

Chapter 1

**Aiming For A Quality Of Life: What Makes For A 'Good Enough' Life For A
Child Or Youth With Intellectual Disability And Their Family?**

David Dossetor

What Makes A Quality Of Life?

What does 'a quality of life' mean? Quality of life is a subjective and personal perception that means different things to different people. A 'good enough' quality of life is what everyone can and should aspire to. Nonetheless there are consistent objective qualities as to what contributes to that sense for most people of 'how satisfied are you with your life as a whole?' But what makes up the main components of a good enough quality of life? The research shows that it entails having an adequate standard of living and feeling safe (Cummins, 2005). Generally a 'good enough quality of life' means having reasonable health. It also means being connected to other significant people and having valued relationships. It entails being connected to a community and contributing a worthwhile role, a sense of purpose and productivity, and having a hope for the future. For many, a hope for the future involves having children for whom there are also hopes. This has been summarised as 'being, belonging and becoming' by Renwick, Brown, and Nagler (1996). They described that *being* related to the basic attributes concerning the individual, *belonging* centred on the fit between the individual and their environments, and *becoming* related to the individual's attempts to attain goals and fulfil hopes.

The empirical research shows the evaluation of quality of life is similar and fairly good for most of the population, generally scored at 75% +/- 20 (Cummins, 2005). One extraordinary element is that most people find a 'good enough' quality of life in the face of considerable adversity. For example, most people with chronic ill health adapt to finding adequate quality of life. Being particularly intelligent or being a slow learner is not a predictor of quality of life, nor is being rich or poor. Against this

background, it has been suggested that psychiatric disorders are important ‘disorders of quality of life’.

Health services have to justify their interventions by demonstrating that they contribute to health-related quality of life in the context of an affliction. Indeed the internationally accepted concept of health is not just a concept of an absence of disease but a sense of health and wellbeing in physical, psychological, social and spiritual or cultural dimensions (WHO, 1948). So what does a quality of life for a child or adolescent with intellectual disability or other developmental disorder mean? There is limited research in this area, but what exists suggests that it has similar domains (Cummins, 2005). Even for the young person with autism (with a central disability of difficulty understanding other people’s thoughts and feelings, and difficulty communicating) quality of life still involves the *quality* of social relationships (not so much the number). This can occur even if a lack of social skills limits this to a sense of belonging, of friendship, or friendliness, or shared activity (Burgess & Gutstein, 2007). Even for the alienated, hostile, neglected young person living in a refuge, family relationships despite their problems are still the most important (NSW Commission for Children and Young People, 2002). For someone with an intellectual disability, developmental achievement such as walking or developing functional communication is as valuable to them in one context as a achieving first place in an exam is to another person in another context.

A prerequisite for a quality of life is the recognition of the individual’s choice. For someone with a disability, this may include enabling the capacity to express a choice and supporting it, while appreciating their values and culture (Brown & Brown, 2005). For children with or without a disability quality of life also depends heavily on

the health and happiness of the family system. The *Beach Centre Disability Family Quality of Life Scale* (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Smith-Bird & Turnbull, 2005) found five important contributing domains of family quality of life including, *family interaction* (e.g., enjoying spending time together); *parenting* (e.g., helping family members with school work and activities); *emotional wellbeing* (e.g., having the support needed to relieve distress); *physical/material well-being* (e.g., the feeling of safety at home, at work, at school and in neighbourhood); and *disability-related support* (e.g., the family member with special needs has support to make friends).

A study conducted by the author (Dossetor, 1991), involving in-depth interviews of ninety-two families with teenagers who had severe intellectually disabilities, demonstrated what an extraordinary group of people these families were. The families were able to make the best of circumstances of considerable adversity, but they also valued the relationships with their teenagers with intellectual disabilities and celebrated their achievements just as they would siblings with average development. Nonetheless, there are different or special challenges for a young person with an intellectual disability and their families. Some exceptional families are able to see these challenges as advantages, but for the most, it also involves hardship, persistence, and problem solving.

