



a note from David Dossetor...



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How much do we value families and what impact does this have on children with intellectual disability?

Part I

The complexity of families

Many years ago, during my training the eminent child psychiatrist Sir Professor Rutter taught that you can't tell a family by its external appearance. The qualities of parenting and of parent-child relationships are unpredicted by other measures such as parental income, or quality of housing or indeed family constellation. It certainly means you cannot judge a family by your prejudices. Indeed it is remarkable how children bring out the best in people. People make extraordinary sacrifices for the sake of their children, and are often open to modifying habitual behaviour if they come to appreciate its potentially harmful influence on their offspring. All parents want the best for their children.

The opposite is also to some extent true. Families are the source of the most intense relationships, not just for nurture but also for harm. For example, almost a quarter of all homicide are between spouses (Wallace, 1986). We have witnessed the measurable rise of child physical and sexual abuse with 1 in 10 children being notified as at risk in NSW, and the number of children in care going up by 60% 2002-8 to 16,000 (Wood,

2008). There are similar increases of domestic violence, and of parental and teenage depression and drug and alcohol misuse (Wilkinson & Pickett, 2009).

Parents influence children and children influence parents

Witnessing family relationships gives a richness of experience to child psychiatry, but over the course of early and middle childhood, family relationships have more impact than all other factors in how most children turn out (Barker, 2007). This is not as simple as it sounds because genetics and biological differences affect children and these manifest attributes in children bring out different attributes in parents (Reiss & Neiderhiser, 2000). Everyone knows how a disruptive child who externalises the explanation of their behaviour ('its not me', or 'you made me') is more difficult to like. Children who are sickly or anxious are more likely to elicit protective parenting behaviour, which for the period of stress is beneficial. Indeed it has been shown that parental behaviour is influenced by the genetic attributes of the child. What this also means is that where such "instinctive behaviour" in parents becomes entrenched it reinforces maladaptive behaviour. Conversely, the learning of empirical skills of optimising childhood development by parents is the best thing we can do for our children. There is widespread research that shows that improving parenting skills, rather than relying on parenting instincts, is the best intervention for the population in preventing maladaptive behaviour and psychiatric disorder in children (Guralnick, 2006, Ferguson, 2009). We also know more about how maladaptive childhood behaviour also has significant impact on the further development of the brain. It makes sense of why factors of childhood adjustment and resilience have a lifelong impact for example on adult mental health, especially when it goes wrong. This makes sense of another of Mike Rutter's dictums: poor peer relationships are the best measure of childhood adjustment and is the best predictor in childhood of mental health problems as an adult.

The paediatrician Donald Winnicott said there is no such thing as a perfect parent, and we should aspire to be "good enough parents" (Winnicott, 1965). Partly, he was describing that aspiring to being perfect as a parent, can take away the fun and flexibility needed for children. Life is com-

plex and stressful with recurrent adversities, but better functioning families are more likely to cope with and resolve problems (Dattilio & Epstein, 2003). The emotional capacities of these complex human units have greater survival capacities than individuals especially in supporting and enabling youngsters.

Relationships and mental health

There is considerable research available on how excessively emotional/depressive or critical/hostile relationships in your next of kin is harmful for any type of mental disorder (Hooley, 2007). Such emergency emotions in relationships are critical stressors particularly to those in close relationships. In fact, the quality of relationships in the context of a mental disorder has more effect than medical treatment. Although Schizophrenia is generally considered a genetic disorder, the genetic risk for this major mental illness is as strong as it is for Tuberculosis. That is to say, although Tuberculosis is caused by a different environmental factor, an infectious bacterium, the susceptibility to becoming infected is similarly significantly genetic. Thus all illnesses are a combination of genetic risk and environmental factors. The current focus of research on genetics is due to the new technology increasing our specificity of this component of knowledge. The lack of scientific progress on human relationships is due to their complexity.

