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RAISING A CHILD WITH HIGH CARE NEEDS

**The parental experience of caring for a child who
experiences disability and has high care needs**

A thesis presented in partial fulfilment of the requirements for
the degree of Master of Social Work

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Abstract

This thesis explores the experience of raising a child who has impairment in bodily function as well as high care needs. A small group of mothers who are bringing up a child who has required a high level of parental input were interviewed to explore the experiences that had influenced the development of parental skill.

The thesis is backgrounded by a literature review that traverses the development of services to support child disability in New Zealand, meanings and definitions of disability — specifically those definitions used in New Zealand policy and service delivery, parenting, implications when parenting a child has a disability, support systems, accessing services, and the role of caregiver parent.

Data from the interviews carried out was analysed and revealed variables that were common to all the mothers interviewed. All the mothers had been fully involved in the clinical aspects of their child's assessment, treatment and rehabilitation from the time their child was diagnosed as having a condition that required medical intervention. All the mothers interviewed could be described as having developed competency and parenting strength that had lead to them becoming 'experts' who were caregivers, medical technicians, advocates and case managers for their child, because they had the means to become involved in specialist aspects of their child's life.

Preface

I enrolled in a MSW programme because I had enjoyed completing an undergraduate degree. In undertaking academic study after a working career in community and social work, I was given a view of how a sound understanding of the philosophies and understandings that come from academic study provide a firm grounding to social work practice. Having had an opportunity to take up study after working gave me tools to separate out agency protocol and understandings of social worker practice. The separation was a process that made it clear that sound social work practice comes out of fully understanding the philosophies that ground the work.

I took up study part time many years ago (in the late 1970s) when I commenced work after being a DPB mum. In the mid-1990s I took two years to study full time at Massey University Albany and I completed a BSW. The work challenged me, as I had been working as a social worker whose career over the past 20 years has been with community, families and children.

When I enrolled in the papers that made up a component of the MSW degree, I changed employment to working directly with children and their families in a therapeutic and resolution social work role with families. This move gave me a working knowledge as I completed the theoretical work required. The work I took up was with a major health organisation that provided services to children and their families where the child had a diagnosis of physical disability. It was while I was employed to work with the families of children who had a diagnosis of physical

disability that I met children and families who viewed their circumstance as one that gave them challenges, but challenges that were focused around the positives in their lives.

I also learnt that there is no such thing as one diagnosis to suit every child and that physical disability, while a diagnosis based upon bodily impairment, is a circumstance created by moving through an environment where impediment arises in the social and physical world. Technical equipment and planning for structures in the environment took on a new meaning for me and changed forever what I see when I look at how our social and physical worlds are constructed.

I chose to look at the journey of a parent and what has given them the resilience, strength and tenacity as a parent because of the parents I met while working directly with children and their families where the child had very high care needs. I met parents who grappled with services across health and education where there seemed no rationale for how the services were separated or linked, while all the while showing a joy and satisfaction with the job they were doing for their child. These parents seemed to have taken on a world that put great barriers in the way of their children, yet they had moved themselves into becoming very competent advocates and case managers for their child. This experience motivated me to complete this thesis.

Chapter One

Introduction.

The world of parenting a child who has high care needs is a world where expectations of parenting are thrown into crisis when a parent is first told that their child has impairment. This is a time when parents find themselves in a situation where all the maps that they were to use to raise their child need to be rewritten. This thesis explores the experience parents of a child who has impairment and high care needs have in the world of medical specialists, specialist medical clinics, medical care, home-based support, and multi-agency involvement.

The thesis:

- outlines a very briefly a history of disability services for children who experience physical impairment and disability in New Zealand;
- discusses beliefs and definitions related to disability and physical disability;
- discusses parenting and discusses implications this may have when a child has a disability;
- discusses service delivery aimed at supporting high care needs parenting and the implications of this for parents;

- analyses the reflections of parents who have raised and still care for a child in their family who is physically disabled and who also has high care needs;
- discusses what experiences have led a parent to success in their parenting.

Parenting takes place in the private arena of home and family and support for a parent often comes from within the family group. The public arena of support for families raising a child with disability and high care needs brings families into contact with social service agencies, health service agencies, and local community-based agency support.

The interviews carried out with a small group of parents indicate that parenting a child who has extraordinary care needs can have both benefits and costs for a parent. All the parents interviewed for this research reported a focus on meeting needs for their child, while developing personal skill in areas that increased over time as they interacted in, with, and across services that they accessed to assist their child. What has enabled parents to successfully parent is the question that is central to this thesis.

Outline of thesis

Chapters Two, Three and Four form a literature review around the issues of disability, child disability and parenting in the western world and specifically in New Zealand. Chapter Five presents a discussion of the theories that ground this research in high care needs parenting. Chapter Six outlines how the research was operationalised, from planning through to completion. Chapters Seven and Eight provide an analysis

of the data from the interviews and Chapter Nine summarises the analysis, drawing together the findings of the research.

Chapter Two reviews literature related to family care and support systems that have arisen in New Zealand. Disability is a factor that impacts on 11% of New Zealand children (Statistics New Zealand, 2001: 129) and beliefs about disability have been influential in the development of support systems for high care needs disability parenting. Disability has been framed into two major models: the medical and the social models of disability. A third model, the political model, has emerged in the literature in the past decade. I give an overview of these three models of disability. I then review definitions of disability and physical disability as they are used in New Zealand.

Chapter Three discusses the literature related to parenting and caregiving. The experience of parental caregiving is a gendered role. Parenting a high care needs child does not take place in isolation but in the context of family, community and agency support. The impact on family cuts across partner relationships, to siblings and to wider family such as grandparents. The parental caregiving role comes at a personal cost and is a role that calls on parents to build up personal support strategies. Every family in the western world is likely to build up systems of support for their parenting role and the support they receive is critical to how they fulfil their caregiver parent role. In a modern world, family support is often not adequate and support from social service agencies and the state can enhance the care a family provides for a child. It is here that families directly experience the practical implications of social policy and professional intervention.

Chapter Four discusses service delivery and social policy. In the western world, there is public recognition that the role of caregiving for high care needs children requires some support. In New Zealand, families have access to services as they parent their high care needs child, but over time, the way these services are delivered has changed. In New Zealand, policy is in place to promote an inclusive world for disabled citizens. There are no policies that specifically promote services for children, but the ethic of family centeredness and inclusion run across all services for disability. The literature tracks a lack of cohesion between social policies for children that is replicated across the agencies and services parents access for their child. The United Nations Convention on the Rights of the Child (hereafter referred to as 'UNCRC') is a convention that New Zealand has signed. This document recognises that children who experience a disability are 'entitled' to support. The Convention is a document of intention rather than a document that guarantees rights. In New Zealand, human rights are also subject to statutory recognition under the Human Rights Act and the Human Rights Commission has a role under law to take complaints from citizens who consider that their rights are being compromised or not met. This legislation is also one that signals a right but does not provide a means of guaranteed access to services. The means of accessing services in New Zealand is via the 'Needs Assessment' process and if eligibility is established, a child and their family will be able to gain access to services. However, eligibility for services arises first from a medical diagnosis of loss or impairment and it is only then that the needs assessment eligibility protocol will be implemented.

In Chapter Five, I outline the theoretical views that provide a lens through which to view the data extracted from the interviews carried out. Systems theory, feminist

theory and attachment theory are the lenses through which data was analysed. Systems theory gives an understanding that families are systems, rest within a myriad of systems, where influences shape the life of each parent and child (Luster and Okagaki, 1993; Smetana, 1994). The balance and counterbalance that systems theory proposes rest at the heart of the argument that a parent develops the skills they use to raise their child because of the support they experience. Feminist theory provides the foundation for discussion around the role of caregiver, as a genderised role, that takes place in the privacy of home (Oakley, 2000). Feminist theory also provides grounds for discussion around professional intervention (Mukherjee et al., 1999) and strengths-based family work (Dominelli, 2002; Munford and Sanders, 1999).