Having a child with an intellectual disability is an atypical experience with some very significant differences or challenges for the child and his/her family, yet all should aspire to having a 'good enough' quality of life. It is in this context that many families and professionals prefer to emphasise 'diffability' rather than 'disability' (Jordan, 2001) as what some may experience as a disability, others may see as a gift. It is therefore

important to identify and examine what are the specific challenges for the family and child with intellectual disability, and in turn attempt to define what community-based clinicians can do to enable this process, and what skills may be important.

How Can Clinicians Contribute To Others' Quality Of Life?

So what can a group of experienced clinicians contribute to improving the quality of life of young people with intellectual disability and their families? Clinicians can provide testimony of the ways others have resolved similar challenges. They can interpret what the scientific literature has to say and take the challenge of making science relevant and meaningful for families. Demystifying jargon used by different professional disciplines is also a challenge.

Clinicians can use language that is accessible to individuals and families that receive intervention services. They can be holistic in considering the biological, developmental, educational, family, social and cultural context of a child, and to be specific about the evidence that supports interventions that bring about change. Clinicians can also provide information about what families can do themselves to help their child with intellectual disability achieve an adequate quality of life. Through training, knowledge and skills can be shared with community clinicians so that they know what professional skills are required to facilitate this process for families. Through experience, clinicians often become experts in what can go wrong for individuals and families, but this knowledge should be used to promote skills to improve situations that are likely to go wrong, and even prevent them from occurring. Increasingly there is literature about how these children and families can get it 'right',

which gives insight into the adaptive, proactive, and preventative components of achieving a quality of life.

So What Are The Main Challenges?

One essential ingredient for success in growing up is having expectations that are challenging but achievable. In the same way, it is important to take on board the elements of what contributes to a quality of life and how this is applied to a young person with an intellectual disability. A prerequisite for happiness is also accepting what you cannot change.

As mental health clinicians, the aim is not to ‘cure’ intellectual disability. Although science sporadically discovers miracle cures, it has been frequently demonstrated that a ‘search for the holy grail’ of a cure has harmful effects on the quality of life of the child and the family. Alternative treatments are not without major costs, risks, side effects or time commitments, and yet many families don’t subject them to scrutiny for scientific evidence of effectiveness. This book tries to take into account some of the main challenges of difference and vulnerability that makes achieving a ‘good enough’ quality of life a special challenge or an individual road for a young person with an intellectual disability and their family. Table 1.1 lists both the traps and the challenges for a family caring with a child with intellectual disability. Although the challenges arise progressively as the child with intellectual disability grows older, for those families that are under threat, several or all traps apply (Nankervis, Rosewarne, & Vassos, 2009).

[Insert Table 1.1 here]

Getting To Know A Special Child

Do children grow up too quick or too slow? This perception is so dependent on expectation and ‘which end of the telescope you are looking through’. The physical bodies of people with intellectual disability grow old at the same rate (and may be more quickly in some situations such as the risk of premature Alzheimer’s Dementia in Down Syndrome), but what is more evident is that cognitive development is slowed. Indeed some families talk about the advantages of having to spend more of life outside of the fast lane. Central to their quality of life is a high value on caring for each other and what that teaches about life and its values (Dossetor, 2001; Stainton & Besser, 1998). Perhaps the first big challenge for the family is for them to ‘get to know the child’ and the differences from ‘average’ expectation. However quality of life is not related to the destination, but about appreciating the journey and marking its milestones and achievements.

For many families, an understanding of early development is an important building block for understanding and accepting how this stage can be slowed, extended, and uneven as part of their child’s intellectual disability. Most of what individuals know about being a parent comes from having been parented. Accordingly, individuals are attuned to parenting someone like themselves, and according to whether childhood was happy or not, parents will do the same or the opposite. What is also known is that for most individuals, their parenting response is conditioned to be modified by the genetic nature and temperament of their child (Reiss & Neiderhiser, 2000). However for a parent of a child that is not developing in a typical manner, or whose relationship with his/her parent is disrupted by complex medical or developmental needs, these intuitive

processes are not sufficient. In these situations, parenting becomes a process of modifying expectations to understand *this* child's needs and his/her developmental journey. This is where it may take more time, thought, and individuality to work out what is involved in parenting in order to understand the child. It may also require breaking down skill development into smaller steps and allowing for mastery of skills to develop in smaller stages.

