



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

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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 19th 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).

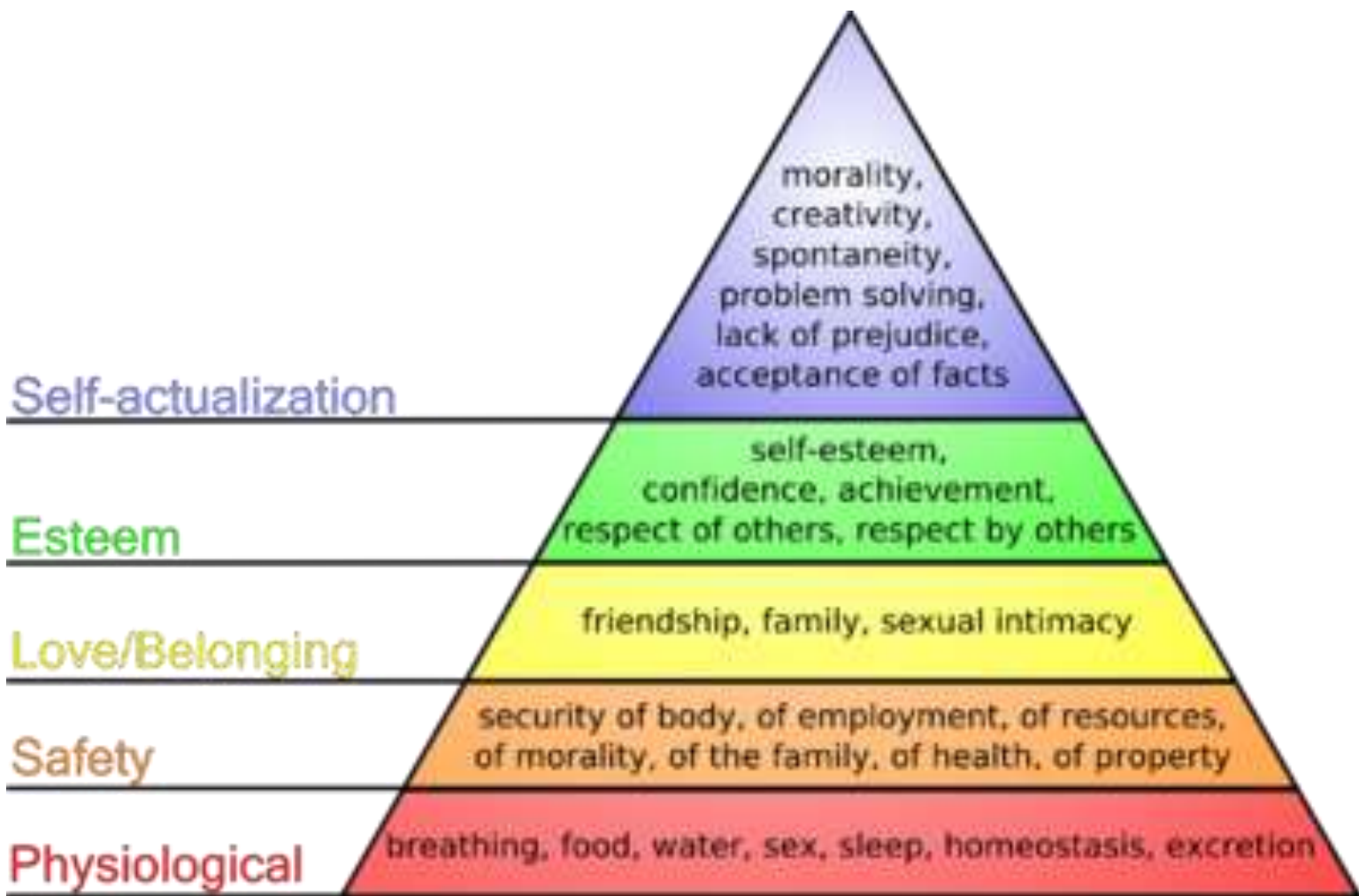
Arriving in Australia in 1991, with Ken Nunn our reforms in the department of Psychological Medicine at **the Children's Hospital included giving children with IDD the same equity of access and respect as any other child for assessment and treatment.** This equity of access to health services for people 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). 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.