Relationships are important for everybody. The NSW Commissioner for Children and Young People's survey found that even for those children who were homeless and rejected by their families, their family relationships were still the most important to them (NSW Commissioner for Children and Young People, 2002). Occasionally we witness how devastating the most severe forms of deprivation can actually cause intellectual disability, autism and failure of language development. One example was a child that was raised in a bamboo cage and given food on the end of a stick from the age of 2, as the villagers thought she had Rabies. At the age of 8 she was rescued by nuns but remediation had only a moderate effect (Bartlett & Limsila, 1992).

Changing family values

How much are family values critical to our national and cultural success? I suspect that most families ascribe a high importance to the influence of their values to their children's development, from the value they put on learning and education, to the value they put on altruism and caring for others. Conversely, one also hears about how politics can have a dramatic effect on family values. For example the

communist take over of East Germany or of China dramatically affected the way children were valued. Family loyalty and nurture declined and allegiance to the power of the state as the source of child-care and education. So how much are politics and economics altering family values in Australia?

We all talk about the changes in family values. But which changes are harmless or positive adaptations to modern lifestyle, and what changes really affect family culture and the way we bring up children? We measure national success by the rise in Gross National Product of the country, rather than measure the health, mental health and social failures arising from the rise in relative social inequity. Much of the rise in prosperity has been due to the rise in the number of families in which both parents work. Yet the corollary is that the amount of time parents spend with children has gone down dramatically in the last generation, approximately by 20 hours per week. It seems that parenting is considered of little or no cost or value. The notion of a two speed economy doesn't seem just relevant to commerce, but to education, health, the justice system and welfare. Maybe there are no votes in children, but successive governments have failed to incorporate an office of children, whereby the interests of children are considered centrally in every piece of legislation.

Similarly, some colleagues are concerned that the new *youth* mental health concept of services is providing services for teenagers and young adults but at the exclusion of their families. Certainly a lot of kids seem to grow up quickly, with an independence of thinking, and a greater electronic connectivity with other youth. It may be that families feel they have less influence over them. Neurobiology suggests they are still developing mentally and remain vulnerable till their early 20s. Has the value of caring for young people declined, so that kids are no longer brought up by a community, as a sense of community declines (Putnam, 2000)? The decline in community care contributes to the rising of childhood homelessness, whereby these days a refuge is the place of safety provided for a 12 year old by government care and protection agencies.

One of the problems is that economic figures are easily measurable. The rise of violence, delinquency, substance abuse and depression are also measurable. Even though the cost of Autism in UK has been measured at 27 billion pounds/year to the economy (Knapp et al, 2009). In Australia, Autism was considered too infrequent a problem to be measured in the last Na-

tional Mental Health and Well-being Survey (Sawyer et al, 2001).

The problem is that relationships are complex to measure scientifically. Firstly, although you can describe the behaviour e.g. violence or drunkenness, in a partner, you cannot reliably know what someone else is thinking and feeling, unless they are open and honest with you, and vice versa. Secondly, family relationships increase in number by a logarithmic scale, not a linear scale. The table below describes the number of relationships there are according to the number of members in a family there are (assuming each direction is a separate relationship):

<i>Number of relationships in a family depending on the number of family members (each direction is a different relationship).</i>	
Family members	Number of Relationships
1	0
2	2
3	6
4	12
5	20
6	30
7	42

This illustrates why families are extremely if not infinitely complex, especially when scientific research has really struggled with reliability and validity, or the reality and meaning, in even single relationships. Accordingly working with children and families is a humanist challenge. Although our concepts of families and relationships have grown, it is bolstered by smatterings of specific science to strengthen a practitioner's knowledge.

There certainly is epidemiological data providing associated risks. For example, the financially disadvantaged suffer from increased risk or rates of learning problems, emotional and behavioural problems, life events and live in less safe communities, with less access to services, and a poorer response to treatments (Emerson, 2009). However these are risk associations not established causal mechanisms. We also know that these problems can be faced by anyone. Families are also expensive, as only adults are allowed to work, which places families immediately at a greater risk of economic disadvantage.