For the child with an intellectual disability to be accepted and loved not just by his/her parents but by grand parents, extended family, friends, and neighbours, then they too also have to know and understand the individuality of the child. There are natural and normative stigmatising processes that work against this happening. When dealing with the new and different, understanding and positive challenge are needed for positive support (Sensky, 1985). Accordingly, parents and others who understand the child with an intellectual disability (including community clinicians) have to model and explain what may be atypical and how to adapt or manage this. Adapting to, and understanding the differences, enables recognition of the consistent and familiar features of childhood. This process of sharing concern for a child is necessary to open the door to a community of especially caring people. Human nature so often provides surprises, when you look for caring qualities. In this way all parents need to be advocates for their child.

The Burden Of Caring

Most children with intellectual disability are generally happy, like typically developing children, or 'neurotypicals' (as the community of people with autism spectrum disorder like to call 'average' people). All babes and infants are highly dependent on their parents, needing help with feeding, dressing, and toileting. However, what are probably

more important are the attentional and interactive needs of infants to engage with adults who can understand and respond to their preverbal communication. There is no doubt that caring for an infant is hard work, and it is possibly the social role that is least financially valued in our community as it is seen as a rewarding challenge. For a child with intellectual disability, this phase doesn't last two to four years but may last five to seventy-five years. It is this burden of long-term caring that most distinguishes families with a child with intellectual disability.

The process of sharing the understanding and capacity to care for the child with an intellectual disability with family and friends is crucial to having them involved in the child's life. Emotional support and understanding may be good, but survival as a parent in the long term depends on having friends or relatives who will provide a practical helping hand (Dossetor, Nicol, & Stretch, 1993). Even having one friend or relative who provides an occasional hour of care makes a critical difference. A baby consumes about seven hours a day of individual parental care time and attention, and for the child that has a disability, this demand continues for the long term. For children with disabilities who are hyperactive or have poor sleep patterns, this can be a gross underestimate of parental care time. Typically developing children experience visiting friends, sleep overs, birthday parties, and can visit other homes while parents are shopping, or going to the doctor. Having the same resource for a child with an intellectual disability involves the parents having a special trust for the substitute carer, and a special capacity for care by the carer for the child with the disability. What clinicians see often is the parental sense of undue responsibility, and a defensive belief that no one else would, could, or should provide substitute or supplementary care for their child. This is probably the single most important determinant to predict parental

(usually mother) coping and survival. It has been found that even having one or two people who even only occasionally provided that additional special child minding support made all the difference (Dossetor, Nicol, & Stretch, 1993). For parents, families, and their social networks to work out, the processes of support needed means that they need to learn about the needs and future potential for a quality of life for the child with the disability and resolve the practical challenges for the burden of care.

One of the practical challenges associated with the burden of care, is meeting the specific needs of the child with intellectual disability concurrently with those of the rest of the family. Balancing these needs can be complex and challenging, and generate significant levels of stress within a family. Family research indicates that well-being is generally maintained by creating healthy routines that are manageable and sustainable yet meaningful and accommodate the needs of *all* family members (Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993). For example, if sharing the evening meal together is an important routine for a family, scheduling dinner for a time that enables older siblings and parents to arrive home and settle back into the household will be important. The time everyone sits down to eat will need to remain flexible to account for evenings where one parent is delayed by traffic or a meeting, or a sibling is late home from sport. In this way a valued routine remains sustainable for everyone.

Family routines provide stability and predictability but should also be dynamic, flexible, and responsive to new demands. Such routines should enable a family to

- Balance the demands of everyday life – both inside and outside the home;
 - Engage others in the lives of their children;
 - Allow parents and siblings to spend adequate time together in various combinations;
- and

- Allow time for individual members to pursue their own interests (Schneider, Wedgewood, Llewellyn & McConnell, 2006).

