknowledgement that difference may create additional challenges for which there will be future answers (Silove, 2011). Developmentally, most babies are remarkably similar, and differences often only occur later in development. This modelling of acceptance provides a model that may be passed on to wider family and friends and sharing the joys of a newborn child **is key to the child's wider acceptance and engagement.**

Regardless of disability, the most cost-effective intervention to prevent psychiatric disorder is parent training.

**“The most cost-effective intervention to prevent psychiatric disorder is parent training...”**

ing. This can reduce violence and crime and the need for prisons, as much as reduce the need for psychiatric services and hospital beds. This evidence is so strong that I would argue that the privilege of government funded education should require all parents to participate in parent training. This simple universal intervention not only improves both disruptive and emotional disorders in the child but improves parental mental health and marriages, as success as a parent is so rewarding. Conversely a failure in parenting leads to a cycle of worse child behaviour and in turn worse parenting. The best evidence in families with a child with IDD is with Stepping Stones Triple P Parent Training (Sanders et al, 2008). Stepping Stones Triple P (SSTP) is based on behaviour therapy, applied behavioural analysis and positive behaviour support, developmental understanding, and the principles of normalisation.

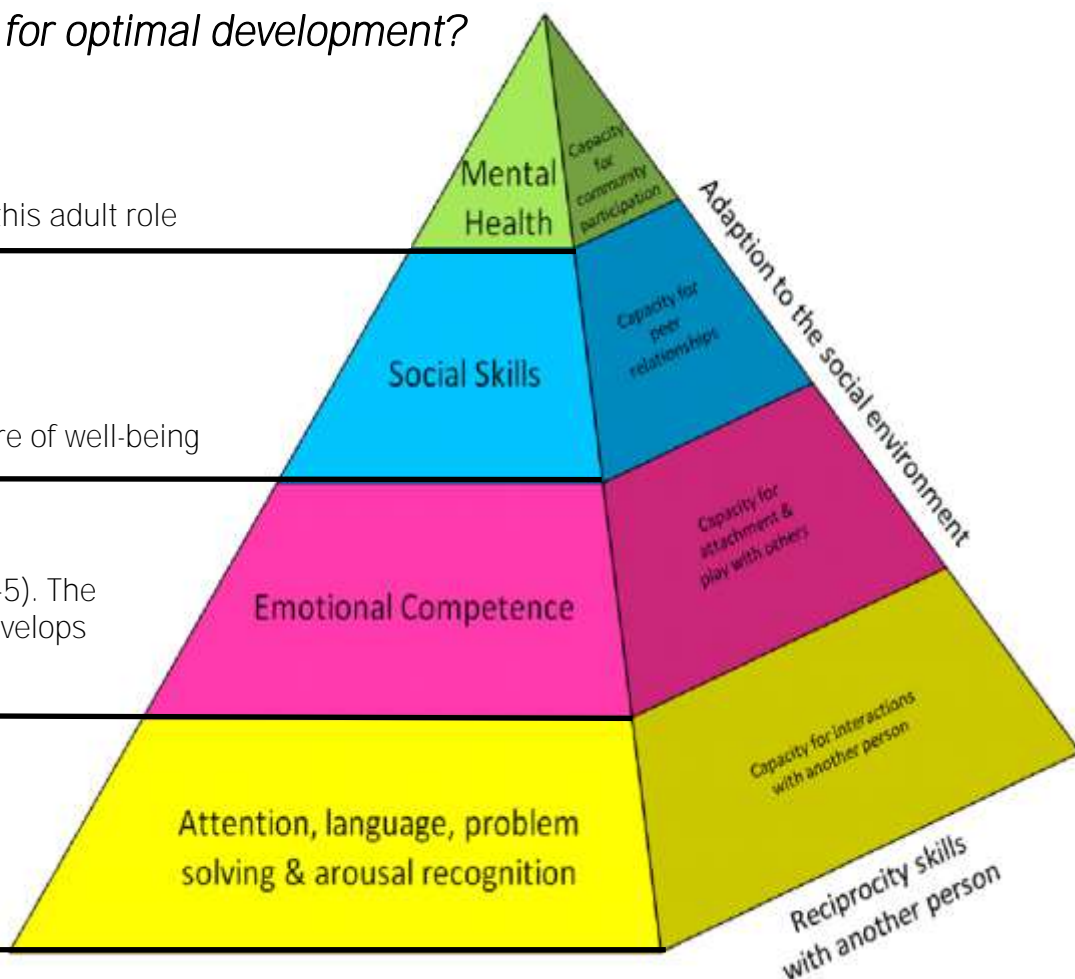
### What is needed for optimal development?

Adolescence is preparation for this adult role

Primary school age best measure of well-being

Emotional competence skills (2-5). The **Westmead Feelings Program** develops these skills

Behavioural regulation & management (0-4yrs)





The principles involve creating a safe and positive learning environment, using assertive discipline, adapting to a child with a disability, realistic expectations, being part of the community and taking care of yourself as a parent. Strategies involve developing a positive relationship, encouraging good behaviour and new skills, and managing misbehaviour.

Our own study in NSW Schools for Special Purposes was dramatic (Ray, *et al*, 2019). As one school principal said, by the time a parent gets their child into an SSP, the idea that anything they can do will change the behaviour problem feels ridiculous. Yet the study reduced behaviour and emotional disturbance by 25% and had dramatic impact on parental stress, anxiety and depression, and their parenting skills and competence. Understanding delayed child development and the priority of behavioural intervention enables more normative behaviour for a child with disability and is the first step to better mental health.

A key element in success is reducing coercive parental behaviour, while enabling skill building in the child's self-regulation. Building self-regulation is a key skill to protect a child from future mental disorder for internal-

ising disorders of anxiety and depression and externalising disorders of ADHD and disruptive behaviour disorder (Burton *et al*, 2020).

Despite the massive scale of funding, it is unfortunate that NDIS has not yet appreciated the whole of life priority that includes SSTEP early intervention especially for group Stepping Stones. The economic evaluation showed that a year later families that completed this program were over \$500 better off, as better behaviour enabled them to have greater access to employment. Because of the economic imperatives, a political solution will need to be found, either by the NDIS or by the state government, which is what has happened in Queensland (Qld Gov announcement, 2017).

### But my child is different:

I remember one child with Smith Magenis Syndrome (SMS) who in my clinic started scratching himself where my registrar had accidentally touched him until he made himself bleed through his shirt. Smith Magenis Syndrome is a genetic syndrome that has a dreadful behavioural phenotype. I have seen remarkable developments in the last 20 years in the management of these behaviours, that previously challenged the best psychiatric services (2001). Greater awareness of how *challenging* these children are has led to small but remarkable improvements in outcome. Firstly, paediatricians are likely to recognise the disorder earlier and it can now be confirmed by a genetic test. Secondly, the SMS parent group has had a huge effect in supporting parents faced with this challenge. SMS parents have supported the sense-of-feeling-helpless that new parents suffer, which also enables a persistence of caring and behaviour management. These changes are documented in chapter 13 of our textbook on parental perspectives: Here two mothers of a child with SMS describe their challenges of how parents couldn't get a diagnosis or services. 10yrs later a third mother described the same biological vulnerability, but, with supra-ordinate patience and behavioural persistence, **was able to improve her child's behaviour. The fourth** author Judy Brewer Fisher who is a national hero as an advocate for services for autism, argues that the parents of children with IDD not only have to learn to care for their children, they also need to advocate to our wider society for the acceptance and service provision for these children. Mutual parental support from those who have the lived experience is really valuable.

A strong focus of the traditional child psychiatry movement has been helping parents to overcome their own adversities to help the emotional and behavioural disturbance in their child; in high needs disabled children it is now recognised that the biological difference in the child is a greater determinant of future disturb-

ance than any family quality not just in SMS but in autism and Fetal Alcohol Spectrum Disorder (FASD) as other examples. That said, the parents of children with SMS show that supra-ordinate parenting still makes a difference, but also the professional standards of parenting that is taught in Stepping Stones, remains the best evidenced intervention, for even the extraordinarily disturbed children for example with FASD (Elliott, Personal communication) and autism.

To summarise: Two-years-olds are recognised as the most violent beings on the planet, and the role of parents is to teach them self-regulation, emotional recognition and socialisation. This does not happen without skilled parenting. In those with IDD, the challenge is greater, but these higher-level skills are readily taught to parents and failure to optimise parenting causes greater hardship and cost to all, especially if it leads to a long-term family breakdown. Conversely emotional and behavioural regulation are the first requisites for developing closeness to parents and other family members. This is also key for developing and integrating a subjective sense of self, as concentration and theory of mind develop.

#### 4. Promoting development and independence, especially in the context of Autism

Along with behavioural management, it is important to understand the different domains of development. Where there is a delay in development it is likely that that delay will be uneven, and therefore a parent needs to both understand the domains of development and look for the skill development, across these domains. The main domains of development that progress with mental age are as listed:

- Motor and Sensory development & integration, including coordination, sitting still and calmness a pre-requisite for concentration.
- Independence skills eg dressing, eating, hygiene & toileting skills. These are the best measure of **general IQ before developing the '3Rs'**.
- Communication & Language: receptive, expressive, verbal, non-verbal (including object and picture communication).
- Emotional, Social and play skills, the most complex skill; difficult to measure but we have well recognised descriptions of the sequence of skills.
- Quality of imagination: stereotypic rigidity or imaginary preoccupation at the expense of social interaction versus ability to build reciprocal ideas
- Educational and Community integration skills: keeping safe, accessing services, managing money. Schools are the primary setting in which these skills are tested and developed.

Promoting skill development even in small steps is key

---

## “Promoting skill development even in small steps is key to independence...”

---

to independence and self-efficacy and can be supported by specialised disability allied health professionals such as: physiotherapy, occupational therapy, speech therapy and behavioural therapy which can now be funded by NDIS. All these domains of development have complex genetic factors driving their processes, which means that if one area is delayed, then another is likely to be delayed. If there is a general delay, then the domains are likely to be unevenly delayed and this will influence behaviour. A developmental-age framework is necessary before one has educational skills, as psychometrics have limited validity before you have the 3 Rs (reading, writing and arithmetic). Further parents usually know these stages from their knowledge of neurotypical children.



---

# “Emotional recognition skills, emotional perspective taking and emotional problem solving is key ...”

---

In my own study of high needs teenagers with IDD I found that that behavioural disturbance is related not to chronological age but to developmental age. As Dr. Lorna Wing, a mentor of mine and the founder of the **UK Autism Association pointed out, as a child’s mind develops, they become more exploratory, energetic and intrusive, until their capacity for theory of mind develops at 2.5yrs when not only do they become aware that other people have thoughts and emotions separate to them but they develop a capacity for**

thought and imagination into which to direct energy, and their externalising energy settles down. Autism is the specific delay of the development of emotional understanding and theory of mind, that also leads to problems of empathy, and cognitive rigidity or stereotypes. Accordingly, a child with autism still has emotional understanding under the age of 2 years and one with Aspergers is under 4.5 years. This delay in emotional intelligence is what also needs specific intervention. There is a growing literature on how the stage of emotional development is a critical determinant to mental well-being in children and adults with IDD (Burton et al, 2020).

Other factors also contribute to whether a child is easy or difficult to raise:

- health problems including Neurological & sensory deficits
- intellectual ability, including learning problems & neuropsychiatric deficits
- temperament with genetic & environmental contributors
- rnvironmental milieu: emotional warmth, stimulation, predictability and consistency
- earlier experiences, positive, or traumatic
- attachment style and strength

All contribute to the development and neuro-



connectivity and to vulnerability and resilience.