So as our economy becomes more efficient and more competitive, so the availability of caring adults for children declines. Schools are also expected to perform better providing higher expectations on children and putting more pressure on growing up quickly. Some schools are remarkable in the achievements, resilience and quality of relationships they engender. However with this performance pressure, it doesn't surprise me that biological vulnerability in children is more evident for example with the rise in recognition of Autistic Spectrum Disorders and such children are more likely to develop emotional and behavioural disturbance. Against this tide of complex changes, an eminent paediatric colleague observed that "the future welfare of our children will be more important to the future of Australia than climate change". Yet the welfare of children is not a central part of politics. At a state level, all the main child orientated agencies work to different geographical areas, as if to make it intentionally difficult to work across government agencies. Over the last decade the Federal Government expenditure was focused to support a free market economy approach to health, and to act to limit the costs rather than strengthen the public health framework of the state health systems. Yet public health systems have provided the most cost effective health outcomes for the country.

This is a child psychiatrist's view of the background to understanding families with a child with intellectual disability. In NSW a start is being made to ensure that for the mental health of children and adolescents with intellectual disability that mental health, education and disability meet to discuss the problems of managing the mental health of the children and adolescents and consider evidence based approaches to improving the situation, one of these is the CHW School-Link, part of NSW School-link.

Part II Families with an intellectually disabled child

Working in this area of child psychiatry, has brought me in contact with a highly caring, committed, thoughtful, knowledgeable and determined group of parents. There are some particular differences about these children and families that distinguish them from "mainstream" families. They have special needs but the numbers of families with a child with severe (1%) intellectual disability has always made me feel this is a discrete population that a community should be able to optimally provide for. In NSW that would be approximately 80,000 of whom 25,000 are less than 20 years. Unless there is a



debate as to what should be done for and by these families, and what services we should be providing, then nothing will be done.

Early in my specialist training in 1987-9, I interviewed extensively an epidemiological sample of 92 families with a teenager with intellectual disability, in Leicestershire, UK (1990/91) (Dossetor, 1991). Leicester is a university town with a large health district, with slowly growing services for children with intellectual disability. Meeting a community sample, separate to those who presented to my mental health practice was an important learning experience. It also gave me first hand insight into what family life is like with a teenager with intellectual disability. It is interesting to see how much has changed with progress, albeit on this side of the planet. After all, NSW Government has given over \$2 billion over the 5 years to 2014/15 to improving services for people with an intellectual disability in Stronger Together 2, indicating political will, and there has been a definite growth of professionalism in the disability services.

In 1990 (Dossetor & Nicol) I reported that families wanted information about what services are available. Knowing what was available should they need it contributed to them coping with the present and being able to anticipate a feasible future. The second wish was to have a case manager to provide consistent support and to guide them through the challenges, enabling access to other more specialised services as needed. The families feared what the future held for their teenager with ID, and the lack of options should they be unable or unwilling to continue caring. This was illustrated by 7% saying they would rather kill their disabled teenager than allow them to go into an institution.

The recently released Ombudsman report on services for families with a child with disability (2011) also reported that avail-

ability of services had increased, but their survey of families still reported the lack of available information on what was available. Further, there is a recurrent challenge to obtain a case manager due to the strict adherence to protocols of eligibility criteria, and then to keep one for any length of time before the case file is closed again.

In my 1990 study these families were not distinguished by their family relationships or their social contacts, and in these terms they were basically 'normal families'. There were however a number of differences. First is the burden of care, estimated to be an average of 7 hours a day 7 days a week caring for the dependency needs of their young person with intellectual disability for as long as they live with the family. The second was the lack of practical assistance for that burden of care. Whether the family had a friend or relative who was available and able to care for their teenager with ID (even for a couple of hours a week) was highly predictive of the mental health of the primary carer, the quality of the relationship between the carer and the young person with ID, and their need for hostel based respite care (that being the only source of funded respite care). I felt that more family orientated sources of respite were needed.

The burden of care is still present with carers reporting 2-3 times greater financial burden of care for care, treatment and education and reduced income capacity, over half of carers (59%) experienced a decline in physical health and two-thirds felt that their mental and emotional health was affected with depression, anxiety or stress (Cummins et al 2007).