It is not surprising therefore, that respite care is seen as a crucial cornerstone of enabling a quality of life for a family with a child with an intellectual disability. Over the last twenty-five years, since the change in community opinions and government policies about putting children with disabilities into long term institutions, there has been a very gradual process in making respite care more child and family orientated. Such respite services have included the provision of in-home family based respite, and the funding to develop the skills of families and friends to provide respite. This model is currently being trialled through the Family Solutions project of Uniting Care Burnside in Northern Metropolitan Sydney in New South Wales. However enabling 'respite' or alternative care and affectional relationships within their own family, social, and community networks is what families would like to have. If only some of the extra cost involved could be supported by 'the system'.

Managing 'The System' And How To Survive It

Systemic thinking is an important part of consideration for mental health and survival. It is the term used to study or contemplate the way that everyone is part of a greater whole. As a social species, people may see themselves as individuals, but they are often defined by who they belong to. Furthermore, although people have an influence on those groups or organisations that they belong to, these groups and organisations also influence people. In the context of having a child with an intellectual disability, the system can really be divided into two parts,

1. The special challenges of the parents maintaining wellbeing and balance in themselves, the other members of the family, the extended family, friends, colleagues, and community organisations; and,
2. The challenge of making the specialist disability, educational and health services provided by the community, and the government provide adequately for the special needs of a child with an intellectual disability.

Winnicott (1996) a famous paediatrician, noted that an infant cannot be considered without a parent, because of his/her intimate interdependency on that relationship. In the examination of the difference of disability, society has neglected the greater importance of the relationship of the child with a disability with their immediate carers. Accepting and integrating children and adolescents with intellectual disability into our community requires clinicians to put special value on the young person's parents or carers and immediate family. Yet the special challenges of accessing necessary services, in a cost limiting system (e.g., managing the rotating front door of trainee clinicians in the government system), requires considerable skills of discrimination and assertiveness. The skills of advocacy are necessary for every parent but they also need to take on superlative dimensions of patience, skill, persistence, and toughness when providing for the special needs of a child with intellectual disability. The necessity of these life challenges frequently brings out special or even heroic qualities in the parents that clinicians meet.

Understanding Delayed And Uneven Development

The following section aims to set the scene for some of the principals behind the shared knowledge base of a team of multidisciplinary clinicians working in intellectual disability and mental health.

Development

What distinguishes a child from an adult? - *development*. What distinguishes child psychiatric disorder from adult psychiatric disorder? - *developmental psychopathology*.

This contrasts with adults who are seen to have substantially matured and no longer rapidly developing; indeed they are seen as autonomous with an egalitarian right of responsibility. Similarly, psychiatric disorders in adults are generally seen as disease equivalents that need treatment to resume a previous state of wellbeing, and social and emotional competence. Although adolescents can suffer these psychiatric disorders such as schizophrenia, bipolar disorder, depression, and post traumatic stress disorder, children and adolescents also have an additional range of emotional disorders and behavioural disorders. It is these childhood specific disorders that are substantially related to development and developmental competence. What are these emotional and behavioural disorders of development? These childhood disorders of emotions and behaviours are caused by,

1. The vulnerability of development and developing temperament, in the context of learning skill competence; and
2. The physical and emotional environment of the family and other relationships (Hudziak, 2008).

Developmental Versus Psychiatric Disorders

Take the example of Disruptive Behaviour Problems, where persistent naughty behaviour is largely a learned behaviour in response to inconsistent management, and where emotional displays get what you want. There are some temperamental/genetic risks factors, but environmental factors including emotional deprivation or abuse are important contributors. With the exception of Attention Deficit Hyperactivity Disorder (ADHD), these behaviours and angry feelings/thoughts are treatable by energetic change of the environment to improve warmth, rewards, supervision, and consistency of contingencies for behaviours.

ADHD (i.e., problems of attention, restlessness, impulsiveness with or without hyperactivity) is substantially a genetic and constitutional component of disruptive disorders, but it also occurs on its own where it contributes to learning problems. However, all children have to learn to concentrate, sit still, and think things through. So what are the developmental processes necessary to be able to concentrate, sit still, and think things through? These are complex processes that there is little understanding of at a scientific level, yet clinicians have lots of experience of what helps children develop skills and mature. What gives the diagnosis of ADHD significance is the predictive validity, that is, if you do poorly in these areas of developmental competence, there is a high chance that these features will lead to other problems of academic achievement, emotional and behavioural regulation, and in establishing good quality new affectionate relationships (Reid, Patterson, & Snyder, 2002).