Parenting and caregiving a child are linked and it is attachment theory that draws them together. An attachment relationship between a child and their parent and a child and their family provides a pivot upon which a family balances and re-adjusts to meet the needs of a child who has high care needs.

In Chapter Six, I outline how the research was implemented and carried out. Semi structured interviews were a means of collecting qualitative data that could be analysed for themes and contrasts related to support received when parenting a child. All the research participants were women who were in some way associated with a support agency. This creates a bias as the research only reflects the experiences of parents who have positively engaged with a dedicated support group. The research is also limited in size and scope and was not designed to research cultural or socio-economic influences.

The research method was designed as an individual interview process rather than a group process to ensure that all participants were given privacy to express their view. Privacy was also the reason that participants were initially left to make an independent approach if they were willing to participate in the research. This process was not successful and I briefly discuss why.

The chapter also contains a discussion on the ethics related to the research, as well as a brief discussion around three ethical points that relate to child disability.

In Chapters Seven and Eight, I analyse data from interviews with five women who have parented a child who has impairment and who also has high care needs. Understanding what the influences are in the experience of parenting that have led to the development of specialist skill arises from understanding that the world is structured around beliefs about disability, about parenting, and about rights and entitlements that mix to form the basis for caregiver parenting. Support and services have been available to assist parent a high care needs disabled child and it is this world that provides the information that leads to the discussion in Chapter Eight about professional intervention.

In Chapter Nine, I discuss the key themes that the analysis of the data revealed. Family support, the influence of being able to be present with a child through their assessment, diagnosis and treatment allows a parent to enter into a world where they very quickly develop the expertise to parent a child who requires specific care to be carried out if their needs are to be met. In this chapter, I also discuss professional intervention and the possibilities that a model such as the 'key worker' model

(Mukherjee et al., 1999) model of family support can offer to a family raising a child who requires a high level of care in their home.

Chapter Ten summarises the thesis and presents three recommendations that have arisen out of the research. The chapter then concludes with a comment on the bias in the research followed by a summary of the influence of parental involvement at the early stages in a child's life and the factors that have facilitated this.

In Appendix 1, I present a model of social worker practice established from the literature and from an ecological model of social worker practice that was drawn up by R. Prasad, in the time he was lecturing at Massey University in social work theory. Appendixes 2 to 6 are related to the information that was provide to prospective and actual research participants, and Appendix 7 is a glossary of terms used in the document.

Chapter Two

History, models of disability and definitions.

Introduction

The history of support for families to raise disabled children in New Zealand goes back to early last century. For a period spanning the middle decades of the last century in New Zealand, as elsewhere in the western world, children diagnosed as having a physical disability were often placed in residential care for treatment and rehabilitation. Understandings that children need to live in families, coupled with a move to deinstitutionalise all those who were living in residential care, saw a change in this policy from the 1980s onwards. Over the past 30 years, social policy rewrote the practice of institutionalisation for disabled children and now the state supports all children with disabilities to live with their family. Long-term hospitalisation and institutionalisation have been replaced with day-based clinics, or short-stay hospitalisation and provision of home-based support services. Policy was primarily informed by the theoretical debates that have reframed disability from a notion that is based in the lack of ability, or loss of function in an individual, to a wider concept where disability arises from structures in the day-to-day world that individuals live in. Concepts related to disability have been categorised into three models of disability and these models form the basis for intervention and provision of services in New Zealand today. Services available to the families raising children who have a diagnosis of physical disability and who also have high care needs are dependent upon the working definitions that the Ministries of Health, Education and Social Development use to assess eligibility for support. It is only by being measured against these definitions that families can access services. There is a contradiction

built into this process, and disability theorists argue that this serves to entrench notions of disability that reinforce beliefs defining disability as 'loss' and 'lack of'. There are arguments that the assessment process has the potential to build on individual and family strengths, but that this can be lost due to the singular definitions that are used when assessing for support. This chapter examines the development of services for disabled children in New Zealand, understanding and working definitions of disability, and the contradiction between measuring loss and building strengths that is built into the assessment of an individual's needs based on a diagnosis.

Family care, service development and disability

In New Zealand up until early last century, family had been the only real means of support for those who required assistance with their care. In New Zealand, as elsewhere in the western world, family cared for those members who required assistance (Carey, 1961; Mitchell and Mitchell, 1985; Schwartz, 1997). Injured men returning from the 1914 – 1918 world war (Carey, 1961) and advances in medical technology and scientific knowledge drove the rehabilitative view of disability that saw specialised services set up to rehabilitate and treat disability (Carey, 1961; Mitchell and Mitchell, 1985; McClure, 1998). At this time in New Zealand, children with a physical disability could be placed into residential treatment centres for rehabilitation (Carey, 1961). In the later part of the century, through the 1970s and 1980s, new understandings of disability arose out of the debates that redrew the definitions of disability as an experience arising directly out of structures in the physical and social world and not from a personal impairment or a medical condition (Oliver, 1996; Schwartz, 1997). New understandings of disability brought about a questioning of the practice where children were placed in residential facilities and

over the last two decades of the 20th century, across the western world, children were increasingly supported to live with their families.

Critical to children living at home is the provision of home-based support services. Systems of support provided to families (in the western world) by the state had been rooted in a history where difference and impairment of bodily function had been treated as abnormal and deviant (Marks, 1999). The philosophies that challenged disability as a personal construct play a major role in the home-based services and support that developed to support families who provide care for those needing support at home (Marks, 1999).

Two events early in the 20th century were influential in persuading the New Zealand Government to become directly involved in assisting families with members who required specialist assistance. A major influence was World War I, when men who had sustained injuries that required a rehabilitative treatment programme were being returned to New Zealand for rehabilitation. The other influence was the poliomyelitis epidemics of 1916 and 1924–25 which left a number of people with permanent impairment in mobility. Both these events influenced the growing acceptance that care and rehabilitation were an issues that required the state to intervene and provide taxpayer-funded services to facilitate rehabilitation (Carey, 1961: 3–4). These influences underpinned the social policy that shaped the treatment and rehabilitative programmes set up in the 1920s through to the 1950s to support those who were disabled in New Zealand (Carey, 1961: 2).

It was during this period that community services were established to assist families with the treatment and care of disabled children. One service that has remained a major influence in support for families of physically disabled children to this day was the New Zealand Crippled Children's Society (hereafter referred to as 'CCS') which was established in 1935 (Carey, 1961: 5). As well as becoming a direct provider of equipment, specialist medical personnel, and specialist clinics, CCS also took a wider role and lobbied for increased state responsibility in the provision of services.

Services moved further toward specialist intervention for children after 1948 when Dr Carlson, an American specialist in the treatment of cerebral palsy, visited New Zealand. Dr Carlson recommended the setting up of remedial treatment centres within hospitals and dedicated educational programmes for children who had cerebral palsy. By the 1950s medical services for children with physical disability had been established in some hospitals, and specialist educational programmes were being provided both in separate educational establishments and within mainstream schools (Carey, 1961: 48; Mitchell and Mitchell, 1985: 34).

The development of services also took a step forward with the 1949 legislation to register and train both physiotherapists and occupational therapists (Mitchell and Mitchell, 1985: 35). At the same time, there were also some community-based initiatives to provide social support being set up, this included CCS - appointed Field Officers to work with children and their families in the community (Carey, 1961:51).

It was during this period that medical treatment was seen as best undertaken while the 'patient' lived in a residential facility (Carey, 1961; Mitchell and Mitchell, 1985) and

these facilities become a key component in the rehabilitative services provided for children by both CCS and the Government. In 1935 the Wilson Home had been set up in Takapuna by CCS for 'crippled children' and in 1957 the Government funded the Pukeora Home in Wellington to provide residential care facilities for disabled children (Carey, 1961).