It impresses me that we now have "in-home" respite care widely available. However until recently it has not been possible to use friends or relatives to provide

funded respite. This is a major achievement of the recent pilot respite study run by Burnside (reference?) as it required legislative change and formal 'working with children' police checks etc. Unfortunately this project has been ceased as so few families now had friends or relatives to introduce to the project. Despite an active media recruitment process, few families came forward interested in becoming respite carers for young people with an intellectual disability.

Families often feel there is still completely inadequate support, and therefore make the mistake on depending only on themselves, and giving up on what community support may be available. I suspect that this contributes to understanding why approximately half of the parents I meet have significant burnout, anxiety or depression. The extent of the feeling disconnected from the wider community reaches alarming levels with the frequency with which I encounter parents with murder suicide ideation. I suspect this is a disconnect at multiple levels. I do not accept that although behaviour disturbance in intellectual disability is known to be widespread and persistent that nothing can be done about it. The longitudinal data is gloomy and suggests that despite some variation, and slight diminishment over time, that 20 years later disturbed behaviour is still the best predictor of disturbed behaviour. With our growing economy compelling both parents to work, there is major service threat: that for every 10% decline in informal care requires a 40% in formal care.

In my 1990 study 35% of a group that we sampled, mainly with teenagers with moderate/severe intellectual disability, still reported that life with their teenager with ID was "OK" or "enjoyable". This contrasted with cohorts studies of children with Downs Syndrome where this figure went up to 80%. It suggests to me that we need to tackle challenge of ID with its associated features with a program strategy.

Nankervis and colleagues (2011) identified through case file and stakeholder audit, the factors that led to families relinquishing care. These were divided into individual factors (high support needs, high medical needs, limited communication and young adult age), family factors (psychological distress, single parent family, parental expectations, marital breakdown), support factors (social isolation, desire to have 'normal' life, availability of respite care services, availability of appropriate informal supports, relinquishment being used as a strategy to gain out-of-home permanent accommodation) and service factors. Families had been stating for a considerable period of time to staff before relinquishment that they could no longer cope and that they would relinquish care. Offering respite was the main intervention used which was a band aid to a long term failure of policy and intervention service provision. Staff reflected on interventions that could enhance the carer's ability to cope: "value adding" interventions to decrease challenging behaviours and increase skills in daily living, parent training, linkage with informal supports.

The recent early cohort study of families with a child with borderline intelligence or intellectual disability (Emerson et al, 2011) suggests that even by 4/5 years of age, maternal stress and burnout is widespread and it is the combination of disruptive behaviour in the child with ID and maternal burnout and associated emotional hostility that leads to disruptive behaviour persisting.

Components to a family orientated comprehensive universal approach to mental health and intellectual disability

This situation is asking for an early intervention program to be implemented. First active case management/ mentoring are needed, to support the mother/parents and to provide support and advice over time. Such a process of engendering hope needs to lead onto building skills to optimally manage the burnout and behaviour disturbance. Stepping Stones, the level four version of Triple P is specifically developed for children with intellectual disability and or autism. It introduces parents to special behavioural skills for reducing difficult and promoting prosocial behaviour and communication. It also focuses on looking after the parent and promoting community integration. This specialist intervention introduces state of the art behaviour management skills but is family orientated and normalising for the behaviour of the child with ID and the wellbeing of the family. Such parent skill promotion programs need to be made

universally available in the preschool years. One of the remarkable developments of the last 20 years is how frequently I come across incredibly skilled parents, who know more about minimising the behaviour and building the skills in their child than most professionals (Carroll et al, 2011). Making knowledge and skills available is the most cost effective way on making a difference to even the most complex and extreme behaviour problems.