The validity of mental disorders in intellectual disability can be tested. For example a review of ADHD in mild intellectual disability showed that although the syndrome features are much more common (i.e., in a third of the population or even higher where there are additional developmental problems), that in many ways they act

as predictors of other problems and therefore can be seen as a disorder (Antshel, Phillips, Gordon, Barkley, & Faraone, 2006). Conversely developing a capacity for attention, concentration, sitting still, and thinking things through is a problem that every developing infant has because these are all challenges of normal development.

Ambiguity therefore follows in trying to determine when is a disruptive behaviour in a child with intellectual disability a part of normal variation of behaviour, or a 'challenging behaviour', or a psychiatric disorder? For example, high activity and attention seeking behaviours in a child with intellectual disability may reflect,

1. Part of a normal developmental phase, even if chronologically delayed particularly in the context of abnormal or vulnerable brain structure and function i.e., 'its normal for him';
2. The developmental challenges of developing motor coordination, or exploring the external world i.e., 'he learns from activity';
3. Awareness of a difficulty, such as fear or confusion about the language used, or the noise of other features of the environment i.e., 'he feels stressed and doesn't understand what is going on';
4. Frustration in someone else not understanding how they are feeling or what they want i.e., 'he is trying to let us know what he thinks or feels';
5. Abnormal activity levels, fidgetiness and distractibility with marked impaired concentration despite other areas of normal development i.e., specific developmental ADHD; or
6. A disordered pattern of behaviour with awareness of intent to do harm to others in the context of a persisting rationale of low worth of self or others i.e., 'he has a

conduct disordered pattern of behaviour that is likely to persist, that he has learned from his social environment’.

Different mental health clinicians might ascribe any or none of these different scenarios as a psychiatric disorder. They all reflect problems of behavioural interaction in the context of developmental impairment. Although, the last scenario may emphasise the adaptation to an inconsistent learning environment, rather than the capacity to learn modulation of socially meaningful behaviour. All scenarios require developmentally supportive interventions with different approaches, and all may be better considered as developmental disorders.

Conduct disorder, which is resistant to change and tends to persist, may be more likely to be viewed as a psychiatric disorder. Although it is treatable with environmental changes, unfortunately these environments of family and community interactions are often difficult to influence. These descriptions also suggest that having calmness, stillness, alertness, and concentration require achievement of key development milestones in motor development, proprioception and modulation of arousal, receptive and expressive communication skills, and sufficient intellect or mental energy. Closely linked to these is a theory of mind (i.e., a sense of one’s own thoughts and feeling in relation to one’s sense of others). An absence of any one of these is likely to lead to a lack of attention and concentration, which are the key long term predictors of educational failure.

Accordingly, if development is delayed in various areas, then delay in developing these skills become normal for the population of intellectually disabled and not a disorder. Indeed some disorders such as language and coordination problems, sequencing and memory problems, ADHD and Autism Spectrum Disorders are

generally described as developmental problems. This means that it may be as helpful or even more helpful to think about these as developmental challenges or delays rather than disorders. Such a model also requires a range of caring and educational approaches and not strictly a psychiatric designation.

‘Ontogeny Repeats Phylogeny’: Developmental Sequences That Occur In Evolution Occur On Embryology And Human Development

Heinz Werner described the universal principle of development as ‘where there is life there is development in a systematic sequence’ (Hodapp & Barack, 2006, p237). The second principle is the orthogenetic principle, that is, ‘development progresses from relative globality and lack of differentiation to increasing differentiation, articulation and hierarchic integration; both individual and context differentiate, leading to a development-transactional approach’ (Hodapp & Barack, 2006, p237). Real development is complex and involves relations constantly changing or transacting with its environment.

One of the truths of human development is that skills in a developmental domain are seen to occur in sequence. The remarkable observation is that, regardless of the genetic or neuroanatomical cause for delayed acquisition of skills (e.g., motor development or language), progress follows the same sequence of gaining skill competence. For example, head control precedes sitting skills followed by standing and walking; or preverbal noises precede single words followed by short word sequences. It is suspected that these sequences are governed by rules of developing mathematical complexity at a level of nerve connectedness, more importantly than one particular neurone or brain region doing one particular task.