In 1960 when a Professor Jack Tizard visited New Zealand, he questioned the rationale behind residential services for children, and this triggered debate around the need to separate children from their families for treatment and rehabilitation. Awareness grew and took hold that residential care was not a beneficial living environment for either adults or children and this influenced social policy (Carey, 1961: 54). Legislation was re-drafted to reflect understandings that services to address disability must promote an environment where disabled people lived their lives in, and with, family. In the late 1970s and throughout the 1980s long-term residential services for both adults and children were closed, and rehabilitation and intervention refocused on family and community-based intervention. The rationale behind deinstitutionalisation was accepted and the idea of 'community care' and 'family care' became well established (Bennie, 1993).

Throughout this time there was recognition that caregiving carried a cost and needed to be supported. The passing of the 1975 Disabled Persons Community Welfare Act established the right for parents of children who were 'seriously handicapped' to four weeks respite care per year, as well as a right to some financial aid under certain circumstances (Bennie, 1993). For the first time it was recognised that caring for a disabled child carried an extra financial cost for families. In the same year, the Social

Security Amendment Act was passed into law, and parents who were in receipt of a state benefit could claim a benefit for any 'disabled child' who was in their care (Bennie, 1993).

The number of New Zealand children who experience disability has never been exactly defined but in the 1996 Census, parents reported that 11% (90,000) of all children (children defined as being under the age of 14) experienced disability (Statistics New Zealand, 2001: 129). This figure, based solely on parent definition, is one that in comparison with other OECD countries (McDonald et al., 2001: 12) must be considered very high. In the census, one-third of the 90,000 New Zealand disabled children were reported to experience chronic health problems, and 4,500 children required technical assistance (McDonald et al., 2001: 12 – 16). It is not possible to deduce accurately from these statistics the number of New Zealand children who have a physical impairment and very high care needs, but the number would be quite small. The reason no exact figure can be drawn out of the census data is that the use of technical equipment does not necessarily mean a child has a physical disability nor does it mean that they have high care needs. What is known is that, internationally, the number of children with complex care needs is increasing. Medical advances have increased survival rates for those children who are born at a low birth weight and for those children who have 'severe and complex disorders' (Read, 2000: 8). These children may remain 'technologically dependent' (Beresford, cited in Read, 2000: 55) well past childhood, and Beresford's research (cited in Read, 2000) reports that this group of children are cared for at home by mothers who find the role physically taxing; that by the time these children are 12 to 14 years of age, four out of

five of them still require some assistance with self-care; and that one out of two of this group of children need a great deal of assistance to dress, wash, or toilet.

Societal beliefs about disability

Asking parents to categorise disability by placing a child in the category of 'disability' opens up questions about how beliefs form, and how these beliefs impact on family, on community, on social policy and on service delivery. Definitions used in the New Zealand literature are the definitions used in Great Britain and have in the past focused on loss of, or impairment in, bodily function. British theorists Oliver and Barnes (1998) argue that the rise of industrialisation (in Britain), along with the growth of science, combined with the values placed on 'social progress' and individualism, have defined disability across the western world.

They argue that economic organisation, such as in a modern factory, defined those who were 'successful' and those who were a 'liability' in a capitalist economy. (Schwartz, 1997: 130; Oliver and Sapey, 1999: 34 — 35) and thus industrialisation created a 'category of persons with social liabilities peculiar to the conditions of our society' (Oliver and Sapey, 1999: 35). This view ties an individual's worth to the economic model that underpins capitalist organisation.

The concept of 'disability' is also rooted in beliefs about those who were considered to be the 'deserving' poor rather than the 'non-deserving' poor. Charity work with those believed to be 'unable to work' in contrast to those 'unwilling to work' was also an important definer of those who were 'disabled' (Oliver and Barnes, 1998:14).

This notion of disability as a liability was challenged in the political activism that arose out of the debates that redefined disability as a socially created construct (Oliver and Barnes, 1998). Activism established disability as the experience that is created when people with bodily impairment interact with the physically and the socially created aspects of the world they live in. Views of disabled people as 'incapable, powerless and passive' (Oliver and Barnes, 1999: 71) were challenged, and beliefs about inclusion, rights, and power questioned. The role structural constraints play in keeping groups of people from participation (Oliver and Barnes, 1999: 51 — 77). These arguments were critical in reframing disability as a socially and structurally developed and maintained construct, rather than a 'deficit' in, or a 'dis'-ability that was sited in the individual.

Challenges to views of disability also arise from the understanding that citizenship is a notion that entails rights. Citizenship holds within it a right for all to live in a world that actively facilitates participation and inclusion for all citizens (Oliver, 1996: 44 — 55; Munford and Nash, 1994: 284 — 288).

The literature also highlights the differences that people who carry the label 'disability' experience in the way they are viewed in society. Schwartz (1997) argues that by taking a view across a lifespan, the need for support can be clearly seen as part of any life journey and is clearly a circumstance that is present in each person's life pathway. He outlines how in childhood, during illness, after an accident, or with the infirmity of age, a person will require support and care because they are not able to independently care for themselves. Schwartz argues that the need for support at these times is accepted as standard and thus does not attract the term 'disability'.

In the wider world, however, the use of a term to categorise disability is recognised and accepted as a measure to assess entitlement to support and services for the group of people defined as impaired in bodily function (Weaver, 1999; Mukherjee et al., 1999; Read, 2000: 91 – 92). In New Zealand, entitlement to services occurs via a process where the label ‘disabled’ is required to be proven and it is only after a medical diagnosis of ‘disability’ has been established that services and support can be accessed (Ministry of Health, 2001).

Models of disability

A framework for understanding meanings held within the term ‘disability’ in the world today are what have been termed ‘models of disability’. These models can be considered a lens that enables an understanding of disability and what this means to individuals and families who seek support and services in today’s world.

There are three models of disability in the literature and these categorise disability according to the beliefs that underpin each model (Sullivan, 1998: 9). Definitions that arise from viewing disability as loss, or lack of, due to impairment in the individual, are known as the individual or medical model of disability. The second model, the social model of disability, is viewed as a circumstance that arises out of interaction with the physical or social world an individual lives in. The third, the political model of disability, is based upon the oppressive and discriminatory effect social and political environments have on people distinguished by their abilities (Oliver and Barnes, 1998; Oliver and Sapey, 1999).

Each model of disability informs an understanding of disability. Although there are three models of disability, assessment for services is carried out based on the medical model. There is a Catch 22, a contradiction, built into the assessment and service-delivery processes when this is considered alongside the other two models. Simplistically, the individual or medical model promotes individual treatment and rehabilitation, the social model promotes adaptation to the environment and inclusion, and the political model promotes a view highlighting the experience of oppression and discrimination. There is a view that to 'treat and rehabilitate' promotes the beliefs that centre on loss, deficiency, and defect. Oliver and Sapey (1999: 23, 54) argue that this process serves to reinforce those beliefs and attitudes viewing impairment as the disability, rather than taking the view that disability arises from barriers and structural organisation in community.

However, when a child is first diagnosed, medical intervention is of paramount importance. When a child is experiencing pain, or when they are not meeting developmental milestones, parents are clear that rehabilitative services are essential and the debates focusing on social and political issues take second place (Mukherjee et al., 1999, Weaver, 1999). Munford and Nash (1994) argue that intervention must support families to see disability as an issue that goes outside personal boundaries to organisational structure and the way society is organised (Munford and Nash, 1994.: 24).

The individual / medical model of disability

The literature discussing individual models of disability assumes tragedy, loss, grief, 'a problem', an individual issue, medical definition, cure and/or rehabilitation (Oliver and Sapey, 1999: 13 — 19). The assumption in viewing disability from an individual model is that difference is 'abnormal'. The model assumes that an individual has to adjust and undergo rehabilitation, and to 'come to terms' with their impairment (Oliver and Sapey, 1999: 12). The model also reinforces the view of disability as 'personal tragedy and disaster' that is to be surmounted and overcome (Oliver and Sapey, 1999: 33).