In terms of psychological development in IDD, teaching emotional recognition skills, emotional perspective taking and emotional problem solving is key to developing attachments and social relationships. In the Westmead Feelings Program: emotional learning for autism; our dictum is **“You can’t have social skills without emotional skills”** which is what the Westmead Feelings Program targets specifically (Radcliffe et al, 2014, 2015).

Interventions to promote skill development have a growing literature and in our textbook (2011) the topics include:

- sensory integration and motor development
- promoting communicative competence and Alternative and Assisted Communication
- building life skills
- developing emotion-based social skills in Autism and ID
- promoting healthy sexual awareness and relationships, and lastly
- transition

The journal has additional valuable articles on: for example **‘Learning to move and moving to learn’** is an article highlighting Amanda Kirby’s work on the problems that are associated with motor coordination disorder and shows how interconnected different disorders of development are (from the Dyscovery Centre in Cardiff) (Dossetor, 2012).

## 5. Mental health and the bio-developmental-psychosocial-cultural framework.

Identifying a co-morbid psychiatric disorder is important. In those with autism 50% have ADHD and 50% have crippling anxiety. The critical element is that the emotions or behaviour are more handicapping than one would expect for their development and opportunities for learning better behaviour. Mental health awareness is critical for identification: For example, some special education teachers may be highly **skilled in behaviour management, but don’t consider** the possibility of the additional biological handicap of ADHD when reasonably straight forward medical treatment can be so helpful. Conversely, identifying crippling anxiety in a child with limited communication is difficult unless you are carefully considering this option.

In the last 20 years we have come a long way when different agencies were using different terminologies, according to a particular ideology and discipline. Parents along with their professionals need to consider different models of understanding behaviour and work out in collaborative ways the most valuable model for

each problem in each child. Indeed, study of behavioural phenotypes teaches us that different presenting symptoms may have different causal mechanisms in the one child.

I have real concerns about some of the discriminatory ideology of the NDIS such as restrictive practice: when the NDIS attempt to deny young people with IDD access to pharmacological treatment by ascribing it as **‘restrictive practice’** or **failing to recognise the need for assertive discipline and control** when a child with IDD acts without insight or clear intent, secondary to their developmental delay and needs safety management. Safety management is an important consideration in many persistently violent disabled young people, and I use my article on this topic in our journal more than any other to educate parents and disability professionals (2016).

The need for skilled assertive discipline was illustrated by a recent comment of the Royal Commission into the abuse of people with intellectual disability, when a school claimed a disabled child was being deliberately violent, and the commissioner advised that, in Australian law, any child under the age of 10 cannot be considered to have intent! What a responsibility we share with parents and as a community to show responsible management of disturbed children, which often needs multidisciplinary understanding and skills to establish an optimal reactive management plan.

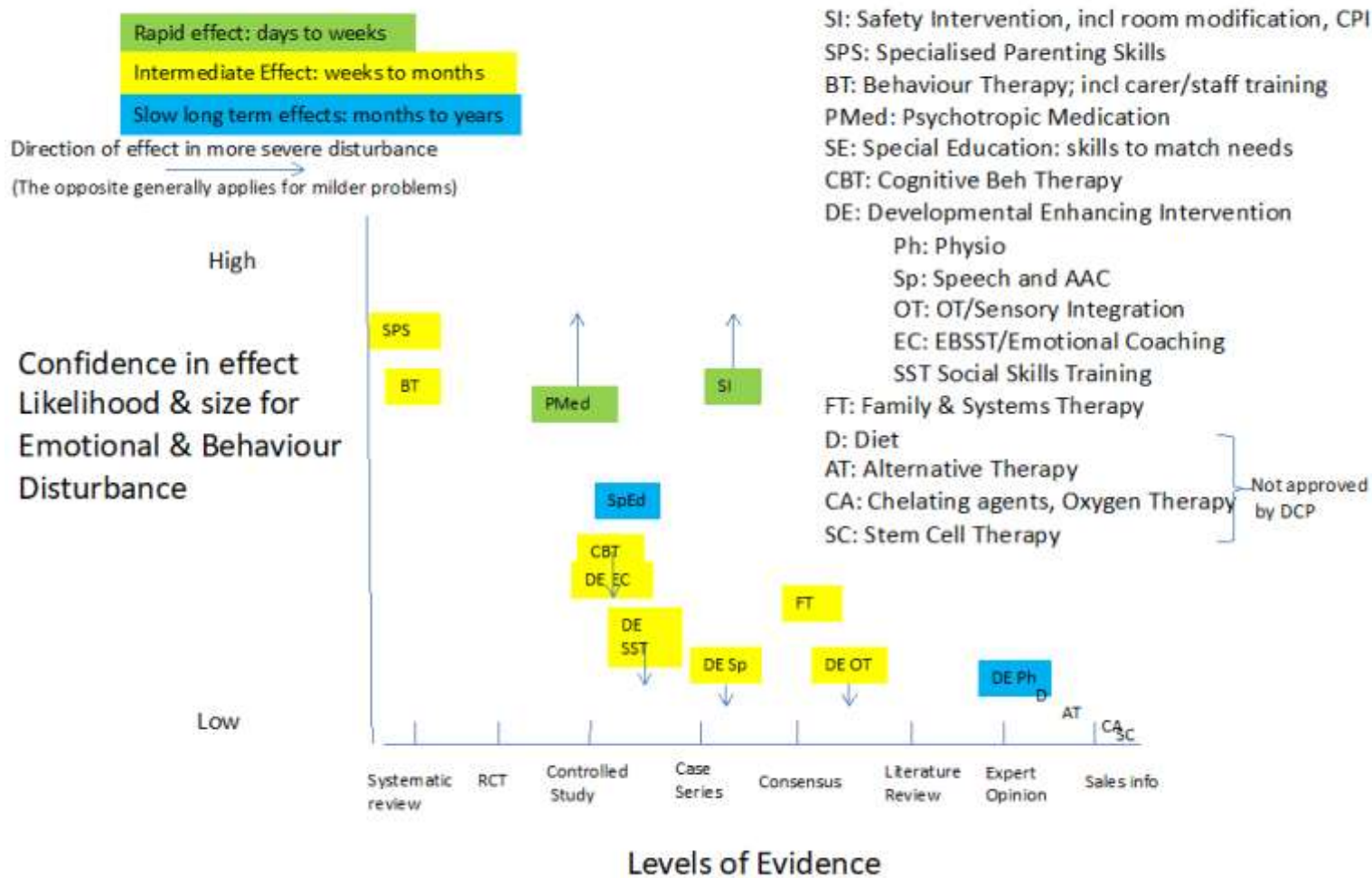
## Interventions to promote mental health: key elements from curriculum and textbook.

### Promoting Safety and resolution (Ch 21):

High risk behaviours of violence or self-injurious behaviour often need multidisciplinary intervention as described in our chapter on safety and resolution. This also took a systems approach to examining the effects **of a child’s perception of the different agencies and professionals on their problems.** Parents also have a powerful legal authority to keep their child safe, so **long as they don’t inflict harm. Approaches start with** behaviour management, consideration of co-morbid psychiatric disorder and then safety management. Safety management of its own can be highly therapeutic, and any intervention has to be judged by the outcomes (Managing violence in young people with intellectual disability and the importance of safety. Dossetor, 2016).

**Graham (Ch22) described ‘modifications of Cognitive Behaviour Therapy (CBT) and counselling’.** Modification of trauma focused CBT is also important, but most for those with mild ID. **The regulation of arousal (Ch23, Chenoweth)** looks at the relationships between development, trauma, attachment and anxiety and how extreme distress also affects the response of carers

# Treatment Effectiveness in Intellectual & Developmental Disabilities



which in turn contributes to the problem. Intervention and repair are therefore a complex multifactorial process.

**Psychopharmacology** is often a necessity when non-medical approaches have failed. However, there are differences in the way mainstream medications may react in those with IDD, and often different medications are needed. My own clinic audit of 150 cases found they had an average of 3.5 diagnoses, excluding the developmental disability, and required an average of 2.5 different medications for best outcome (2015). I have recently summarised my approaches to the evaluation of the need and the use of medications in this population (2019). In my training, my mentor taught that any doctor who wishes to help high needs young people with IDD has to be prepared to prescribe. When I first trained, ADHD was a controversial diagnosis, and in UK medication was seldom used. Now ADHD is a well-recognised biological and genetic disorder for which medication is established as the most important effective intervention. The importance of biological diversity in children has been slowly established, and medication is an important treatment in more impairing emotional and behavioural disturbance. Paediatricians

are generally skilled in identifying these problems.

Graph (Above) of the level of evidence on different therapies is presented. Much of the therapeutic evidence depends on cohort studies, professional expertise and consensus, but mainstream clinicians often mistakenly dismiss the lack of high levels of methodological evidence as an absence of evidence. The colours represent the speed of change, and the arrows indicate likelihood of value in an acute situation.

Modifying mainstream treatments for young people with IDD often requires special skill and experience such as arousal management treatments, eg relaxation skills, slow breathing, massage, distractions, chill-

**“Medication is an important treatment in more impairing emotional and behavioural disturbance...”**

out systems, traffic lights, zones of regulation, visual communication and social stories. Young people with IDD are exposed to a range of interesting but novel therapies. Some despite limited research evidence may be valuable as they evidently have a capacity to engage and motivate, such as animal therapy, e.g. horse riding for the disabled, music therapy, hydrotherapy and a range of other sensory interventions. Some such as poo transplants and stem cell therapy are highly intrusive and experimental and in the absence of evidence cannot be recommended. Some such as chelating agents can be positively harmful.

One research study illustrated that the parents of children with autism are particularly vulnerable to **'alternative' and unvalidated treatments in early years**, but over time come to accept views more in keeping with professional consensus views and scientific evidence. Similarly parents have to judge when a therapy is not providing useful benefit. The business model of the NDIS can present a conflict of interest, versus what is in the best therapeutic interest of the child. In this free market economy of disability, we also lack systems of evaluating the quality of intervention from

different service providers, and then in other settings find there are no providers to provide a prescribed service. I know some advocates despair at the quality of **'positive behaviour support' provided by NDIS registered practitioners**, and disability advocates have been a critical part of the workforce to see community justice in accessing service systems (personal communication).

## 6. Collaboration between disability, health and education.

The language for describing issues of mental health is confusing, and often there is a lack of a common professional language, and different agencies may fail to understand different perspectives, or miss-use them to avoid providing a service.

This table (below) introducing the service language that is used across agencies and explains some of the service routes from mental health and wellbeing to challenging behaviour, to mental disorder to mental illness.

The policy guideline between disability and health

# Definitions of Mental Illness & Health in ID

## Guide to Services framework in Australia

Term	Service	Disturbance	Severity	Examples
Mental Disorder/ Illness (3 <sup>rd</sup> NMH Plan) 3%	Diagnosable Illness from DSMV Priority for <b>Mental Health Services</b>	Managed in community +/- short IP admission +/- MH Act	Significant impairment and high risk of harm to self or others	-Major Depression -Bipolar Disorder -Schizophrenia -Acute Mental Disorder
Mental Health problem (3 <sup>rd</sup> NMH Plan) 20-40%	Diagnosed from DSMV but seen as a developmental disorder Rx by <b>Paediatrics &amp; disability service, +/- specialist ID MH.</b> (not a serious MI)	EBD is as severe as impairment from ID. The combination makes for complexity and severity	Severe impairment, risks to care esp in acute exacerbation <b>Needs high expertise MD subspecialty collaboration of disability &amp; health</b>	-ADHD/ODD/CD -ASD --Depressive symptoms -Anxiety Disorders, OCD, -Lability of mood, -Panic disorder, -Dissociation -Trauma based problems
Challenging Behaviour 40-60%	Culturally Abnormal Behaviours <b>Disability Services,</b> ABA approach	the physical safety of the person /others	High impairment, intensity, frequency or duration big impact on QOL	-aggression/self harm -behaviour disturbance -stereotypy -habits, Pica
Mental Health & Wellbeing (3 <sup>rd</sup> NMH Plan) 100%	emotional & social wellbeing. PPEI across family, school, community & interagency	Promote resilience to cope with the normal life stressors	Chronic moderate severe EDBD probs. Aim to achieve potential & QOL	attention, restless, behaviour, reciprocity, self esteem, autonomy, skills, part'n, employm't

agencies used to be that ‘there is no wrong door’ and there was an important MOU between disability and mental health (2010) which is now redundant with NDIS, unless state governments re-establish the disability services of last resort. However, I contend that mental health is the most important and underfunded area of health. Mental health services are understandably defensive as they are generally overwhelmed. NDIS is a massive enhancement of funding for people with a disability and more than twice as big as mental health services of all funding types. Yet as a massive banking/insurance scheme it has no mechanism for collaborating with mental health. In the days before NDIS, NSW Department of Ageing Disability and Home Care (ADHC) was the main resource for emotional and behavioural disturbance in disability, and emotional and behavioural disturbance was probably half of their professional work. The lack of collaboration with mental health risks an attempted massive cost shift for behaviour problems from disability to health. The scale of the problem will continue to trouble politicians, as it remains wedged between state and federal funding systems.