Muir (2006) identified the complexity of the resilience processes for a family with an intellectual disabled young child. First the family experiences a traumatic event or stressful situation that can place a family at risk, second the family has protective factors, to help them adjust to the event, and third the family recovers by adapting their functioning (even though there is a chance that the family does not adapt). The most important protective factors are: family problem solving and balanced relationships; family hardiness; social support; family time and routines; hope; flexibility; financial management; truthfulness and transparency of information; equality and empowerment; finding meaning; good health and practical family support in medical care. UK evidence suggests that service provision can be most effective when coordinated by a 'key worker', followed up by a prevention and intervention framework. These key workers, who inform, link, co-ordinate, follow-up and refer families, have been found to decrease stress and protect families. Thus a key worker service model should be followed by supporting parenting skills. This could also be part of the introduction to early intervention programs such as those for promoting independence and communication skills. This in turn should also naturally transit to specialist education that promotes emotional literacy and social skills in the education environment (Dix et al, 2010). However it is arguable that skill promotion is only a means to an end of developing awareness of others and building the connections of social relationships. Equally important is understanding and helping with maladaptive behaviour.

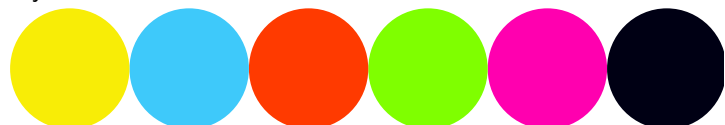
In addition a child with ID may have additional disadvantages of health problems which may be associated with chronic pain, recurrent hospitalisations, abnormal neural systems eg with epilepsy or behaviour due to specific biological drivers such as found in behavioural phenotypes. In the 1990 cohort study where 50% had significant emotional behavioural problems 22% had seen a psy-

chiatrist. In the Australian longitudinal cohort study of the 40% of the cohort had significant psychiatric disorder, yet only 10% of them, ie 4% had seen specialist mental health services. Services have further improved in Leicester.

In NSW, Disability Services have provided a start up of 5 years of funding for a chair in the psychiatry of intellectual disability and funded 9 one-year mental health fellowships to psychiatrists to develop a special interest in intellectual disability. It evidently is a concern of disability services who talk of it being a priority for their clients. Equity of access to mental health services mainly means they can be seen in the emergency mental health services, but mental health has not recognised their priority of need or recognised the need to fund specialist mental health services. The recent publication of Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities (Dossetor et al, 2011) is designed to enable a multi-disciplinary, multi-agency evidence based, family orientated holistic framework for the mental health needs of these children.

Human nature has a habit of providing surprises. Just when you think no one cares about you and your problem, it is remarkable how often a caring figure materialises from your neighbourhood. Building respite resources, particularly from friends or relatives or other member of the community can be done, despite the growing tide of economic rationalism and selfishness. That children need care remains true and with resolve, it remains possible to influence community attitudes. Not only can we help people believe that they contribute to the wellbeing of children with intellectual disability and their families, but we need to be more skilled at enabling them with special skills and supporting them with attractive means of engagement and funding.

The "Listen to us: Supporting Families with Children with Disabilities: Identifying Service Responses that Impact on the Risk of Family Breakdown" (2002) report on behalf of the National Disability Administrators reiterates the above messages: "in the context of the UN Rights of the disabled child, there is a need for a range of quality services for families with children with disabilities, and for more consistent policy goals (both across services and across early childhood and school age periods), that address both child and family outcomes. The value of early intervention services is highlighted, along with the possible need for broadening of early intervention models and practices,





to include stronger focus on parent-child relationships, social competence in children and prevention of challenging behaviours.” The review stresses “the importance of both change-oriented/interventive and supportive/facilitative strategies being available at primary, secondary and tertiary levels of intervention”. The report further highlights the importance of “informal support systems for families and the impact that community attitudes to disability have on the adaptation and capacity to support within the extended family and friendship networks. It is acknowledged that Australian service systems have not yet explored the capacity and limits of informal support... To create informed and inclusive communities, education in disability awareness should be undertaken for the following groups: the general community; family members and friends with potential to participate in support; the disability services workforce, and health, education and wel-

fare professionals; and support be given to community building and community development initiatives designed to enhance support to families and their community membership.” Such a government sponsored report comprehensively and concisely summarises what is needed for children with an intellectual disability.