This view of disability is criticised as being a view that promotes the interests of 'expert' professionals in what is known as the 'disability business' (Albert, cited in Oliver and Barnes, 1998: 14). The literature argues that power and control issues remain at the forefront of service delivery and definitions that underpin how services are delivered to individuals and to families serve professionals rather than those individuals who experience impairment (Munford and Nash, 1994: 267). The argument is that if intervention is to be successful, there must be a move away from the definitions that pathologise and continue to categorise individual impairment as disability.

Some literature distinguishes the 'personal tragedy' view of disability from the medical model of disability. A 'personal tragedy' view assumes that the parent of a disabled child will experience grief and mourning as a reaction to loss in their child. A parent may experience grief associated with their child's impairment but this is not universal.

Views in the literature encompassing 'defect' and 'negative impact on function' come from a model that assumes that those who have impairment in their body have experienced loss and have a 'problem'. Within this frame of reference disabled people are regarded as really able-bodied people imprisoned in imperfect bodies' (Shakespeare, 1998: 32).

Service provision for disabled children in New Zealand has been built around the medical model of disability. Services available are based primarily on a child's disability being a medical condition and not a structural product of the way the social and physical environments are organised (Munford and Nash, 1994: 267 – 268). Munford argues that interventions underpinned only by the medical model of disability and focusing solely on a remedial framework for rehabilitation, 'cure', and adjustment can only fail. Munford argues that it is important for families to be given access to information that allows them to understand disability is sited not in the individual. The argument is that success can only come from interventions where it is clear that the consequences of 'disability' arise out of structural organisation and ideological constructs, rather than personal characteristics.

The social model of disability

The social model, sometimes referred to as the 'barriers' model of disability, explores the way physical and social environments interact to form barriers for some groups of people. The model does not centre on the individual but moves the focus to the barriers they face in the physical and social world (Oliver, 1996).

The model is not aligned with illness and individual impairment, but with the social construction of disability that develops from the way social and physical environments are organised (Hales, 1996:3; Oliver and Barnes, 1998: 51 – 62). In this model, ‘disability’ can be understood by deconstructing the way the environment affects people who have impairment in bodily function (Oliver and Sapey, 1999: 21; Munford and Bennie, 2001: 158).

The social model of disability can be just as oppressive as the individual model if the experience of the individual is denied. For those children and adults who require assistance with personal care, or who require medical intervention to assist with pain control, treatment and rehabilitation, individual service is critical and as important as interventions aiming to impact upon organisation in the social world (Baldwin and Carlisle, 1994: 34; Weaver, 1999, Mukherjee et al., 1999).

The political model of disability

The political model views disability as a minority group experience arising out of discrimination and oppression, and emphasises citizenship and equality as a means to bring about change (Hahn, cited in Oliver and Barnes, 1998: 55 – 56). Oliver and Barnes (1998) argue that advocacy, self-help, affirmative action and activism are the means to change the status for the group of people distinguished by their abilities. They argue that without political activism the situation for those with impairment will not change.

The Union of Physically Impaired Against Segregation (hereafter referred to as UPIAS) has been seminal in reframing beliefs about disability to focus upon social and political constructions of disability. UPIAS redefined the meaning of disability as related to restriction, exclusion and disadvantage arising from the social world:

‘the disadvantage or restriction caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities’ (cited in Oliver and Barnes, 1998: 16 – 17).

These ideas have been partially absorbed into the definitions that are now in use when disability is discussed in the New Zealand literature. The definitions currently in use in New Zealand by service funders and service providers refer to exclusion, a right to participate and a right to services to promote inclusion (Health Funding Authority, 1999; Ministry of Health, 2001; Ministry of Education 2002).

The political model also highlights how the use of language affects disability experience. Terms and concepts have been deconstructed and meanings that hold notions of passivity, illness, loss and limitation are challenged and have been redefined (Oliver and Barnes, 1998). This is also reflected in the literature that underpins service delivery in New Zealand today where disability and impairment have been separated out in the definitions used to set out eligibility for services and support (Ministry of Health, 2001; Ministry of Education, 2002).

The political model adds to the debate around meanings of the term 'disabled'. The term has no universal meaning in the literature and a political view informs the debates that the term 'disability' serves to reinforce beliefs that individual impairment is a deviation from 'normal' and as such is an unacceptable term (Shakespeare, 1998: 22).

Language remains a site of oppression and struggle but there are arguments that place the use of the term 'disability' at the forefront of activism. The literature uses the term 'positive self naming' for language that promotes identity. Marks uses the term 'defiant self-naming' for the use of terms such as 'crips' to illustrate this point (Marks, 1999: 147). In the context of 'self-naming' language is used to challenge colonisation by non-disabled people. The term 'crip' is seen as a term that recognises each individual as someone not 'differently' abled, or 'dis'abled but an individual who is challenging those who use terms to label 'dis'ability as loss, impairment, or lack of (Marks, 1999: 137 – 152).

Defining disability in New Zealand

In 1980, the World Health Organisation (hereafter referred to as 'WHO') published *The International Classification of Impairment, Disability and Handicap*. This document included a section classified 'Handicap', where disability was defined as a

'Handicap, for "a disadvantage" ... resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age sex, and social and cultural factors) for the individual' (WHO, cited in Barnes et al., 2002: 175)

At the time, the WHO classification was considered a basis for the provision of services in the western world. Impairment was included and the definition was considered an important move from viewing disability as illness, disease or defect. The definition also recognised that disability did not arise from a personal disorder but from socially imposed restriction (Read, 2000: 92).

This view was criticised because 'ability' in this context was still a norm and the 'dis' remained a deviation from a norm (Oliver and Barnes, 1998: 14-16; Baldwin and Carlisle, 1994: 13).

New Zealand commentators argue, as do international analysts, that the structural constraints associated with disability create disadvantage and the conditions that lead to exclusion, thus limiting the ability to participate (Munford and Nash, 1994: 267). One such constraint is poverty that is seen as a major factor related to disability as it is directly associated a lack of access to resources such as housing, health care or education (Munford and Nash, 1994; Oliver, 1996: 21 – 22; 114 – 115). There is robust critique that the lack of access to the resources in society, such as education and employment, remains a key to unlocking disadvantage and promoting economic well-being (Oliver and Barnes, 1998; Oliver and Sapey, 1999; Read, 2000: 91).

The literature acknowledges that definitions used to allocate services and support to individuals and families are important as a means of initiating inclusive and participatory services and remain an important means of addressing disadvantage (National Health Committee, 1998; Oliver and Barnes, 1998; Seligman and Darling,

1998; Mukherjee et al., 1999; Oliver and Sapey, 1999; Ministry of Health, 2001; Rosenblum and Post, 2002).

In New Zealand, health and home-based support services are allocated through a process of 'assessing need' that is grounded in the diagnosis of impairment and loss. The critique is that assessment of need based upon a functional definition of disability does not focus on an individual's or a family's strengths (Munford and Sanders, 1999).

'A disability limits or impairs a person's activities and ability to participate. A disability is an impairment or loss or abnormality of psychological, physiological, or anatomical structure or function. A disability is defined as lasting for more than six months, and may be physical, sensory, intellectual, psychiatric or caused by an age related fragility' (Ministry of Health, 1999c: 1).

The definition of physical disability used by the Ministry of Health is also a functional one that focuses on the physical state of the individual.

'reduced physical capacity (for example through loss or impaired use of limbs)' (Ministry of Health, 1999c: 5).

These two definitions are qualifiers for support via state-funded service delivery. It is here that the contradiction between the models of disability can be seen. Health service literature acknowledges that disability is experienced when people with

impairments come up against social barriers in their day-to-day activities in their community, yet the qualifier for services remains a diagnosis based on loss of ability in bodily function.