What can parents do in the meantime? Health literacy is the term used for the level of knowledge and skills in understanding health problems and accessing



health services. It is my view that in dealing with complex children with IDD, a parent needs to become an **expert on their own child's problems, and as a psychiatrist** it is valuable if they keep the records including what medications have been used in the past and what effects or side effects they had.

None of us like to depend on health professionals but when you need one, make sure he/she is someone you can trust. This starts with a good GP to be available for intercurrent health problems, and a general paediatrician to coordinate inputs from a range of professionals from health, disability, education & NGOs. You need a GP who knows you and your family and has patience and understands what helpful assessment **can be made, despite a child's limitations of communication and behaviour.**

As a problem becomes more challenging, high risk and resistant to intervention, it is likely to need a wider range of skills in a multidisciplinary multiagency tertiary team review. The range of skills might need to include paediatric, and psychiatric skills to assess health, mental health, multidimensional formulation and medication. Multidisciplinary allied health skills including clinical psychology, occupational therapy, speech therapy, special education, pharmacy, case management; skill building approaches as described above; specialised therapies e.g. emotion-based learning skills, play therapy or modified or trauma focused CBT; family and system assessment and management skills which may be different to mainstream families; cultural knowledge is often needed, as cultural difference can affect health literacy and access. Awareness of child protection and human rights issues and the interface with DCJ and care systems of those in Out of Home Care.

No one agency has all these skill sets so lastly there is a need for a high level of interagency collaboration. It is no wonder that parents often develop a professional proficiency in managing collaboration because of the range of services, professionals and skills involved. Integration of service systems probably remains a major and complex challenge with a growing literature on

---

**“No one agency has all these skill sets so lastly there is a need for a high level of interagency collaboration...”**

---



# Tiered Pyramid of Services for C&A with ID & MH problems: The specialist MH in ID Service for C&A when there is none.

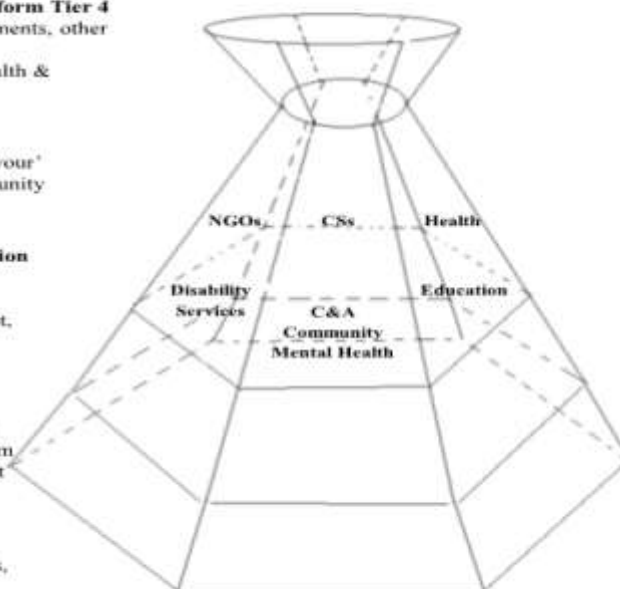
**Tier 5: Acute short/medium term interventions that inform Tier 4**  
Includes: Emergency departments, MH in-patients assessments, other residential behaviour services; and **Specialist/Tertiary MH in ID clinicians** from mental health & disability services.

**The Tier 4 Circle: The Final Common Pathway**  
Complex case management decision making; 'best endeavour' obligations including decisions about out of family community placements.

**Tier 3: Multidisciplinary and Multi-agency Collaboration**  
**Disability Service:** ADHC behaviour clinician, speech pathologist, OT, other specialist psychology service;  
**Health:** GP, paediatrician or neurologist; MH Psychologist, SW, family therapist, psychiatrist; and  
**Education:** teacher, aide, school counsellor, principal, behaviour support specialist.

**Tier 2: Community Disability Services providing case management and specialist parent training.** Mainly from ADHC but can be MH or other agency or non-government organisations.

**Tier 1: Generic Health Provision** for families  
Includes: GPs, community nurses, child community teams, Families NSW, Triple P



*3D Model provides for all other human services to be part of the pyramid*

how it can go wrong (chapter 27), what approaches can enable constructive collaborations (CDS, 2014) and some resource intensive approaches on how to build solutions (such as the Intensive Services Response which health has now been shut down). Probably it works best when a parent takes control of this. In a responsive service system, one should hope that a more complex problem would naturally engage more professionals and a greater range of expertise. I tried to describe this in this diagram (pictured above) of community-based management of IDD with increasing clinicians and agencies the more complex a problem became in tiers 1-4, with acute response and a tertiary problem-solving interagency in tier 5. I know there is the expertise in the NDIS/NDIA to realise we need this again, and reason would suggest that at some stage in the development of NDIS funded services this will need to be developed again.

There is no doubt that additional NDIS funded resources has helped many families. I am encouraged that so many professionals from different agencies are interested in the evidence-based bio-developmental-psycho-social-cultural model of MH in IDD. I feel that education and support for specialist approaches is helping to improve collaborative systems in health and education.

Over time, although we see that home is the most important influence, schools are appreciating that they are the second most important influence on the mental health of our children and becoming more skilled and programmatic in working to build mental well-being and resilience.

## Families and The Burden of Care

The biggest handicap with a child with IDD is the additional burden of care for the family: 24 hours a day 7 days a week way beyond when one expects a young person with IDD to become independent. Possibly the empowerment that arises from the SSTP training, can have a strong effect, partly through improving behaviour but partly from engaging family and friends to be **part of the child's life. It helps with the parental helplessness and self-sacrifice** that I see often leads to dangerous violence when the adolescent with IDD becomes bigger and stronger than the parent.

**NDIS doesn't directly focus on supporting carers. They do provide indirect respite in term of support for 'community access and other independence enhancing activities'.** I have seen the impact of in-home support breaking the intensity of behavioural dysfunction for example between a fraught mother and a self-injurious child. It can also help with the domineering teenager who never leaves his room or his social media for what can be years of stagnation. The Department of Communities and Justice (DCJ) used to support families with a child with IDD, with residential voluntary out of home care, emergency respite and even shared care arrangements for some of the most demanding, and sometimes impossible young people with IDD. There is no doubt that there are massive costs for families and society of a failure to intervene early and to prevent total family breakdown. As I understand it, disability services are responsible for **'challenging behaviour', and most violence is not due**

to mental illness although they often overlap. However, the interaction between NDIS and DCJ is a problem area which will need greater development, particularly systems for complex cases and ready access to the Complex Support Needs Pathway. In a similar vein there is a lack of cooperative systems between health/mental health and NDIS/NDIA which is critical to provide the best of multiagency/multidisciplinary care for complex cases.

Parental well-being is critical to the well-being of any child, including those with IDD. Families are the building blocks of society (Epstein et al, 2003). They are both the source of emotional communication and practical problem solving. Families depend on structure, rules and accountability with rewards and consequences for all. They are the source of love and welfare emotions, as well as providing practical resources. Relationships are healthier with appropriate closeness, not too enmeshed and not too remote. And managing emergency emotions: emergency emotions include anger, anxiety, depression or rigidity, (e.g from OCD), are highly infectious and can have harmful effects, even if another member of the family experiences a different emergency emotion. GPs and Paediatricians need to check out the well-being of the carers they consult to, as the parent child relationship is part of patient centre care. Family social isolation is a poor prognostic factor of mental health.

## Conclusions

To conclude, a parent of a child with IDD needs to become a developmentally attuned behavioural expert **for their child's wellbeing, but also their own. They** clearly need medical support for the increased risk of health and psychiatric disorder, which is mainly managed by paediatric care. CAMHS are skilled in the community management of supporting family relationships and major mental illness and disorder. We also need skilled clinicians in the other specialist disability-based disciplines in helping a child with IDD. Schools have a key role in adequately supporting special needs, not just for education but for building emotional skills and peer engagement, with greater empirical focus on building mental health and resilience. These families need social support from wider family and friends as **well as 'personal support and community access'**, funded by the NDIS to cope with the burden of care. The NDIS has made progress in providing support for skill development but skilled NDIS funded positive behaviour support remains critical. There is now an NDIS system for recognising complex support needs, but it is still in its early days. The quality of disability-related allied health skills is growing, but is it adequately funded for complex cases? Hopefully the Royal Commission into the abuse of people with a disability will cast

---

**“Schools have a key role in adequately supporting special needs, not just for education but for building emotional skills and peer engagement...”**

---

light on areas that NDIA has not adequately funded. In the meantime, the management of the NDIA seems to have an internal battle between cost cutting economists versus the need for disability professional expertise that understands some of the complexities of tertiary emotional and behavioural service provision. I hope that wedge politics do not prevent the development of collaborative multiagency, multidisciplinary systems that have been so valued by families. One of my concerns is that the recent NDIS health agenda is driven by other priorities such as dysphagia support for those with feeding problems, physiotherapy support for those with cerebral palsy and mental health support for those with long term psychosocial disability from chronic psychosis and personality disorder. Meeting the needs of high needs young people with IDD can get lost and needs continued advocacy. We live in an era where we should expect expertise and affluence continue to grow. There are now skills and knowledge **that weren't there a generation ago. I feel all parents can aim for 'a good enough' quality of life for their child with a disability, but raising a child has never been easy.**

**I started this talk with the question: 'Are we there yet?'** We certainly have not arrived at the destination to value all children equally. I hope I have given a bit of a map, with different roads to explore further, that still allows the individuals and their families to discover their own path. However, I am a believer in miracles with the changes I regularly witness in these families. Perhaps comparisons can be found in the fable of the Wizard of Oz: Dorothy and her pet dog were swept off course by a cyclone such as happens when you find yourself disorientated with a child with IDD, but miraculously with the brain, the heart and the courage of the unlikely friends that she met along the way, she was able to find the yellow brick road and get home.



## References

Burton T, Ratcliffe, B., Collison J, Dossetor, D. & Wong, M. (2020). Self-reported emotion regulation in children with autism spectrum disorder, without intellectual disability. *Research in Autism Spectrum Disorders*, 76.

Cummins, R.A. 2012, The determinants of happiness, *International journal of happiness and development*. vol. 1, no. 1, pp. 86-101.

Dossetor, D.R. (1991). A Study of the dependency needs of adolescents with developmental retardation: an evaluation of short-term care usage, expressed emotion in the primary carer, and the contribution of community services. Doctorate of Medicine, University of Cambridge.