The recently proposed National Disability Insurance Scheme (NDIS) is clearly a much more ambitious proposal for all forms of severe and profound disability with age at onset up to age 65, but presents a chance to correct the failing of our community to recognise the needs of those with “severe or profound core activity limitation”. People with a profound or severe disability are those who always or sometimes need help with a core activity or task. They would be eligible for life. Each group represents 3% of the population and on 2009 prevalence of this population is about 600,000, with condition groupings as follows: congenital anomalies and intellectual disability (82,000) nervous system disorders (41,000) injury (15,000) mental illness (206,000) sensory conditions (12,000) physical conditions (223,000). This is a small proportion of the 20% of the population who otherwise suffer a mild degree of impairment and the 21% who suffer a chronic illness without on going impairment. Although those with profound and severe disability are the primary target, the report does consider other degrees of disability. The funding would be brokered to coordinate services based on need for care and support including respite, aids, equipment, transport, home modifications and a range of community and day programs. There would be an emphasis on early intervention and access to education and training to maximise long-term independence and potential. People with disability and their families would have certainty and clarity about options from the point of determination of a disability. Eligible people would be entitled to services determined on an individualised plan and needs basis, giving them access to an appropriate whole-of-life suite of services and support. Families would have more choices about the combination of work and informal care for family members at various life stages, as in other families. The proposed scheme addresses the current unmet and under-met need for care and support and the unsustainable reliance on carers. For the first time there would be clear incentives in the service system to invest in timely interventions that promote independence and produce long-term benefits. The NDIS would double the total funding for disability services by adding a further \$6 billion. Despite the size of the budget, the NDIS reports that

there is a large and expanding unmet need for care and support for people with severe/profound disability, and also a large unpaid volume of care and support provided by family and other informal carers – an estimated 2.5 million carers providing nearly 650,000 full-time equivalent carers (with a replacement value of \$35 to 40 billion per annum). Health systems are also undergoing concomitant radical change, moving from treating potentially fatal illness (which do not dominate our lives now) to the need to minimise chronic and complex disability and the diseases that create them. NDIS predicts that improving chronically disabling diseases will consume 80% of the \$100 billion health budget by 2020. It is projected data like this that indicates why the NDIS is essential to the further growth of our economy and doing things better and smarter for our communities.

Judy Brewer a parent and disability/autism advocate described the necessity for every parent of a disabled child to advocate for all children with disability (Carroll et al, 2011). Since my early career study in 1990, it is gratifying to see how far this public debate has come with so many sources of information, from governments, economists, university academics and parents articulating a common approach on what the community needs to do to enable a better quality of life for children with intellectual disability and their families. It is now time for action. ●

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facts and figures...

Interesting Facts to Know!

As of 1 July 2011, children who are aged under 6 years and have been diagnosed with Down syndrome, cerebral palsy, Fragile X syndrome, or a moderate or greater vision or hearing impairment, including deafblindness, can be registered to access early intervention funding. –FaHCSIA www.fahcsia.gov.au

Around 20% of the world's children and adolescents are estimated to have mental disorders or problems. Yet, regions of the world with the highest percentage of population under the age of 19 have the poorest level of mental health resources. Most low- and middle-income countries have only one child psychiatrist for every 1 to 4 million people. – WHO www.who.int

Expressive language disorder means a child has difficulty with verbal and written expression of language. The child may have problems with producing sentences, recall of words and vocabulary. The cause is often unknown; it may be associated with other developmental difficulties such as Down syndrome, autism or hearing loss. –Better Health Channel www.betterhealth.vic.gov.au

In 2007, the World Health Organization (WHO) argued that the world faces a critical problem with the growing number of people with mental and neurological problems, including autism, which accounts for 11% of global disease. The number is projected to reach 14.7% by 2020 – WHO www.who.int

Depression and anxiety are the most prevalent mental disorders experienced by Australians. Depression alone is predicted to be one of the world's largest health problems by 2020 – *The Global Burden of Disease*, World Bank Harvard School of Public Health, Geneva 1996