‘Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments that people have. Our society is built in a way that assumes that we can all move quickly from one side of the road to the other; that we all see road signs, read directions, hear announcements, reach buttons, have the strength to open heavy doors and have stable moods and perceptions’ (Ministry of Health, 2001: 3).

This last definition of disability places disability directly in an arena where the disability is socially created by structures and processes in the daily world. However such a definition does not fully encompass the experience of parents of a disabled child.

New Zealand policy focuses on the importance of accessing services in a child’s early years and policy acknowledges that children who have impairment in bodily function face a pathway that is important for their future.

‘For children, it is hard to get the best start to their life ahead. Children’s needs put big demands, including financial pressure, on their families and whanau’ (Ministry of Health, 2001: 7).

The definition also recognises that a family faces some strain and pressure as it sets out to cope with the changes brought about by parenting a child who is disabled.

By 2000, policies were in place that entitle each family of a disabled child (where the child meets the Ministry of Health's definition of disability) to apply to have access to the services and support, as available in their community, to assist them in their parenting role (Ministry of Health, 1999a). The New Zealand Government has a stated commitment to services that aim to support children to live in a world where all barriers that make participation in every day life challenging or difficult are removed (Ministry for Disability Issues, 2001; Ministry of Health, 1999b), and where families in their role of carer for a child with special needs will be supported.

The definitions of disability used in health and education in New Zealand incorporate facets from all the models of disability. However, while beliefs held about disability have created an understanding that disability arises from social organisation and oppression, it is definitions used in the medical field, and based on individual assessment, that are used to assess and access services for any child and their caregiving parent.

Placing aside the differing models and definitions of disability, the literature points to each parent's understandings and experience of disability being centred around the day-to-day life of their child. Access to services is critical for any parent as they work to ensure that they are able to care for their child in their home, and their experience remains one that centres on their child and on their family (Weaver, 1999; Ministry of Youth Affairs, 2000; Bennett, 2002).

Conclusion

Disability has a history of family care that for a period in New Zealand's history was put aside when residential services were provided to rehabilitate disabled children. In the 1970s and 1980s activism drove a re-defining of meanings that had been given to disability and definitions now in use were developed. These definitions site the source of disability in the social world and not in an individual's lack of bodily function. Awareness of a child's need to live in their family group, and understandings that disability was a community issue, and not an individual deficit, influenced social policy and saw residential services for disabled children replaced with home-based services. By the 1990s disability was clearly defined as a social construction created and maintained by social, economic and personal belief systems. However, the medical definition of disability as impairment and loss remains a definition of importance for families as those who wish to access state assistance can only do so via a process of assessment that is rooted in the individual medical model of disability. As parents have become the first option as caregivers for their children over the past 30 years, services and assistance to support disabled children have developed. It is in this process of assessment for assistance from specialised services that parents are made to revisit definitions of disability that are rooted in personal impairment and loss, and it is also in this process that such definitions are reinforced.

Chapter Three

Parenting and family

Introduction

Bringing up a disabled child follows the same pathway as that of parenting any child, as the primary care tasks involved are 'the same for any child' (Read, 2000: 67). When a parent is called upon to parent a disabled high care needs child there are extra dimensions to the job that are specific to the 'disability experience' and the 'high care needs experience'. This part of a parental journey is usually one that a parent is not expecting and has not prepared for (Weaver, 1999; Read, 2000: 54).

As a disabled child grows, their parent becomes aware of differences that become part of the parenting experience. These differences create an environment that generates added dimensions to their parenting pathway. Differences and extra dimensions are determined by the personal, family and community responses parents and immediate family experience (Marshak et al., 1999; Weaver, 1999; Read, 2000). This chapter discusses the genderised role of parenting a disabled child, attachment bonds, the impact of having a disabled child in the family on a parent and on other family members, some of the costs of providing care, coping strategies that parents build, and support systems and interventions that are used to assist with parenting.

Caregiving is gendered parenting

Parenting is primarily carried out by women, who also carry the primary responsibility for parenting when there is a disabled child in the family (Beresford,

1995; Read, 2000: 51 — 52). Research in Britain suggests that 96% of caregivers for a disabled child are female (Beresford, 1995).

The situation in New Zealand is not likely to be very different but no research has been carried out that reports on the number or the gender of caregivers for children with high care needs in New Zealand. What is known about the New Zealand situation is that most caregivers are caring for elderly people and they are generally women (National Health Committee, 1998).

Parent and child bonds

Parenting is about hopes and aspirations for a child, about relationships and about responsibilities. A primary relationship for a parent of a new baby or very young child is the attachment relationship that they establish and develop with their child. The process of developing an attachment bond between a parent and their child arises out of the caregiving process between mother and child (Ainsworth, 1991: 39). It is a process that has a biological basis as well as a basis in a parent's own history (Ainsworth, 1991: 19). The need for a child to have stable and adequate care arrangements is cemented by the process of bonding that arise from responding to and caring for a child (Ainsworth, 1991: 43). There is a view in western cultures that conflict exists between the interests of the mother and the interests of the child in meeting child-rearing responsibilities (Trivers, cited in Hinde and Stevenson-Hinde, 1991: 58). This view highlights the argument that a balance must be achieved between the biological role of caregiving and nurturing that women have filled for centuries, and the place of women in a modern world where there are conflicting interests such as employment or other roles and responsibilities. When a mother is

called upon to compromise her own dreams and plans because she now finds herself parenting a child who has high care needs, there is a conflict between parenting and personal plans (Weaver, 1999; Read, 2000). Attachment becomes a bond that provides a link to focus a parent on their child's needs. What is also known is that the development of a bond with a child is a process that does not stop when a child has impairment even though some of the factors known to promote an attachment bond may be affected (Read, 2000).

Understandings of the role

Parenting is firstly underpinned by a parent's perception of what is required in a parenting role. Gruse (cited in Smetana, 1994) defines parenting in terms of the parenting cognitions that form the basis for the 'parenting style' a parent develops. Parental expectation of their role and their responsibilities arise out of the 'maps of guiding behaviour' a parent has developed (Smetana, 1994: 2). When a parent is told that their child will experience disability, they are faced with forming a new set of understandings of parenting, and new 'maps of guiding behaviour' to inform and guide their parenting. Understandings of parenting and expectations are important in that a mother's expectation of parenting, and her view of her situation after she is informed about her child's diagnosis, will be influential in how she moves on to parent her child in the future (Read, 2000: 115).

Parental expectations can also be viewed as multi-faceted and multi-dimensional experiences that fuse to form a base from which a parent will develop the expertise to raise their child. This base forms around how the family functions and rebalances to meet a child's needs. This will be overlaid with beliefs about disability; with family

and extended family responses; with concerns about the child's health and future; with the experience of interacting with professionals and the respective agencies they represent, and with the experience of interacting with neighbours and community (Baldwin and Carlisle, 1994: 30 — 32; Weaver, 1999: 80 — 107; Read, 2000: 115 — 121). It is in this combination of expectations and interactions that a parent develops understandings they will use to raise their child.

Impact on the caregiving parent

The birth of a disabled child has a direct impact on a caregiving parent. Disability is about new expectations, about emotional stress and grief, about disruption in family life, about new financial burdens and about experiencing community and agency response to 'disability' (Seligman and Darling, 1998; Weaver, 1999; Read, 2000). The implications for a caregiving parent carry across their personal life and their social relationships. A caregiving parent is likely to experience an impact on their marital relationships, on their relationship with their other children, as well as on their career plans. (Baldwin and Carlisle, 1994: 20 — 27; Munford and Nash, 1994: 267 — 271; Marshak et al , 1999; Weaver, 1999; Read, 2000)

The first step for any mother on a parenting pathway is the development of an attachment bond with her child. This first influence will define the caregiving system and the interactions that take place between a mother and child as the child grows (Ainsworth, 1991; Belsky and Nezworski, 1988; Kendler, 1996; Thompson, 2001). This view does not exclude the understanding that genetics is a major influence on a mother-child bond, but acknowledges that bonding is a complex process arising out of

the quality of mother-child interaction, as well as being a process that develops from genetically triggered responses (Kendler, 1996).