Dossetor, D. R., Nicol, A. R. (1990/91). Community care for adolescents with developmental retardation. *Proposals and Problems*. *Health Trends*. 22(4), 148-151.

Dossetor D. 2001. Parenting a child with intellectual disability: the chosen and those that chose. *The Clinician* 1(1) p 61-63. **Published by Children's Hospital at Westmead.**

Dossetor D, 2001. Evaluating children with disruptive disorders and intellectual disability. *Clinician edition on Endurance and Disruption*. 1(2): 76-80.

Dossetor D. The Evolution of the 'Photon Catcher': Implica-

tions for Social Development and Autism. *Clinical Child Psychology & Psychiatry*. Vol 9(3) Jul 2004, 443-451. Sage Publications, US.

Dossetor D. 2010. How much should we worry about the mental health needs of children and adolescents with or without intellectual disability? CHW School-Link News Letter 1(1). PDF.

Dossetor D, White D, Watson L. (Eds) August 2011. *Mental Health of Children and Adolescents with intellectual Disability: A framework for professional practice*. IP Communications: Melbourne. [www.schoollink.chw.edu.au](http://www.schoollink.chw.edu.au);

Dossetor D. Moving to Learn, Learning to Move: The importance of Motor Development in Mental Health and Intellectual Disability. CHW School-Link Newsletter 3(3). 2012.

**Dossetor D. 2011. Aiming for a quality of life: what makes for 'a good enough' life? Chapter 1 in (Eds) Dossetor D, White D, Watson L. Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities: A framework for professional Practice. IP Communication, Melbourne. [www.ipcommunications.com.au](http://www.ipcommunications.com.au).**

Dossetor D. 2012. Mental Health Problems: Disorders of Social Development caused by Maladaptation's of Theory of Mind? A Developmental Psychiatry View. CHW School-Link Newsletter 3(1).



Dossetor D. 2013. A stitch in time saves 83: Health Economics for Mental Health and Intellectual Disability: Evidence based medicine and the growth of health economics of preventative mental health intervention. CHW School-Link Newsletter 4(2).

Dossetor D. 2015. The Developmental Psychiatry Clinic. Journal of Mental Health for Children and Adolescents with Intellectual and Developmental Disability. 6(2), 4-12.

Dossetor D. 2015. Diagnosis, Psychotropic Medication and Outcome of an audit of 150 child and adolescent neuropsychiatric patients. Journal of Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities: an Educational Resource. 5(1): 4-9.

Dossetor D. 2016. Violence in children and adolescents with an intellectual disability and the importance of safety. Journal of Mental Health for Children and Adolescents with Intellectual and Developmental Disability. 7(1): 4-13.

Dossetor D. 2019. Some personal guidelines for prescribing for the mental health needs of children and adolescents with intellectual disability and/or autism. Journal for the Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities, 10 (1): 4-16.

**Dossetor D. 2017. Book Review: “Interventions for Autism: Evidence for Educational and Clinical Practice” by Phil Reed,** Professor of Psychology, Swansea University, 2016. Published by Wiley Blackwell (1-360pp). Journal for the Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities, 8(1): 18-27.

Dossetor D. 2017 Young People with Learning Disabilities. Chapter 7: in Child Psychology and Psychiatry - Frameworks for Practice. Skuse D, & Dowdney L. (Eds). 2017. Wiley-Blackwell: London.

Dossetor D. 2020. How to treat Autism. Australian Doctor. <https://www.ausdoc.com.au/>

Einfeld et al. 2018. Is statewide delivery of stepping stones Triple P Effective? Research Program Findings at a glance. <https://pfsc.psychology.uq.edu.au/files/2129/The%20Stepping%20Stones%20Triple%20P%20Research%20Project%20Report1.pdf>

Einfeld S, Sanders M, Tonge B, Gray K, Sofronoff K, and the MHYPEDD team. 2018. Is Statewide delivery of stepping stones triple P effective? [https://www.monash.edu/\\_data/assets/pdf\\_file/0007/1507552/triple-p-research.pdf](https://www.monash.edu/_data/assets/pdf_file/0007/1507552/triple-p-research.pdf)

Einfeld, S.L., et al. (2006). Psychopathology in young people with intellectual disability. *JAMA*, 296(16), 1981-1989.

E Emerson, C Hatton 2007. Mental health of children and adolescents with intellectual disabilities in Britain. *BJPsych* 191 (6), 493-499

Emerson E, Honey A, Llewellyn G. 2013. LEFT BEHIND: Monitoring the social inclusion of young Australians with self-reported long-term health conditions, impairments of disabilities, 2001-2011. [https://www.sydney.edu.au/health-sciences/afdsr/docs/left\\_behind\\_080811.pdf](https://www.sydney.edu.au/health-sciences/afdsr/docs/left_behind_080811.pdf)

Jackson A, Waters S, Abell T. 2015 Taking Time: A Trauma Informed Framework for Supporting People with Intellectual Disability. Berry Street: Melbourne.

Epstein N, Ryan C, Bishop D, Miller I, Keitner G. 2003. The McMaster model: A view of healthy family functioning. The Guilford Press.

Nankervis K, Rosewarne A, Vassos M. Why do families relinquish care? An investigation of the factors that lead to relinquishment into out-of-home respite care. *Journal of Intellectual Disability Research*, 55 (4) (2011), pp. 422–433.

NSW Department of Health. 2010. Memorandum of Understanding and Guidelines Between Ageing, Disability and Home Care, Department of Human Services NSW and NSW Health In the Provision of Services to People with an Intellectual Disability and a Mental Illness [http://static1.1.sqspcdn.com/static/f/551166/21253531/1355354725927/mouandguidelines\\_full.pdf](http://static1.1.sqspcdn.com/static/f/551166/21253531/1355354725927/mouandguidelines_full.pdf)

O' Brien P, Espiner D, Arnold S, Riches V & Roberts L. 2014. Evaluation report on the Developmental Psychiatry Clinic: A Partnership between The Children's Hospital at Westmead and Statewide Behaviour Intervention Service (ADHC). <http://static1.1.sqspcdn.com/static/f/551166/26540531/1442370712890/CDS+Evaluation+Report+on+the+DP+Clinic+FINAL.pdf?token=FvO5m46ovM0iTBux9xtM4aIEYgw%3D>

Ratcliffe B, Wong M, Dossetor D, Hayes S. 2014. Teaching social-emotional skills to school-aged children with Autism Spectrum Disorder: A treatment versus control trial in 41 mainstream schools. *Research in Autism Spectrum Disorders* 2014; 8(12):1722–1733.

Ratcliffe B, Wong M, Dossetor D, Hayes S. 2015. The Association Between Social Skills and Mental Health in School-Aged Children with Autism Spectrum Disorder, with and without Intellectual Disability. *Journal of Autism and Developmental Disorders*: 45(8).

Radcliffe B, Wong M, Dossetor D, Carroll L, Brice L, Graeme V. 2017. Westmead Feelings Program I: Emotion-based Learning for Autism. An intervention Manual for children with verbal but not literacy skills, or mild intellectual disability.

Australian Council for Educational Research.

Ray P, Dossetor D, Caruana J, Gomes L, Saleh H, Watson L. 2019. Group Stepping Stones Triple P in Schools: An Evaluation of a Parenting Program for Children with Developmental Disabilities in the School Setting. *J for MH of C&A with IDD*. 10(1): 30-39.

Ray P, Dossetor D, Caruana J, Gomes L, Saleh H & Watson L. Group Stepping Stones Triple P in Schools: An Evaluation of a Parenting Program for Children with Developmental Disabilities in the School Setting. 2019, *JMHC&AIDD* 10 (1): 29-39.

Sanders, M.R., Ralph, A., Sofronoff, K., Gardiner, P., Thompson, R., Dwyer, S., & Bidwell, K. (2008). Every Family: A population approach to reducing behavioral and emotional problems in children making the transition to school. *Journal of Primary Prevention*, 29, 197-222.

Simonoff E, Pickles A, Charman T, Chandler S, Loucas T, Baird G. 2008. Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry* 47 (8), 921-929.



Stainton T, Besser H. 1998. The positive impact of children with an intellectual disability on a family. *Journal of Intellectual Disability* 23(1): 57-70.

Watson L, Corfield D, Owens B. 2011. Promoting resolution and safety: a case study example. Chapter 21 in (Eds) Dossetor, White and Watson *Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities: A framework for professional practice*. IP Communications. [www.ipcommunications.com.au](http://www.ipcommunications.com.au)

Wilkinson R, Pickett K, 2009. *The Spirit Level*. Allen Lane.  
Wing L, 1981. A schedule for deriving profiles of handicaps in mentally retarded children. In Cooper B. (Ed): *Assessing the needs of the mentally handicapped*. Academic Press: London.

Winnicott DW, *The Child, the Family, and the Outside World*. Penguin 1973.

## Webinars

Dossetor D. 2020. Kids MHID Webinar: What is different about assessing the mental health of a young person with intellectual or developmental disability? (33 mins).

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

Dossetor D. 2020. Self-Injurious Behaviour: a case series.

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

A new Student Behaviour Strategy: Lifting educational outcomes through early intervention and targeted support.

<https://education.nsw.gov.au/student-wellbeing/attendance-behaviour-and-engagement/student-behaviour/behaviour-strategy/a-new-student-behaviour-strategy-draft-for-review>.

Curiosity, collaboration and action: Understanding & Responding to Behaviour in the Classroom webinar *presented by Kirsty Paul from The Benevolent Society*. (50 minutes) and Cool, Calm, Collected & Connected in the Classroom: Supporting Students with Self Regulation webinar *presented by Debra Corfield from The Benevolent Society* (25 minutes) <http://www.schoolink.chw.edu.au/webinar-series/>

Responsible Prescribing of Psychotropic Medication Podcast. 2017. Prescribing in children and adolescents with intellectual disability.

[Episode 1: Recognising symptoms of mental illness in children and adolescents with an intellectual disability](#)

[Episode 2: Deciding if, when and what to prescribe](#)

[Episode 3: Instituting, monitoring and discontinuing psychotropic treatment](#)

[Handout: Guidelines for an assessment summary](#)

Partnership Projects with The Department of Developmental Disability Neuropsychiatry (3DN) UNSW

(<https://3dn.unsw.edu.au>).

E-learning for IDMH for MH professionals, disability profes-

sionals and carers

Intellectual Disability Mental Health Core Competency Framework: A Manual for Mental Health Professionals and Toolkit. Committee Member and presentation. <https://youtu.be/h15Y3yWfrxc>

Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers.

[https://3dn.unsw.edu.au/sites/default/files/ddn/page/Accessible%20Mental%20Health%20Services%20for%20People%20with%20an%20ID%20-%20A%20Guide%20for%20Providers\\_current.pdf](https://3dn.unsw.edu.au/sites/default/files/ddn/page/Accessible%20Mental%20Health%20Services%20for%20People%20with%20an%20ID%20-%20A%20Guide%20for%20Providers_current.pdf)  
2016.