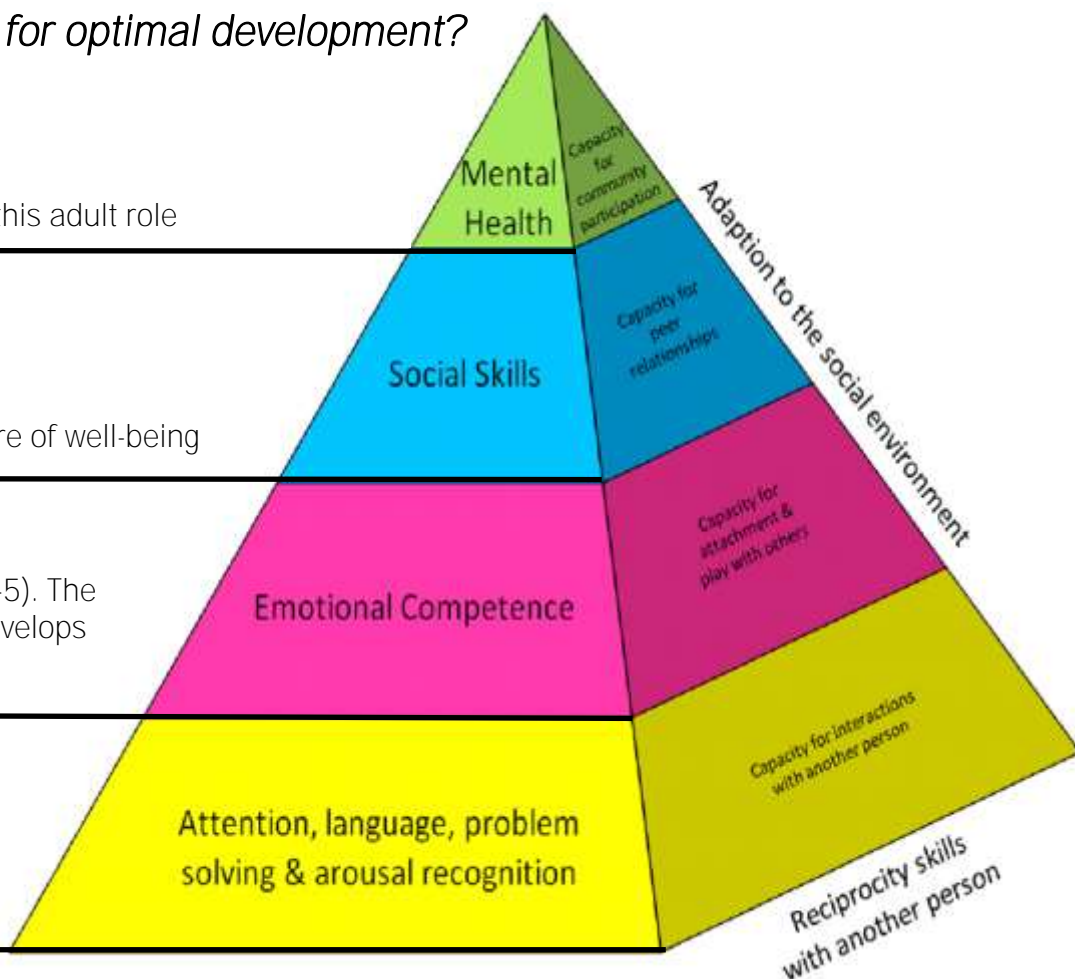
What is needed for optimal development?

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 SSTP 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
- environmental 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.