Parenting a child who has special needs has an added aspect when attachment is considered. A child who has a diagnosis of disability may display explicit characteristics that are known to impede the interactions that promote the development of a mother-child bond.

Individual characteristics in a child such as lack of responsiveness, difficulty in feeding, inability to maintain eye contact, or difficulty vocalising can make it more difficult for a parent to engage in the process of interaction and responsiveness out of which an attachment bond between a mother and her child grows (Marshak et al., 1999).

Separation of a child from a mother immediately after birth is also recognised as a risk to the development of a mother's bond with her child (Ainsworth, 1991). If there is separation between mother and child due to long periods of hospitalisation for a child because of health needs, there can be extra stress on the development of an attachment bond. These experiences are only the beginning of a parental journey through a maze of encounters that will shape and influence how a parent matures into the parental role.

Another common experience for caregiving parents is the hard physical work that has to be carried out in meeting a high care needs child's care responsibilities. Care tasks for high care needs children have constancy in the work that does not greatly change

over time, as tasks such as managing incontinence, washing of linen, needing to assist with dressing, and dealing with night-time disturbances continue well past babyhood. It is the constancy of the physical work that takes a toll on a caregiving parent (Baldwin and Carlisle, 1994: 20 – 21; Marshak et al., 1999: 10) and even if services are used, caregiving mothers see their responsibility to provide personal care as being well outside the tasks that would normally be expected of a parent (Read, 2000: 20 – 21, 50 – 52).

Alongside this hard and continuous physical work are added dimensions of the care role that are associated with the experience of disability.

Exclusion and isolation

One common barrier parents often experience as difference associated with disability is the exclusion, discrimination and isolation they see their child experience. The experience arises out of the day-by-day interactions with friends, school, and other systems in daily life where a parent becomes aware of their child being treated differently (Marshak et al., 1999: 83 – 85; Weaver, 1999). Being treated ‘differently’ comes from ‘outside’ the family, and the ‘differences’ as experienced by families may create a sense of marginalisation rather than building on the strengths within a family (Munford and Sanders, 1999). Research has shown that teachers view parents of disabled children more negatively than they do the parents of non-disabled children (Marshak et al., 1999: 85). This experience of isolation and exclusion is a common one for parents and it is an experience that parents do not easily resolve (Weaver, 1999; Read, 2000).

The experience of grief

The experience of grief is not universal but some parents report experiencing grief both after being given a diagnosis of a child's disability and at times throughout their child's life (Bruce et al., 1994: 49). When a parent experiences grief there is no simple explanation for the sense of emotional stress and the feeling of being overwhelmed that they may experience (Bruce et al., 1994: 37 — 38; Weaver, 1999: 16 — 46). It is the loss of a wished-for child, or a 'nondisabled' child which sets apart grief associated with child disability from grief associated with other losses such as death (Davis, 1987: 352).

There are two major models of grief in the literature around child disability and the parental or family experience of grief (Marshak et al., 1999: 39). In the first, grief is a sequential process of reaction to loss, followed by mourning, and reaching a point of resolution. The second model is a process of re-occurring sorrow that is revisited as a child grows and enters adulthood.

In the first model, grief is a natural part of the human journey and is the human reaction to any loss such as in death and dying. Loss is experienced as emotionally painful and is a sequential process of shock, denial, anger, sadness, detachment and reorganisation, which is followed by a process of adaptation or acceptance (Worden, 1982: 19 — 32; Davis, 1987; Weaver, 1999: 17). In the model as related to child disability, initial shock is followed by denial and a sense of disbelieving the diagnosis, followed by sadness, anger and anxiety, followed finally by adaptation to the situation (Marshak et al., 1999: 43 — 46). Resolution, adaptation, and adjustment are viewed as a goal that can be achieved after traversing the stages in the experience of grief.

This sequential process of parental grief as loss is one that is considered by many as being inadequate to provide understandings of the grief process associated with parenting a disabled child. The parent of a disabled child revisits their grief at stages in their child's life and this does not fit in with a sequential model of grief (Marshak et al., 1999: 77 – 85; Weaver, 1999: 17).

A second, more explanatory, model of grief is termed the 'chronic sorrow' model (Olshansky, 1962). Olshansky presented this model to describe the experience of the re-emergence of sorrow and subsequent mourning that may take place throughout a parent's lifespan as their child passes age appropriate developmental milestones and the loss associated with impairment is revisited. Steps along a developmental pathway such as entering school, the celebration of birthdays, entering adolescence, or reaching adulthood all remain reminders of the 'non-disabled child' and are an ever-present reminder of loss (Worden, 1982: 38).

Although a parent may experience grief as overwhelming at times (Weaver, 1999: 17) the experience is just that, an experience that is an aspect of childhood disability and an experience of difference. Experiencing grief is not a precursor to stress or an inability to cope when parenting a disabled child (Marshak et al., 1999: 84 – 85) but is the experience of loss and grieving.

Apart from the emotional impacts on a parent there are the practical impacts on family and personal life that are also experienced.

Family and community influences

Influences from within the family and from the community are important determinants of parenting. A social ecological model of the family as a system set within a number of other societal systems demonstrates that no one child and family can be treated as a discrete entity. Ideological and belief systems influence the systems that exist at political, economic, cultural, and religious level, which in turn influence all the subsystems in the community as they impact on a family. Bronfenbrenner's social ecological model of systems demonstrates how influences from the systems that surround a family are significant in how any one family copes. Bronfenbrenner ranked the micro, meso, exo and macro systems to describe the systems that, while being increasingly removed from a family unit, are systems that affect how an individual family unit functions. Bronfenbrenner's model of social ecological systems provides a framework for understanding that a matrix of influences impact on any one family in their parenting role (Seligman and Darling, 1989; Marshak et al., 1999: 9 – 10). Political influences, economic organisation, social policies, community programmes, community actions, and the beliefs and attitudes of family, extended family, friends, neighbours and agency personnel, all influence the development of a parent's understanding and the skill they developed to parent a child who has high care needs and a diagnosis of disability (Munford and Sanders, 1999: 82).

Partner relationship

The research in relation to marital adjustment and parental separation when a disabled child is born to a family is conflicting (Marshak et al., 1999: 53 – 56). Research reports that some parental relationships strengthen while others have an increased

likelihood that the relationship will breakdown when a disabled child is being raised (Beresford, 1995; Crnic et al., cited in Marshak et al., 1999: 55). The birth of a disabled child places relationships between partners under stress and a high degree of adjustment takes place between parents, but it is not known what factors contribute toward some parents reporting a strengthening of their relationship, while others report the opposite (Beresford, 1995; Marshak et al , 1999: 54 – 56, 271 – 271; Gavidia-Payne and Stoneman, 1997). It may well be that pre-existing stressors and conflicts in a relationship come to the surface and this causes a marriage to break down (Marshak et al., 1999: 65).

Beresford surveyed parents who were raising a disabled child with high care needs and she reported that in Great Britain there were a greater proportion of sole women parenting disabled children than parenting in the general population (Beresford, 1995). Disabled children are more likely to be parented by a sole parent, who is less likely to remarry, and who is also more likely to report that they experience stress in their role as parent (Marshak et al., 1999: 54 – 55; Baldwin and Carlisle, 1994: 27). The literature does not report a universal impact on families when a child with disability is born, and each family's situation is relative to their personal experience (Seligman, 1983: 214).