CardioMetabolic Syndrome in Adolescents with Intellectual Disability. Presenter <https://youtu.be/rqS20Sy7Uy8>

SCHN MHID Hub: Service leaflet with range of services, including consultation and capacity building: Plus referral form and criteria. On SCHN website or on [www.schoolink.chw.edu.au](http://www.schoolink.chw.edu.au);



# Resources



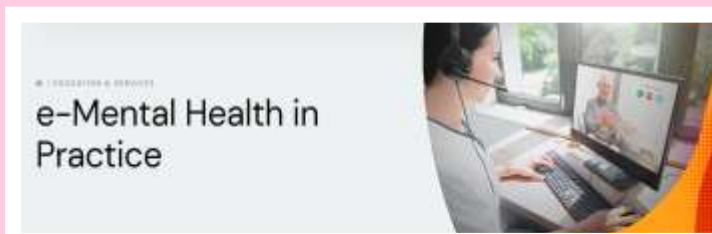
**Social Story Creator and Library** (App for iPhone or iPad)  
Created by Touch Autism

An app for easily creating, sharing and printing educational social stories, visual schedules and beautiful memories. The app also comes with over 20 pre-made social stories that cover a variety of social and behavioural skills, an incredibly valuable tool for any teacher, carer or parent. Free to download with In-App purchases. You can download as part of the Touch Autism bundle for \$46.99

A new issues paper, [Clearing a path to full inclusion of people with disability in emergency management policy and practice in Australia](http://www.daru.org.au/resource/clearing-a-path-to-full-inclusion-of-people-with-disability-in-emergency-management-policy-and-practice-in-australia) highlights the shortcomings in Australia's capability to plan with people with disability for how to manage the disproportionate impact of disasters on people with disability. Outlines six key issues that present barriers to the full inclusion of people with disability in emergency management.



<http://www.daru.org.au/resource/clearing-a-path-to-full-inclusion-of-people-with-disability-in-emergency-management-policy-and-practice-in-australia>



e-Mental Health in Practice, or eMHPrac, is a suite of online training modules, webinars and e-resources designed to introduce health professionals to online programs and tools, and to demonstrate how e-mental health technologies can be integrated into **primary care**. **Black Dog Institute's Mental**

Health Community of Practice is a private online community for Health Professionals with an interest in Mental Health offered through the eMHPrac project. Visit <https://medcast.com.au/communities/black-dog-institute> to register. The weekly digest is a helpful and informative round-up of information across the mental health spectrum.

The Circle of Security is a visual map of attachment and an early intervention program for parents and children. At Circle of Security International, there is a focus on training providers with many different backgrounds and from many different disciplines to help caregivers connect with the children in their lives. The Circle of Security figure is a central visual used as part of interventions for caregivers, all of which are focused on helping caregivers **reflect upon children's attachment needs in order to promote secure attachment with a child**. Visit their website for more information <https://www.circleofsecurityinternational.com/>



# An interview with Professor Emerita Patricia O'Brien

*On her retirement as Director of the Centre for Disability Studies affiliated with the University of Sydney.*

**Professor Emerita Patricia O'Brien PhD, FASID**

Sydney School of Medicine | Faculty of Medicine and Health, University of Sydney



*Tell us about your career and what some of the highlights of your career have been?*

I started my career as a primary school teacher and then a special education teacher in the state of Victoria. I never worked in primary schools; I went straight into special education. From there I completed a degree at Monash University in the days when Monash University was “the farm”. It was the second university in the State of Victoria which initially was met with some scepticism! As a teacher I was fortunate to win a Rotary Teacher of the Handicapped Award which took me through to the University of Oregon where I completed a **Master’s in Education Degree in the late 70’s**. A program that I became aware of in the United States was called Citizen Advocacy (CA) where people with intellectual disability were matched on a one-to-one basis with community volunteers for advocacy and social connection. When I returned from the states, I gained a position as a lecturer at Victoria State College

(now Deakin University). It was at the time of the 1981, International Year for Disabled Persons and I won a competitive grant to set up the first citizen advocacy program in Victoria. At the same time, I enrolled at the University of Queensland for my PHD exploring the development, maintenance, and efficacy of Citizen Advocacy.

At Victoria State College I was teaching graduate teachers who were doing a Diploma in Mental Retarda-

---

**“Trinity was an amazing place, built in 1592 by Queen Elizabeth 1st and its ancient history...”**

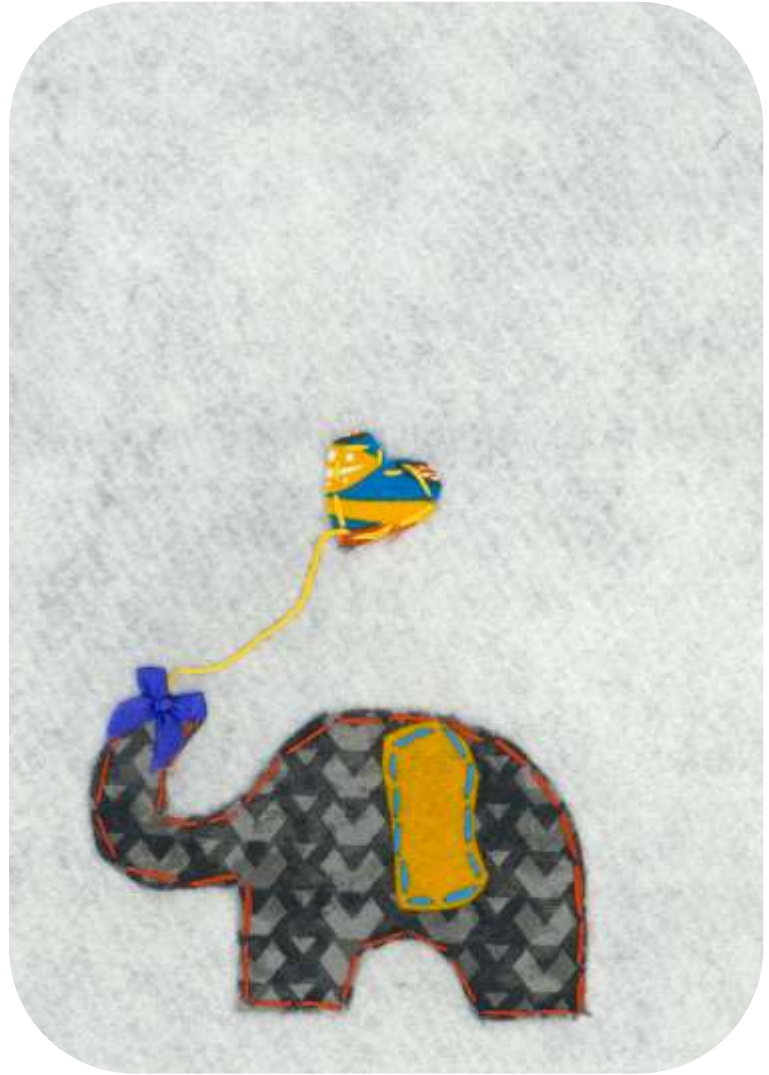
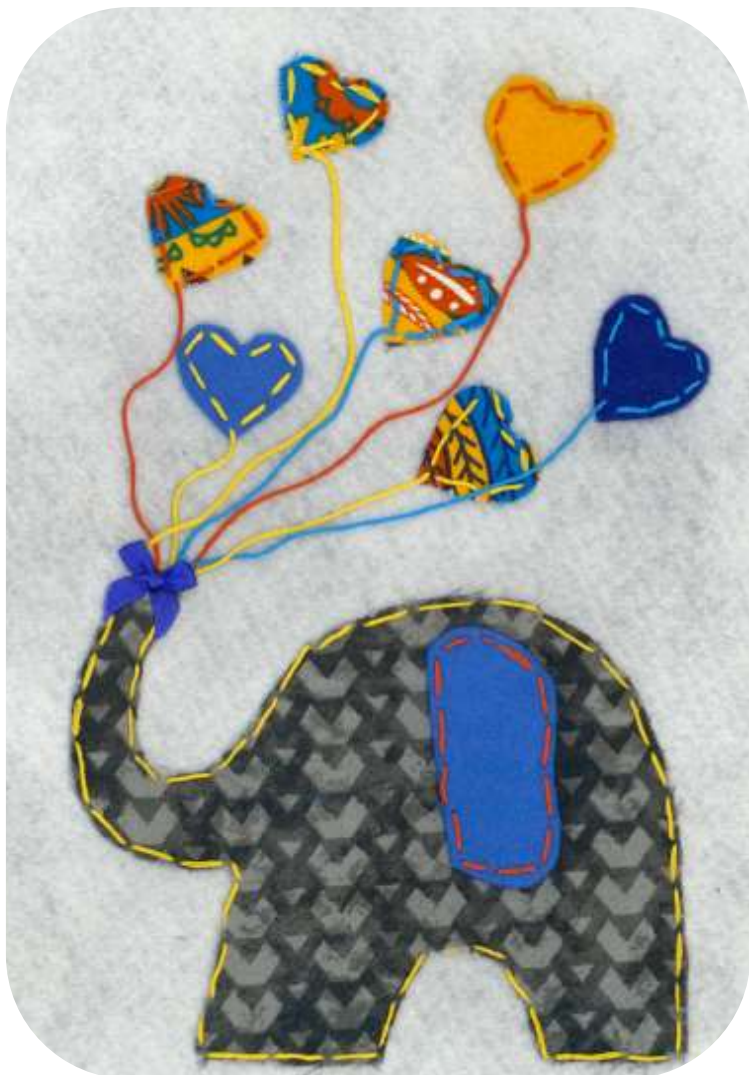
---



tion! The students became the citizen advocates. CA programs then started to spread throughout Australia. It was at this time that I was invited to speak about the program at a conference in Auckland New Zealand where I met my husband, Ray who was widowed with three children. We married in Melbourne in 1985 and then I went to live in New Zealand rather than disrupt the lives of the children further. When I arrived in **Auckland I enquired about university or teacher's college positions and the response would often be, "I think you should contact Ray Murray who works in that area at Auckland Teachers College". I hesitated to say that I had just married him!** Ray ran the Centre for Special Education. I eventually would join the staff there but initially started to work for IHC New Zealand (Inc) where I led a devolution project to bring people with intellectual disability out of two long-stay institutions. It was one of the first devolution projects in New Zealand. To get out to one of the hospitals as a team we travelled off the highway north of Auckland down a long road that the families we meet named as *the road to Calvary*. The wildflowers that grew on the side of the road did not soften the pain of separation aroused through visiting the institution regardless of all its turrets and gargoyles and manicured grounds. The picturesque entrance to the hospital shielded from

view the stark dormitories where their sons and daughters had lived out a lifetime. Across the two hospitals we brought out over 120 people to live in the community and this would be one of the most significant projects of my career. We became aware of lives that had been wasted, where many people had not **retained their teeth, didn't wear undergarments, for fear that they would be discarded into the toilet bowls damaging the plumbing system of the institution.** The degradation of the people was visible and still memorable. Seven years later, by which time I was working at Auckland College of Education I won a Health Research Council Grant to follow up on the lives of these people which showed increases in their quality of life. Some people speaking after years of silence and experiencing the delight of having both their own bedroom and their own clothes rather than selected by staff from the dormitory clothing pool.

Another area of satisfaction from that time at Auckland College of Education (ACE), was co-developing the first degree for New Zealand in Human Services. I then moved into a position of Dean of Postgraduate Studies and Research at ACE in preparation for the transfer of the Teachers College into the University of Auckland.





Second in from right after CDS receiving a National Disability Award for uni 2 beyond presented by Dylan Alcott. 2017.



Opening the CDS Festival of Inclusion held at University of Sydney in 2019



Patricia in top right hand corner with the CDS Inclusive Research Group at 2019 ASID Conference

In 2001 our first grandchild Evie was born in England with Rett Syndrome. To be closer to the family I looked for a position in Europe and was fortunate to win the Foundation Directorship of the National Institute for Intellectual Disability (NIID) at Trinity College Dublin, which enabled us to travel frequently across the English Channel to watch and support Evie grow and thrive. Trinity College was built in 1592 by Queen Elizabeth

1st and with its ancient architecture and customs was a magical place to be for five years. In setting up the Institute one of the major advances for people with intellectual disability came about by developing the first accredited qualification in a university across Europe for people with intellectual disability. Living in Europe also opened opportunities for winning EU research grants, with a major achievement being that of a Marie Curie Grant to explore inclusive research for and with people with intellectual disabilities and their family members. The legacy of this work can be seen in the inclusive research networks found across Ireland today.