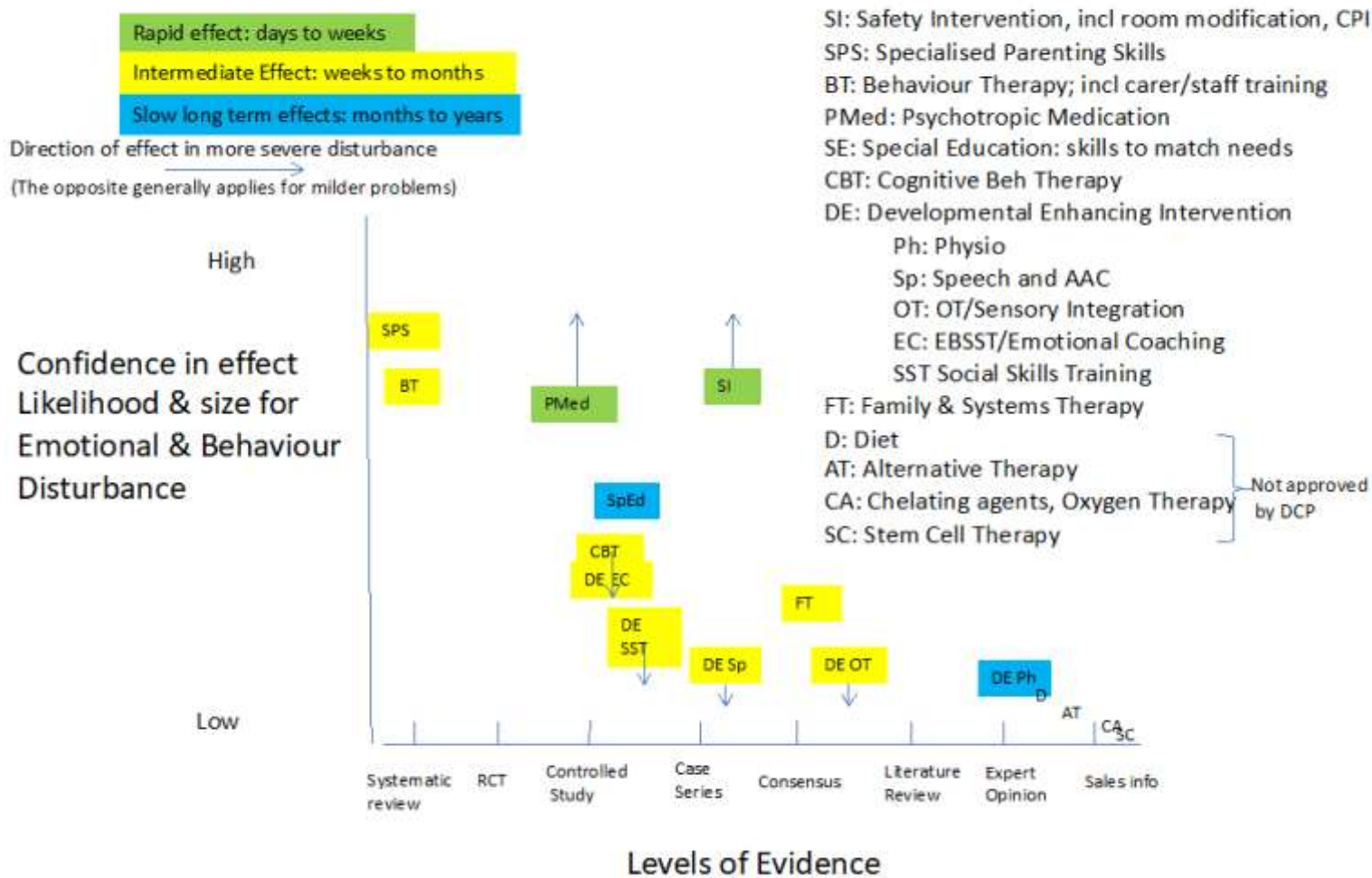
Interventions to promote mental health: key elements from curriculum and textbook.

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 rd NMH Plan) 3%	Diagnosable Illness from DSMV Priority for Mental Health Services	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 rd NMH Plan) 20-40%	Diagnosed from DSMV but seen as a developmental disorder Rx by Paediatrics & disability service, +/- specialist ID MH. (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 Needs high expertise MD subspecialty collaboration of disability & health	-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 Disability Services, 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 rd 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.

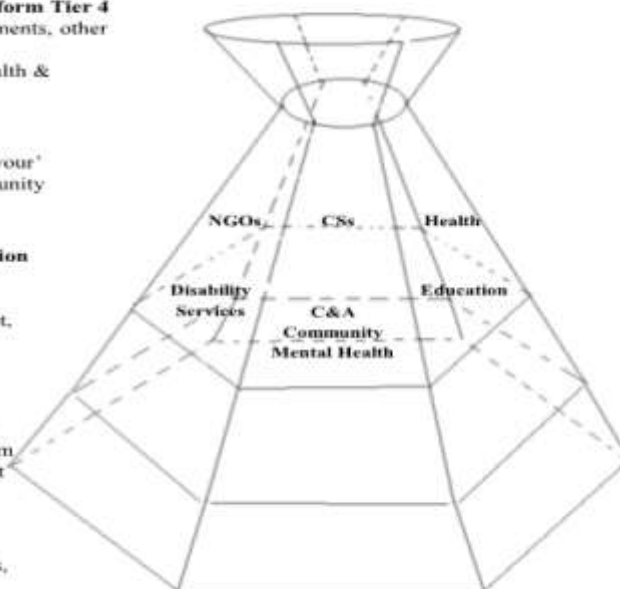
Tier 5: Acute short/medium term interventions that inform Tier 4
Includes: Emergency departments, MH in-patients assessments, other residential behaviour services; and **Specialist/Tertiary MH in ID clinicians** from mental health & disability services.

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.



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