Siblings – consequences

Being a sibling in a family where there is a disabled child does not necessarily have negative consequences. Some research reports that behavioural and psychological problems may arise in a sibling's life and that parents report that they are concerned about the impact of a disabled child on siblings but the studies available are

contradictory (Baldwin and Carlisle, 1994: 38). Some studies report that siblings experience problems while others report siblings have positive experiences associated with a disabled sibling (Seligman and Darling, 1989).

Intervention with siblings who are experiencing behavioural or psychological problems may provide an environment that can help address these issues. Work in providing an environment where open and honest information is imparted, where a child's self-confidence can be enhanced, where their fears are allayed, and where coping skills can be developed are interventions that can support the growth of an environment that counterbalances the negative impact of having a disabled sibling (Seligman and Darling, 1989; Singer and Powers, 1993; Beckman, 1996; Ammerman and Campo, 1998).

Grandparents – a special role

Grandparents have largely been forgotten in the research that explores the impact on a family of raising a child with a disability (Seligman, 1991; Marshak et al., 1999). However, they do feature as important support people in the social support networks that surround a nuclear family. They are support people for a caregiving mother in that they provide advice and practical assistance with care that helps a mother cope with parenting her child (Marshak et al., 1999: 64 – 65; Weaver, 1999: 107).

In some cases, grandparents do not fully understand the implications of a baby's diagnosis of disability, and they can minimise the impact a disabled child's birth can have on a family. If there are already conflicts between grandparents and the parents of the disabled child, these may be exacerbated and further contribute to the

disruption a family may experience (Harris, cited in Marshak et al., 1999: 64 – 65). Some of the mothers Read (2000: 29) interviewed spoke about the importance of family support even if family were displaying a negative attitude toward the disabled child. Other mothers Read interviewed reported that grandparents were an invaluable support to them as parents.

Financial cost of care

Taking on the role of parenting a disabled child has a financial impact for both a caregiving parent and the immediate family. The experience of financial hardship and poverty is one that is common as families take on extra costs such as medical bill and extra heating and dietary needs associated with care of their child. Balancing the family budget can become a challenge (Marshak et al., 1999: 50, 260; Munford and Saunders, 1999: 28, 100; Read, 2000: 260).

British research indicates the cost the caregiving commitment impacts on the income of a caregiving parent, who is usually female. The research cites instances of reduced chances of developing a career and reduced family income as being related to taking up a caregiver role (Read, 2000: 50). The impact for the family of this loss of family income can result in families encountering socio-economic difficulties and evidence from both Britain and New Zealand suggests that this increases stress for caregiving parents (Beresford, cited in Baldwin and Carlisle, 1994: 30; Munford and Saunders, 1999: 101).

Personal coping strategies.

Each caregiving parent will have a range of ways that they (personally) use to cope with the extra work that they find themselves facing. The experience of isolation, stress, and hard work is reported by caregiving parents but determining the factors that actually makes a difference for a parent as they build their skill can be difficult to measure (Read, 2000). What is known is that parents consider the services available to them as critical in how they cope (Mukherjee et al., 1999). It is what actually makes a positive and long-lasting difference for a parent that is difficult to quantify as research in Britain reports parental experience and parental views but reveals no information about personal coping strategies (Mukherjee et al., 1999; Read, 2000).

Parents do not report that it is the lack of coping abilities that create stress for them, but that stress arises because they require assistance in their role as caregiver (Philp and Duckworth, cited in Baldwin and Carlisle, 1994: 29; Beresford, cited in Baldwin and Carlisle, 1994: 30).

Support systems

In the western world, a parent can expect support from specialist agencies and services to assist their child and to assist them as caregivers. These agencies can be an influence for a parent as they develop a working view of their role as parent of a disabled child (Bennett, 2002; Weaver, 1999). The services provided by agencies to assist parents with the care of their disabled child are important as they are seen by parents as influencing how well a family will function (Weaver, 1999; Mukherjee et al., 1999; Sloper et al., 1999; Read, 2000; Bennett, 2002: 41 – 45).

Agencies and services are, however, secondary to the support parents receive from family, friends and community (Read, 2000). Fathers, kinship relatives, non-family social networks, social policies, economic and political environments all form the mix that becomes the parenting support network of any child and parent. Belsky's model of parenting states that support networks are critical to becoming a successful parent (Belsky and Nezworski, 1988: 46 – 48). For the parents of a disabled child who has high care needs, support from family, friends, community, and from professionals and agencies can be critical as to how well a family operates and how well they cope with the work and stress of extra parenting (Cochran's model of Development of the Personal Support Network, in Luster and Okagaki, 1993: Munford and Sanders, 1999; 153; Bennett, 2002; 35 – 48).

Agency support remains important because family support on its own it is not always enough in a modern complex world (Munford and Sanders, 1999; Marshak et al., 1999; Read, 2000: 54) and in some families may not be an option (Bennett 2002: 30).

The experience that parents and family have of dedicated services is viewed as critical to making the parental journey a successful one. Parents consider emotional support, advocacy, information, advice, and services that address specific need as significant influences for them in their role as caregiving parents (Mukherjee et al., 1999: 24 – 37; Mitchell and Sloper, 2001: 237 – 252).

This does not mean that all parents receive adequate support from the state to parent their child, as some New Zealand parents report they have been ill informed about what support they were able to access when their child was younger (Weaver, 1999;

Bennett, 2002). There are parents in New Zealand who certainly consider that the services supporting disabled children and their families do not meet their child's or their family's needs (Ministry of Youth Affairs, 2000: Clauses 264; 555; 556). The fact that parents report experiencing inadequacy in their formal support systems must be viewed as a measure that parents have successfully taken on the role of advocate and service critic for their child. Such a role can be taken as a measure of success in parenting (Munford and Sanders, 1999).

Caregiving parents are at the crux of social policy that underwrites the support provided from outside the family to assist in the care for a child who has a disability. As Schwartz (1997) points out, there are no simple answers when considering how to meet the needs both of a child who has high levels of disability and high care needs, and of the rest of the family. Simplistic responses do not address the need of a child, as well as the needs of their caregiver or the rest of their family (Schwartz, 1997: 107 — 121; Munford and Sanders, 1999: 28, 81 — 84, 140 — 142).

Professional intervention

Contact with professionals can be an experience in 'difference' and 'otherness' that is not always positive (Munford and Nash, 1994: 268) and professionals need to keep a focus on the personal impact their contact has on families (Mukherjee et al., 1999: 28 — 29, Munford and Saunders, 1999: 147 — 176). Workers involved with families must keep a focus on the fact that a professional relationship takes time to develop and they must give a family the time that is necessary for this process.

Marshak et al. (1999: 11) report research where the coping strategies a parent builds are directly related to the social support and social attitudes they experience when a diagnosis of disability is given to their child. They report that this contact with professionals can build positive outcomes for parents as they learn about childhood disability.

Research carried out by Mukherjee et al. (1999) also reported that professional response is one factor that does make a difference for a parent. In this research, parents identified that the support experienced had very little to do with the 'field of disability' but that it was the personal response they received in their interaction with an individual that was important to them (Mukherjee et al., 1999: 28 – 29).

For parents of disabled children, the world of tiredness, hard physical work, financial constraints, grief, family reactions, balancing family needs and the experience of social stigma and isolation can create a sense of exclusion and difference (Marshak et al., 1999; Weaver, 1999).

It is around these issues that professional intervention can make a difference. By focusing on building personal and family strengths, where individuals and families are treated as partners in a professional relationship (that is developed over time, is open, honest, proactive and works across the multiple professional agencies), there is a potential to support parents and help them deal with those issues that cause hardship in their parenting role (Mukherjee et al., 1999: 58 – 60; Munford and Sanders, 1999: 142 – 147).

Conclusion

Parenting a disabled child is not unlike parenting any child. The beliefs and supports available to a parent come firstly from family and friends, and then from professionals in medical and service agencies.