I had about a year left on my Trinity contract and was preparing to go back to New Zealand, when I received a telephone call from Sydney University recruitment asking whether I would be interested in looking at the Directorship of the Centre for Disability Studies (CDS). I was sitting with the chairperson of the NIID Board at the time and asked the caller if they could phone back. The rest is history. Ray had never lived in Australia before but was happy to delay returning to New Zealand. We arrived in Sydney in blistering heat in December 2009. It was a great privilege to take over CDS from Professor Trevor Parmenter, leading to 11 years of guiding and sustaining the Centre in its mission of “Building Capacity for Change” until my retirement in September 2020.

#### *Which country have you enjoyed the most?*

Wherever I am I like the most at the time. New Zealand is a fantastic bi-cultural place to live, landscape is magnificent, people are warm, considerate and inventive. It is also a great place for recognition of the voice of women. I was there for 20 years where at one stage the prime minister, the governor general, the attorney general were all women.

For both Ray and I going to Ireland was getting in touch with our roots. **I didn't have any known relatives still living in Ireland, but Ray did in the North whose hospitality we benefitted from.** My relatives came from the South around Clare and Ennis. As a member of **the O'Brien clan, I could have stayed on in Ireland but I am glad that I have returned to Australia made home by the courage of my forebearers crossing “the seven seas”.** I didn't think Ray would want to move countries as I did to New Zealand, but he is happy here, two of the adult children live in England and one in New Zealand so we move between all three.

#### *What has influenced your work?*

I think theoretically, Wolf Wolfensberger and his theory of social role valorization (normalisation). Similarly, the work of Burton Blatt who worked with Wolfens-

**berger and coined the phrase: 'All people are valuable'**, which has become a mantra for me and Ray. I have had a long career and have lived through many stages and shades of theoretical development positioned to achieve better lives for people with disabilities. The seminal work of Michael Oliver and other social theorists continue to impact my thinking as does that of my **colleague and friend John O'Brien whose five accomplishments** set the scene for person centredness. In terms of other influences, my parents who spent their free time doing charity work, particularly for a palliative care hospice in Melbourne; the Brigidine nuns who were strong role models teaching and preparing us as young women to grow into our own independence; the commitment of my colleagues across several countries as well as the courage of many women and men that I have met who survived institutionalisation to lead valued lives.

### ***The History and Future of the Centre for Disability Studies (CDS)***

CDS started off in 1997 and has been running for over 23 years. Professor Emeritus Trevor Parmenter was the Foundation Director, followed by myself in 2009 and in 2020 I was pleased to hand over the Directorship to Associate Professor **Mary-Ann O'Donovan** coincidentally also from Trinity College Dublin.

The baton of promoting research, training and clinical services has been passed from one director to the next enabling the skilled and committed staff of CDS to support people with disabilities to vision and live the lives of their own self-determination.

### ***While you were in the leadership role at CDS what was its most important work?***

I could outline different projects, but I really think its most important work on my watch was around programs that impacted and positively influenced the way of being and life for people with disability, their supporters, carers, and professionals. There was a whole raft of flagship programs and innovations that looked to supporting people with intellectual disability to become more self-determining, such as inclusive research, the *uni to beyond* program where students with an intellectual disability are going to university, impacting both their confidence and self-esteem. When I first arrived, Ray and I had done a lot of work in Ireland on person centredness and so we continued that at CDS with colleagues such as Rachel Dickson and developed and delivered packages for NGOs across NSW that intensely trained staff, people with disabilities and management boards on what it meant to be person centred. Whether the programs were associated with research /training contracts on quality of



life, *Active Support* or the *I Can* support needs assessment tool, etc., it always came down to being guided by, how could we do it in a way that the findings and or training outcomes could be translated into meaningful and positive action for people with disability.

***How can post school educational settings provide opportunities for participation for people with intellectual and developmental disabilities?***

Such opportunities can come through co-design where people with intellectual disabilities join curriculum committees. This occurred for both the post school programs that I have been instrumental in setting up both at Trinity College Dublin and later at the University of Sydney. The two programs differed in that the one at Trinity enrolled the students into an accredited certificate where most modules although taught within the university setting were only delivered to people with intellectual disabilities. It was a hybrid model whereas by the time I arrived at Sydney my thinking had moved to the benefits of the students attending classes of interest with same aged peers as part of a fully inclusive model. Sydney university has welcomed students to sit in mainstream classes supported by peer mentors undertaking the same subject. Sydney University could not have been more welcoming of students with intellectual disabilities reflecting the leadership and positive attitudes by both its man-

---

**“So I think CDS is a meeting place where people can gain information through research...”**

---

agement and the student body. What would assist these types of programs to grow across universities would be that they are subsidized by government funding. NDIS packages can support the needs of students to attend but the co-ordination of such programs requires more accessible resourcing. In Alberta Canada, the government directly funds the co-ordination of such programs for students with intellectual disabilities who do not usually have the entry level qualifications that can bring resource subsidies.

***What are the most significant advances in opportunity for people with ID that you have seen in your career?***

In looking back over my career, the major changes include the closure of long stay institutions, which initially led to the development of group homes. Over the decades these have now been recognised as a potential form of institutionalisation, so more recently through the adoption of person centred thinking the concept of individualised supported living is growing in



*Patricia in middle preparing to go onto ABC Radio program with two uni 2 beyond students*

acceptance. When I started my career *education for all* was not part of the landscape so the right to education for all students regardless of their level of disability has been most significant. Similarly, the recognition of people with disability being self-determining in directing the quality of their own lives has gained acceptance as illustrated in the UN Convention of the Rights of Persons with Disabilities that Australia has ratified. The role of people with intellectual disabilities **as no longer “being the researched” but “doing the research” has also been recognised.** An area that continues however to be a concern is that of social isolation and lack of community participation. Being present in the community does not necessarily mean being accepted for who you are. The NDIA has started to make a difference here with people being able to be funded for choice of activities. Ongoing advocacy will be needed however to keep the funding and attitudinal flame burning.

### ***Favourite app***

WhatsApp is playing a huge role in our COVID lives. Having the family in 3 different countries, we are using WhatsApp to communicate frequently. We are getting a lot of pleasure from picking up regular group messages.

### ***Favourite book***

Brideshead Revisited (The Sacred and Profane Memories of Captain Charles Ryder) by Evelyn Waugh. There was also a television series and a movie. Evelyn Waugh was an English journalist and wrote a lot in and around the Second World War. This book is about an aristocratic family that live in the UK. They invite into their family a student from Oxford named Charles Ryder and he falls in love with the older daughter. I really like the grandeur, set around the towers of Oxford but intertwined with the issue being faced by the major protagonists that the Catholic Church did not condone divorce which also reflects the pain of the era I grew up in. Other books I enjoy are those of the Bloomsbury set, people like Virginia Woolf. Travelling to and from England regularly to see our family we would often stay in Bloomsbury and walk the squares familiar to those authors.

### ***What do you always take on holidays?***

Too many clothes! We were once on a train going into Paris from Charles de Gaulle airport and a woman helped us struggle into the carriage with our luggage. **She asked “Are you moving countries!! Or at the Cologne railway station where a friend came to pick us up and was stopped by a passer-by who asked if he could take a photo of us as with our two trollies of luggage as he was doing an assignment of people and luggage! Our excuse is that we are always loaded with gifts for family when we travel to England in particular!!**



Screen Shot 2019 Graduation Ceremony , University of Sydney

### ***Finally, will you be keeping your interest in the welfare of people with ID active in retirement?***

Retirement will give me chance to give back through Board work, writing and continuing to support others to research in the area of disability studies that has given me so much across my career.

### ***Further reading***

O'Brien, P., Bonati, M. (2019). From Institutionalisation to Inclusion. In Patricia O'Brien, Michelle L. Bonati, Friederike Gadow, Roger Slee (Eds.), *People with Intellectual Disability Experiencing University Life: Theoretical Underpinnings, Evidence and Lived Experience*, (pp. 3-19). Leiden: Koninklijke Brill NV

O'Brien, P. (2020). "No researching about us without us as decision makers." Commentary on "Are individuals with intellectual and developmental disabilities included in research? A review of the literature" (Jones, Ben-David, & Hole, 2020). *Research and Practice in Intellectual and Developmental Disabilities*, 7(2), 120-125

Visit <https://www.sydney.edu.au/medicine-health/about/our-people/academic-staff/patricia-obrien.html> for further research articles



# The Medicine Cabinet: Storage of Medication at home and school

*Judy Longworth*

*Clinical Pharmacist*

*Department of Psychological Medicine*

*The Children's Hospital at Westmead*

When we take our medications that have been dispensed by the community or hospital pharmacy do we realise that there are specific storage requirements with each medication?

We know that all medication should be stored in such a way as it is out of the reach of children. This can mean using a locked cupboard or storage box but where should that be stored? All medications undergo strict testing so that an expiry date can be applied to the medication but this expiry date is dependent on how the medication is stored. All medications should be stored in a child proof container 1.5m above the floor. For further guidelines <https://www1.health.gov.au/internet/publications/publishing.nsf/Content/nmp-guide-medmgt-jul06-contents~nmp-guide-medmgt-jul06-guidepr8>

The expiry date of the active and non-active ingredients within a medication can be altered with a change in the storage conditions. This will then affect the efficacy and effectiveness of the active ingredient. For example we know until recently the Pfizer/BioNTech vaccine for COVID-19 (COMIRNATY™) had different storage conditions of the multiuse vials. The storage of the COMIRNATY™ is for 6 months at -60- -90° C (deep freeze temperature) but then when thawed it can be stored at 2-8° C (normal refrigeration temperature) for 1 month from the original 5 days but once reconstituted has to be used within 6 hours from reconstituting. This change is envisaging more flexible distribution and thus rollout of the vaccine. So to ensure there is adequate supplies of vaccine these requirements are necessary and monitored.

Most oral medications can be stored at room temperature but this means below 25° C and those that need refrigeration it is stored between 2-8° C. Antibiotic mixtures prior to reconstitution can be stored at room temperature and an expiry date – the one printed on the manufacturer's label. But once made up, ie with sterile water added, then it is stored at 2-8° C in the normal household refrigerator, this will also affect the

expiry date which is then changed when the mixture is made up and each different antibiotic mixture has a different expiry date. The expiry date should be noted on the dispensing label and monitored as it can expire prior to the mixture being consumed. As these mixtures do not contain preservatives, the mixture should be discarded at the expiry date. So when storing medications within the home, the best place to store is in a cool dry place not in the kitchen except for refrigerated items or bathroom. If the refrigerator is accessible by children then any medications should be stored in such a way as to make sure the children cannot inadvertently take a dose or more.

Expiry dates on medication are determined by the temperature in which the medication is stored and as well as the physical nature of the medication's active ingredient. Most medication needs to be stored in cool (under 25 C) and dry conditions to ensure that the dosage form ie the tablets are not absorbing moisture to as the render the active ingredient less efficacious and ineffective. Medications are given an expiry date which is the point in time when a pharmaceutical product is no longer acceptable under the specifications for potency and stability. Further information is available <https://www.nps.org.au/australian-prescriber/articles/expiry-dates>

Within hospitals there are rules about storage of medications and where they can be stored as well as temperature monitoring. Some medications require additional storage requirements in hospital due to the nature of the active ingredient such as psychostimulants - methylphenidate and dexamfetamine, which need to be stored in a locked safe bolted to the floor and a register kept of each dose and who it has been given to. This is because psychostimulants are controlled substances such that the prescribing is controlled and only certain doctors can prescribe and supply to certain patients which can be audited at any time. Even the loss of a psychostimulant prescription which are usually kept by the original dispensing pharmacy is signifi-

---

# “All medications undergo strict testing so that an expiry date can be applied to the medication...”

---

cant and can lead to a lot of investigation including the Ministry of Health.