In the same way as the evolution of the eye has been shown to have a functional sequence which can be reproduced by a mathematical computer program, clinicians may need to look for natural sequences of developmental achievement in other areas of human development (Dossetor, 2004). For example, although autism has long been conceptualised as a discrete disease process, the research community has now accepted that it involves differences of a dimension of developmental competence (Constantino & Todd, 2000; Constantino, Przybeck, Friensen, & Todd, 2000). Based on the analogy of the evolution and development of the eye, it is likely and indeed extremely helpful, to conceptualise autism as a delay in developmental competence of socio/emotional understanding and theory of mind, even though it may not be possible to prove it. In this vein the severity of autism spectrum disorders is related to a developmental sequence (Tanguay, Robertson, & Derrick, 1998) in the following areas,

1. The presence of affective reciprocity - the preverbal interactive skills of a child in their first year of life;
2. Joint attention, i.e., the capacity to perceive whether another person is looking at the same object - a key achievement of a child in the second year of life; and
3. A theory of mind, i.e., a capacity to appreciate that another person has thoughts and feelings distinct from your own - a skill that starts in the third year of life.

Such a developmental framework accepts that there are complexities that cannot be individually seen, but approaches to promoting development is the key to reducing disorder and promoting health. In the last decade, much of psychology has shifted from focusing on 'challenging the deviant' to 'promoting skills in areas of competence deficits' that help young people better manage the challenges of social, emotional and cognitive integration (Emerson, 2001). It is also interesting that some of the skills of

promoting development that have been developed in the field of psychology of intellectual disability have found a central role in mainstream psychology and psychiatry (e.g., chaining of skills, differential reinforcement of other behaviours, and contingency conditioning). Such a framework also means that these conditions, although historically recognised as psychiatric, are better understood as delays in developmental sequence. This means that anyone who knows about how children grow up, like parents, can understand and predict their needs.

Summary

Quality of life and ill health are different, but it is clear that those who have a low quality of life also have marked increased rates of ill health and psychiatric disorder (McConkey, 2009). Accordingly clinicians should pay attention to enhancing quality of life, as this will also affect risk, outcome, and relapse of ill health. The aim of the framework outlined in this book is to describe a range of clinical skills, knowledge and resources and make them more accessible to the core workforce of community clinicians who encounter children and adolescents with intellectual disability and emotional and behavioural regulation problems.

This all needs to be understood in the context of families, community, and culture, with an aim of enabling coping competence and a sense of purpose, belonging, and future for children with intellectual disabilities and their families, and to build a quality of life for this special group of people. Medical diagnoses often help define specific interventions. Emotional, behavioural, and psychiatric disorders have a major influence on, and are influenced by elements of quality of life. Cohort studies of families with a child with Down's syndrome reported that 80% have a good enough

quality of life (Byrne, Cunningham & Sloper, 1988). In the face of apparent interminable disadvantage and disturbance, it is important to remember that all children with an intellectual disability and their families can achieve a quality of life, and as clinicians the aim should be to help them understand and aspire to a 'good enough quality of life'.

Table 1.1

The Traps And Challenges For A Family Caring With A Child With Intellectual Disability (ID) Through The Family Life Cycle

Common Traps	Main Challenges
1. Failure of adjustment to a different child <ul style="list-style-type: none"> ▪ Attunement and developmental understanding and special parenting skills 	1. Getting to know the child 2. Sharing the burden of care 3. Managing the system <ul style="list-style-type: none"> ▪ Accessing specialist disability services
2. Failure to share the care of a different child <ul style="list-style-type: none"> ▪ Adapting to the burden of care 	<ul style="list-style-type: none"> ▪ Caring for the carer and family 4. Understanding delayed and uneven development
3. Problems of psychiatric disorder <ul style="list-style-type: none"> ▪ Seeking special multidisciplinary help 	
4. Failure to look after the carer's wellbeing and family relationships	

(Adapted from Nankervis, Rosewarne, & Vassos, 2009).