Just taking or giving to a child the medication that is prescribed for the individual is a significant concern. Sometimes people think the medication prescribed for one might be helpful to another but without the right medical oversight, problems can happen. So making sure the correct medication is given to the correct patient is an important part of the pharmacist's duty when dispensing medication. This also is important within a hospital where usually 2 people may be needed to give a particular dose of medication. One to get the medication and calculate the dose and another person to verify that the right medication has been obtained and the calculation for the dose is correct and then given to the patient making sure the correct medication is being given to the right patient. A recent press release from the TGA reports on the taking of **pet's medication by humans** <https://www.tga.gov.au/blogs/tga-topics/dangers-taking-your-pets-medication>

All liquid medications should be administered using oral syringes. A 5ml dose might be a standard teaspoon in Australia but each teaspoon in cutlery set does not have to be the standard 5ml. Using oral syringes ensures that the correct amount of medication is given. Shaking a suspension prior to administration is also important as suspensions can settle over time and thus just taking the top portion of the suspension will have less active ingredient than the bottom portion. This can then lead to over or under dosing. Check the ancillary labels put onto the dispensed liquids by the dispensing pharmacist to ensure that the liquids are correctly administered.

Sometimes medications are dissolved in water and a portion or aliquot of the final solution is taken to give a dose. This depends on the solubility of the active ingredient as well as the volume of water it is dissolved in. Each community pharmacy has access to a book 'Don't Rush to Crush' which will give information about

the solubility of medication and approximate time it takes to dissolve or disperse and also about the suitability to administer via various feeding tubes.

What happens in schools and long day care? In NSW schools there are some requirements outlined by the Department of Education. <https://education.nsw.gov.au/student-wellbeing/health-and-physical-care/health-care-procedures/administering-medication> whereby the prescriber of the medications should notify the school about the medication and need to administer the medication during school hours. Also the medication should also be accompanied with any consumables needed to administer the medication such as oral syringes for measuring the volume of a liquid preparation to be given. When not being supervised by an education staff member who has done the required training, a child or adolescent who can safely administer their own medication is encouraged to do so. Parents/carers are also required to fill out the appropriate forms for administration of medication whilst at school.



When schools are administering multiple medications to multiple different children there should be a storage system to ensure the right person gets the right dose at the right time. This could be achieved using different storage aids for different children and these clearly marked to avoid any confusion about whose medication it is or what the contents are.

So the 5 rights of medication administration are;

Right Patient.

Right Drug.

Right Dose.

Right Time.

Right Route.

So we all need to ensure that these happen and the medication being administered is safe and efficacious.

So when travelling for example on holiday or overseas, these principles also apply and further information can

be found [https://www.medicinesforchildren.org.uk/sites/default/files/files/Travelling%20with%20medicines%2030\\_11\\_17.pdf](https://www.medicinesforchildren.org.uk/sites/default/files/files/Travelling%20with%20medicines%2030_11_17.pdf)





# Reading List

Bailey, Tom, Totsika, Vasiliki, Hastings, Richard P, Hatton, Chris & Emerson, Eric. (2019). Developmental trajectories of behaviour problems and prosocial behaviours of children with intellectual disabilities in a population-based cohort. *Journal of Child Psychology and Psychiatry*, 60, 1210-1218. <https://doi.org/10.1111/jcpp.13080>

Baker, Kate, Devine, Rory T, Ng-Cordell, Elise, Raymond, F. Lucy, Hughes, Claire & IMAGINE-ID consortium. (2021). Childhood intellectual disability and parents' mental health: Integrating social, psychological and genetic influences. *The British Journal of Psychiatry*, 218, 315-322. <https://doi.org/10.1192/bjp.2020.38>

Guller, Baris, Yaylaci, Ferhat & Eyuboglu, Damla. (2021). Those in the shadow of the pandemic: Impacts of the covid-19 outbreak on the mental health of children with neurodevelopmental disorders and their parents. *International Journal of Developmental Disabilities*, No Pagination Specified. <https://doi.org/10.1080/20473869.2021.1930827>

Javaheri, Khodadad R & McLennan, John D. (2019). Adherence to antipsychotic adverse effect monitoring among a referred sample of children with intellectual disabilities. *Journal of Child and Adolescent Psychopharmacology*, 29, 235-240. <https://doi.org/10.1089/cap.2018.0167>

Kaushal, Pamela, Hewitt, Olivia, Rafi, Amina, Piratla, Manjula, Maddock, Sarah Rowena, Moye, Barbara, et al. (2020). Training and service provision for people with intellectual disability and mental illness: The views of psychiatrists. *International Journal of Developmental Disabilities*, 66, 67-74. <https://doi.org/10.1080/20473869.2018.1484014>

Rawlings, Gregg Harry, Gaskell, Christopher, Rolling, Keeley & Beail, Nigel. (2021). Exploring how to deliver videoconference-mediated psychological therapy to adults with an intellectual disability during the coronavirus pandemic. *Advances in Mental Health and Intellectual Disabilities*, 15, 20-32. <https://doi.org/10.1108/AMHID-06-2020-0014>

Whitehead, R, Hopkins, L, Hughes, E, Kehoe, M & Pedwell, G. (2021). "Everyone on the same team, all working together": Implementing a co-ordinated multi-disciplinary approach to supporting young people with co-occurring intellectual disability and mental health issues. *Journal of Mental Health Research in Intellectual Disabilities*, 14, 1-22. <https://doi.org/10.1080/19315864.2020.1864689>

Weise, Janelle, Mohan, Adith, Walsh, Jessica & Trollor, Julian N. (2021). Salutary lessons from the delivery of mental health services to people with intellectual disability - a historical perspective from intellectual disability mental health experts in New South Wales, Australia. *Journal of Mental Health Research in Intellectual Disabilities*, 14, 70-88. <https://doi.org/10.1080/19315864.2020.1856243>

Srasuebkul, P., Cvejic, R., Heintze, T., Reppermund, S., Trollor, J. (2021). Public mental health service use by people with intellectual disability in NSW and its costs. *The Medical Journal of Australia*. 1-7. <https://doi.org/10.5694/mja2.51166>

## Websites

<https://www.healthed.com.au/podcasts/womens-and-childrens-health-update-sleep-disturbance-in-autism/>

# The role of attachment in autism – a case study on attachment and its impact on behaviour

Dr. Linda Tran, Child Psychiatrist with an interest in neurodevelopmental psychiatry. The Children’s Hospital at Westmead

## 1. Case overview

Parents are often far more distressed when their child is first diagnosed with autism than the child. This **cannot be explained by the child’s inability to understand** the consequences of such a disorder alone because most parents hearing this diagnosis for the first time have the same struggle. There seems to be another deeper nagging fear that can add to the parental distress: **“Was it my fault?” Because if it is, then “I need to fix it!”** This unfounded guilt can become a constant torment for these parents in addition to their higher stress levels. They can become so preoccupied with **fixing their child that ultimately the child’s emotional needs fall by the wayside.** For these dedicated, loving but guilt-ridden parents sometimes their distress needs to be addressed first before they can become helpful for their child.

The following case study illustrates how reducing the parent’s distress helped the child with autism. Using

the Circle of Security (COS) parenting program **increased the carer’s reflective capacity.** This approach increased her confidence in parenting and strengthened attachment, the relationship between a child and their caregivers. Ultimately, it brought back the joy in **their relationship and led to a reduction in the child’s self-harm behaviour.**

The case (names and some demographics are changed for confidentiality reasons)

Charlie is an 8-year-old boy who lives with his parents Adam, Eve and his 11-year-old sister Bea. He attends a specialised school for children with developmental disorder in year 3. Charlie has been diagnosed with autism Level 3, mild to moderate intellectual disability, severe attention deficit hyperactivity disorder (ADHD), general anxiety disorder, obsessive compulsive disorder and Tourette syndrome. His developmental age was that of a toddler.



The neurology team referred him for a 1-year history of self-harm characterised by head-banging. This was precipitated after he had a paediatric autoimmune neuropsychiatric syndrome (PANS) which was treated with intravenous immune globulin and steroids but his behaviour persisted. A multitude of behavioral, pharmacological and experimental interventions had **limited impact on his head banging. His parents' main concerns** were that Charlie will acquire brain damage secondary to the head banging. Furthermore, he was irritable, had insomnia and behavioural outbursts characterised by unpredictable physical aggression to his family. He was climbing and jumping off heights which the parents experienced as provocative behaviour. They presented to the local emergency department **on a few occasions for Charlie's agitation, harm to self and others** and on one occasion he was admitted under neurology for his behavioural difficulties.

## 2. Background Information

Adam and Eve both have university degrees and are very dedicated parents. They have tried a range of behavioural interventions with limited or worsening **effects on Charlie's behaviour including Applied Behavioural Analysis (ABA) and Time out** as well as other strategies such as holding therapy, chill out room and compression clothing.

Charlie has trialled a range of medications including but not limited to antipsychotics such as Risperidone, Quetiapine and Olanzapine, antidepressants such as Fluoxetine, Fluvoxamine and Venlafaxine, mood stabilisers such as Carbamazepine, Valproate and Lamotrigine, anti-hypertensives/anxiolytic medications such as Clonidine and Propranolol as well as Ritalin. All medications caused some form of (side) effects ranging from mild such as sedation to severe such as **Steven's Johnson syndrome. Medications needed to be reduced or ceased.** Eve also found that the medications did not address his head banging and frequently asked for trials of new medication or would change the dose herself, at times ceasing all medications. She also enquired about alternative treatments including but not limited to L-Theanine and currently cannabidiol oil.

**Charlie's behaviour caused significant distress within the family system** accompanied by feelings of helplessness, depression and grief. Eve had suffered from postnatal depression and felt to have limited support from her husband and own mother when she is feeling down. She was recently re-commenced on an SSRI (selective serotonin re-uptake inhibitor, antidepressant). Adam coped with anger directed at Charlie or **withdrawing and Bea tried to help out with Charlie's care** whilst minimising her own needs.

---

“This unfounded guilt can become a constant torment for these parents...”

---



## 3. Professionals involved

Charlie has a local paediatrician who prescribed most medications apart from neuroleptics. He also underwent CYP 450 enzyme testing which revealed a VAMP2 mutation. VAMP2 is believed to play a role in neurotransmitter release and mutations can manifest as neurodevelopmental disorder. However, it was unclear how much this contributed to the effects experienced on the diverse medications.

The neurology team remained involved by facilitating a **brief admission for Charlie's behavioural problems.** They referred him to Child and Adolescent Psychiatry, neurodevelopmental team. During that admission it became evident that carer support needed to be increased to counter carer fatigue.

Eve tended to call one of the neurodevelopmental **team's psychologists on a weekly basis to report on her issues with Charlie.** The team explained that medications alone was unlikely to change his behaviour. Psychoeducation was provided about the current available treatments for autism but there was no cure. Emotional co-regulation is important and in children with autism this means to structure their feelings. Other approaches such as family therapy, dyadic therapy

such as “watch, wait and wonder” as well as behavioural management programmes such as “Stepping Stones Triple P” were recommended but it seemed that it was difficult for the family to put them into practice. Practical solutions included the use of protective gear.

#### 4. My perspective

The crux of the matter was that Eve was on a quest to cure her son’s autism whilst the neurodevelopmental team aimed to provide ‘a good enough’ quality of life. These divergent expectations nearly inevitably lead to mutual disappointment and re-enforced an ambivalent cooperation. Eve probably felt that no professional has helped her son enough. So she was hesitant to implement and found it difficult to trust the treating team enough to follow through with professional recommendations and instructions. It can be speculated that **changing medication doses without doctor’s approval was the only control Eve had over Charlie’s behaviour and health.** It can also be hypothesised that any of **Charlie’s behaviours is under scrutiny by both parents** because he did not meet their expectations and his negative emotions and behaviours were particularly distressing for Eve. This negative attention and the lack of boundaries may perpetuate some of his behaviours. Although so far the main attention was focused on Charlie, his behaviour seemed to worsen. Changing perspectives, caring for the carer, can lead to change and an attachment based intervention could be helpful not only for Charlie but also for Eve.

#### 5. Intervention

Known first line treatments were exhausted. At times there was only partial implementation of those recommendations. Despite her ambivalence, Eve was able to accept that the neurodevelopmental disorder team would not recommend any medication changes whilst Charlie was on a cannabidiol trial. We recommended an attachment based therapy, Circle of Security (COS), as this has not been tried before and the author is a trained facilitator. Attachment is the relationship between a child and the caregiver, an instinct to seek **care from a specific person who can ensure one’s safety.** This care seeking behaviour can also be seen

amongst adults e.g. when Eve contacts her family or the therapist for support.

COS is not a treatment but a parent reflection model with eight chapters which are delivered in weekly sessions each lasting 90 minutes in a group model. It is recommended for children aged 4 months to 6 years old and uses graphic representations to focus on the **child’s needs. In short, the carer is the “secure base” from which the child leaves and also the “safe haven” to which the child returns.** Hence, the child moves in a **circle. When the child feels ok, it is on the “top circle”** meaning it leaves the carer to explore the environment. Whilst exploring, the child still needs the carer to watch, help, delight and enjoy with him/her. When the **child feels not ok, it is on the “bottom circle” and comes back to the carer needing the carer to protect, comfort, delight in them as well as organise the child’s feelings.** The carer is guided by principles to be always bigger, stronger, wiser and kind (BWSK) and follow the **child’s needs but to take charge when necessary. The carer also learns about his/her “state of mind” with the metaphor of the “shark music”, a carer’s background fear that may be triggered by a child’s behavior.** In this case, COS was provided via tele-health during the Covid-19 pandemic and as individual sessions with Eve to allow discussion of suspected underlying **grief about Charlie’s autism diagnosis, reduce risk of feeling guilty about other parent’s “better” relationship with their children, meeting Eve’s preference and improve engagement with the team.**

COS was provided over 4 months. Initially Eve missed 2 appointments and sought reassurance for medication doses she had changed. Clear boundaries were established between the role as a COS facilitator and the treating psychiatrist prescribing medication. During the first few sessions Eve also appeared distracted by attending to chores during the session. However, with increasing number of sessions Eve became increasingly engaged and she was very reflective and thoughtful throughout. Her regular phone calls to the **neurodevelopmental team’s psychologist eventually ceased and this was maintained even one year after COS had started.**

Eve felt that **Charlie’s high demands have reduced her time spent with Bea which led to feelings of guilt for Bea and resentment to Charlie.** This was further perpetuated by **Charlie’s physical aggression which frightened Eve.** In those moments she was not the BSWK carer but often became **“mean” towards Charlie** which then caused more feelings of guilt. She felt unable to provide safety for him and the family.

---

“an instinct to seek care from a specific person who can ensure one’s safety...”

---



Eve noticed the different parenting approaches to her children. With Bea, Eve wished for Bea coming to seek her proximity (bottom circle) but instead Bea was often on the top circle. With Charlie it was the opposite. Eve wished he would explore independently but instead he was often on the bottom circle. This insight already helped her to remain calmer in difficult situations and set boundaries whilst being mindful not to become mean. **Eve also identified that she struggled “being with” Charlie’s emotion of anger. This was a parenting style she had inherited from her own experience of being parented.** Eve was also able to re-interpret his **“provocative behaviours” of head-banging as Charlie’s attempt to initiate moments of her being with him and enjoy with him e.g. the joy he feels when he climbs the balustrade.** With this understanding she actually put a **mattress below the balustrade, much to her husband’s dismay as it may “invite” Charlie to jump, in case he fell off which has not happened so far.** She experienced Charlie’s protective gear, a helmet, as a **“game changer” as she was not anxious to take charge anymore.** Eve was more confident to set limits and if that led to Charlie being frustrated, she let him headbang

with the helmet on. However, this was hardly necessary because telling Charlie that she will put on the helmet for him was often sufficient to stop him from head-banging. She also made an effort to spend time with him when he was ok e.g. when he was watching TV. This was further re-enforced with Charlie becoming **more verbal e.g. saying “Mummy, kiss”.** **Eve also caught her “shark music” playing when Charlie had Tics** because she then anticipated aggression to himself and her. In those moments it was hard for her to take charge as she did not want to be mean but she tried to remain BWSK which increased her confidence when she was able to manage difficult situations with Charlie. Eve was eager to repair her relationship with Charlie and the mutually positive experiences improved their relationship significantly.

**Eve’s calmness, firmness, reflectiveness and increased understanding of Charlie’s needs seem to be significant contributors to his overall improved behaviour.** As a result, her perception of and attitude to Charlie changed. She is more able to tolerate his distressing behaviours and even finds practical solutions to make things as safe as possible for him.

At the end of the COS program, Charlie's improvement was noted by Adam, his paediatrician and was also reflected in his behaviour. His head-banging reduced in frequency and intensity to about 1-5x/day lasting up to 5 minutes without any injuries and can be triggered e.g. when he is anxious. His paediatrician could cease **Charlie's antidepressant whilst increasing his anxiolytic slightly.**

**One year after starting COS, Charlie's head banging** has reportedly been minimal. He remained mainly settled, even during neurological interviews, and Eve was reportedly doing well. He was also not on cannabidiol anymore. However, school did not allow Charlie to attend full days there due to anticipation of aggression to other children which has happened in the past. It is also likely related to change of teachers. His neurologist has started him on 4-Aminopyridine for his VAMP2 mutation to which he responded well so far.

## 6. Discussion

**Eve's goal was to eliminate autism and if required**

would sacrifice herself to achieve this. Hence, initially the neurodevelopmental team could not engage Eve because there was a lack of therapeutic agreement and any treatment approaches were doomed. Frustration grew on both sides which obfuscated the need to **address Eve's distress. Individual COS sessions provided a structure for Eve to ventilate her distress and frustration whilst allowing the team to examine her goals, hopes and barriers to treatment. COS was the framework into which basic psychotherapeutic approaches such as interpersonal or supportive therapy skills were built in on an as needed basis. It also allowed to tailor its use to the specific needs of the carer and the child, making it more practical. This approach improved understanding and engagement between Eve and the treating team. It also provided "informal" therapeutic support for the carer whilst focusing on the child. Supporting Eve in her parenting skills and reassuring her during setbacks increased her confidence to structure Charlie's feelings. Subsequently, this reduced the carer's distress and translated into a more positive and playful relationship between carer and child which improved the child's behaviour.**

COS aims to shift attachment style to a secure one. However, the practical main goal was improvement in **Charlie's behaviour so that his attachment style was not formally measured before and after COS intervention.**

There is limited research and understanding about attachment in children with autism. The majority of parents have the motivation and skills to form a secure

---

**“there is growing evidence that psychoeducational programs can benefit developmental delays including autism...”**

---

attachment. Yet, in neuro-atypical children these skills alone may not be enough because of the underlying challenges that arise from autism. Children with autism have an attachment that is characteristic of much younger children, so they show more intense attachment behaviours and selectiveness to their primary carers (1). However, their behaviour, immature for **their chronological age, is 'mismatched' to their often neuro-typical physical growth** which may be even a further barrier to meet their attachment needs.

Teague et al (2) found that it is more likely that children with autism form insecure attachment which may have some neurological basis. Nevertheless, secure attachment serves the same function as in neuro-typical children and is a protective factor for social and **cognitive development. A mother's increased insight into this and acceptance of an autism diagnosis is likely to increase secure attachment.** There is some emerging but mixed results on attachment based interventions (1). They also have not been listed in the NICE guidelines, yet. Furthermore, COS has been developed for neuro-typical children and not primarily for children with autism.

### Circle of Security for autism

In this case, Eve acted on a belief that autism is curable. Evidence-based practice indicates that autism is primarily a biological/genetic cause disorder for which there is no medically-based intervention (NICE, 2021) and a level of difference needs to be accepted. However there is growing evidence that psychoeducational programs can benefit developmental delays including Autism. Indeed, the recommended primary intervention for Autism is promoting emotional social skills (NICE, 2021). Many parents and clinicians also believe that the emotional and behavioural disturbance in autism is also caused by factors that are more biological than psychosocial. Our framework describes autism as a delay in the development of skills, and in particular emotional recognitions skills, inter-subjectivity skills, relationship problem solving skills and social skills (1, 3, 4).



The delays in these skills are also associated with a cognitive inflexibility which presents as stereotypic repetitiveness. There may also be additional delays in several other areas including intellect and communication. Historically significant harm was done by trying to treat autism with psychotherapy, as it was not effective. However young people with autism are children too, and although their challenges of adaptability often lead to an increased risk of emotional and behavioural disturbance, they may also become sensitive to emotional communication especially in the relationship with their primary attachment figure(s).

Albeit the development of their attachment may be delayed, they still need parents, not just to teach skills, but also reflect both behavioural skills and emotional skills through an awareness of intersubjectivity and co-regulation. COS provides a setting in which the nature of intersubjective connection and psychological awareness can be collaboratively examined in therapy. In this way COS and the examination of emotions and behaviour in the context of attachment can provide an alternative treatment when mainstream behaviour management and pharmacotherapy have failed. It may

need to be conducted by a clinician experienced with autism and its emotional and behavioural problems.

## 7. Practical Strategies

COS parenting program is rather experienced than explained. Professionals, parents or guardians can become COS facilitators by attending an approved course. However, for parents it may be more helpful to attend COS groups that are offered in various community settings. One needs to be aware that COS is usually provided as group sessions and it is not necessarily tailored for children with autism.

Carers should persistently aim to build a positive relationship with their children with autism although the varying degrees of impaired social reciprocity may negatively impact on a carer's confidence.

## 8. Follow-up learning

1. <https://www.circleofsecurityinternational.com>
2. <https://www.nice.org.uk/guidance/cg128>

## 9. Further Reading

1. Sigman M, Ungerer JA. Attachment behaviors in autistic children. *Journal of autism and developmental disorders*. 1984;14(3):231-44.
2. Teague SJ, Newman LK, Tonge BJ, Gray KM. Attachment and child behaviour and emotional problems in autism spectrum disorder with intellectual disability. *Journal of applied research in intellectual disabilities: JARID*. 2020;33(3):475-87.
3. Ratcliffe B, Wong M, Dossetor D, Hayes S. Teaching social-emotional skills to school-aged children with Autism Spectrum Disorder: A treatment versus control trial in 41 mainstream schools. *Research in Autism Spectrum Disorders*. 2014 8(12):1722-33.
4. Ratcliffe B, Wong M, Dossetor D, Hayes S. The Association Between Social Skills and Mental Health in School-Aged Children with Autism Spectrum Disorder, with and without Intellectual Disability. *Journal of autism and developmental disorders*. 2015;45(8).

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>

## contact us...

**The Children's Hospital at Westmead**  
School-Link Initiative  
Department of Psychological Medicine  
Cnr Hawkesbury Rd and Hainsworth St,  
Westmead NSW 2145  
[schoollink@chw.edu.au](mailto:schoollink@chw.edu.au)  
P: 9845 2005  
W: [www.schoollink.chw.edu.au](http://www.schoollink.chw.edu.au)

If you would like to contribute to our next edition, please contact;

**CHW School-Link journal**  
**MHCAIDD editor**  
Hebah Saleh  
[hebah.saleh@health.nsw.gov.au](mailto:hebah.saleh@health.nsw.gov.au)