It is only as a parent takes up their caregiver parent role that they become aware of the extra challenges they will face to ensure their child has the quality of life and access to all entitlements that all children have as of right. In undertaking this specialist role, parents have available to them a range of services across health, education and welfare to support their child and also to support them as caregiver. How this support impacts on a parent sometimes depends on how professional support is experienced.

Chapter Four

Policy, services and gaps

Introduction

Parenting a special needs child in New Zealand today brings a parent to the forefront of disability social policy as they take on the extra work involved with caring for a high care needs child. Parents take up roles such as medical expert, advocate and service planner in the complex world of medical services, educational services, recreational activities and social interaction that is the world supporting children who have disability and high care needs.

A parent is drawn into this world by the special connectedness that places every parent in a situation where they experience their child's world. This connectedness, the attachment bond, is the environment that is supported and sustained by the services made available to a family as they parent their high care needs child (Scwhartz, 1997). It is this connectedness that places any parent who cares for a disabled child directly at the interface of the experience of having to advocate for, and manage, service provision as they ensure their child's needs are met. In this chapter, I discuss service delivery and parental experience and I draw a connection between services and a child's connection with their parent with a view to highlighting the strengths that a parent has the option to develop.

Service delivery and social policy

Parents of high care needs children report that caregiving is tiring, isolating and a long-term undertaking, and they identify services as essential if their job as specialist caregiver is to be a workable one (Seligman and Darling, 1989, 88 – 89; Mukherjee et al., 1999). Parents also report that the services and support available to them are critical, not only in enabling them to meet the needs of their child, but also in assisting them to meet the needs of other family members (Seligman and Darling, 1989; Mukherjee et al., 1999).

In New Zealand, services for children who experience disability are delivered across the health, education and welfare sectors. By the end of the 1990s a point was reached where policies were in place entitling each family of a disabled child (where the child meets the Ministry of Health's definition of disability) to apply to have access to services and support that would assist them in their parenting role (Ministry of Health, 1999c). The New Zealand Government has stated a commitment to providing services that aim to support disabled children to live in a world where all barriers that make participation in everyday life challenging or difficult are removed (Ministry of Health, 1999b; Ministry for Disability Issues, 2001), and where families in their role as carer for a child with special needs are supported (Ministry of Health, 2001: 19).

While there are services available to support disabled children and their parents there can be problems for individual parents accessing services for their child.

In the health sector, services to support caregiving parents and their children are not set aside within dedicated budgets but are funded from the general pool that funds all disability health services (Carpinter, 1995: 10). For some parents this can mean they find themselves having to advocate for access to services for their child (Weaver, 1999).

In the educational sector, services are not guaranteed to individual children, as budgets are limited. Access to services is dependent on each school having available to it the funding to provide the services an individual child may require if they are to attend school. Ballard (1996) has long argued that in New Zealand children who experience disability often do not receive the full recognition that that a fully inclusive society would deliver. He argues that many children experience exclusion because schools are not funded to provide the specialists services an individual child may require. Weaver (1999) also reports that parents of high care needs children often have to advocate for support services so their child may attend school.

In the income support sector, parents are entitled to claim support in the form of an allowance from Work and Income New Zealand (hereafter referred to as 'WINZ') if their child has a diagnosis of disability. The allowance, the Handicapped Child Allowance (hereafter referred to as the 'HCA'), while recognising that there are extra financial costs associated with child disability, does not go anywhere near to meeting the extra expenses associated with providing for a high care needs child (Weaver, 1999; Ministry of Youth Affairs, 2000: Clause 556).

In New Zealand there is no consistency in much of the service delivery to children who experience disability and their families. Services, apart from the HCA, are not available universally across New Zealand and families experience a lack of consistency in measures to qualify for support that can leave parents feeling confused and unsure of their child's entitlements (Carpinter, 1995: 10; Health Funding Authority, 1999; McDonald et al., 2001).

Parental experience in support sectors

Specialist services for children and their families where the child has a diagnosed impairment in mobility are provided by individual District Health Boards or other groups under contract to the Ministry of Health (Health Funding Authority, 1999). Support services funded from disability support funds within the health budget are predominantly community based and in many districts are provided by non-government organisations (hereafter referred to as 'NGOs') and it is recognised that NGO's provide 'extensive care' that is not fully publicly funded (Ministry of Health, 1999c: 4).

One funded health service available directly to caregiving parents is the respite care support system (Carpinter, 1995; National Health Committee, 1998; McDonald et al., 2001). Access to this service occurs via the 'Needs Assessment' and 'Service Coordination' services set up in each Health Board District (Health Funding Authority, 1999: 13). Services such as respite care are aimed at providing a full-time caregiver 'time out' from their care role (National Health Committee, 1998: 25). Other services such as home modifications and technical equipment, are also available via the needs assessment process. A Needs Assessor will, if a parent and child meet the criteria and

are willing for a referral to be made, refer the family for specialist assessment by professionals. These professionals work with a parent to support them with home modifications and equipment that will assist their child in coping with the barriers in their physical environments (ibid.).

Educational needs are met from Ministry of Education funds but if a child requires specialist support to attend school, Group Special Education will assess the child's need and provide access to any specialist equipment or school modifications that are required (Carpinter, 1995). In New Zealand there is no one piece of overriding legislation that grants a disabled child a guaranteed right of access to education. Ballard (1996) argues that the 'right' ensuring access to education for children and young people who experience disability is an empty right as disabled children continue to be excluded from school. Families continue to be told that their child cannot be catered for in a school (Ballard, 1996: 27) and then the child is excluded. The Education Act 1989 in Section 8 stipulates that every disabled child should receive an education equal to the education all children receive. However, unless a school can access adequate services to support a disabled child's enrolment, it can refuse admission using criteria set out in this Act stating that it cannot reasonably meet the child's needs.

Some parents in New Zealand report they do not meet the criteria to be financially supported from disability benefit measures available from WINZ and that this can cause financial hardship related to extra financial costs associated with meeting a child's needs (Ministry of Youth Affairs, 2000: Clause 556).

Family policy

There is no coherent set of social policies to support 'family' as such in New Zealand; instead each sector develops social policy within set boundaries designed to support family units that contain children (Kamerma and Kahn, 1997). The policies that aim to support families are targeted measures that have no sense of uniformity across the health, education, welfare or economic sectors. Both within these sectors and across them, different measures are used to deliver targeted support (Kamerma and Kahn, 1997: 300 – 301). This lack of coherence across differing policy criteria for the support and assistance of families is reflected in the support available to parents of disabled children.

This lack of cohesion continues to be experienced by families because there is no mechanism or means within policy environments for bringing together the support available in health services, with support available in education, welfare and income transfer services. For parents, accessing services becomes an exercise in fractured service delivery, where entitlements are difficult to understand (Weaver, 1999; Ministry of Youth Affairs, 2000) and the complexity of services used can become difficult for a parent to manage unless they are quite clear about their entitlements and their requirements (Weaver, 1999).

There is, however, one initiative that provides a balance to this inconsistency across the sectors and this is the Disability Strategy (Ministry of Health, 2001). The Disability Strategy provides an overarching influence calling on all other policies to work toward an inclusive world for those who experience disability (Ministry of Health, 2001). As facilitator for change, the Disability Strategy can be viewed as

advocating policy implementation in a way that is based on a view of 'needs' rather than 'rights' as services are still only available to individuals if they are available in their community (Ministry of Health, 1999c). Sullivan (1998) argues that until there is a requirement to mandate individual access to services as opposed to allocating services according to 'assessed need' and resource availability, no policy will ensure individuals are able to lead fully inclusive lives.

Because of the lack of coherence of policy in the health, education and welfare sectors it comes as no surprise that the New Zealand literature contains examples of parents reporting that they experience the systems that support them and their disabled child as confusing and disjointed (Weaver, 1999; Ministry of Youth Affairs, 2000). One example is the financial support made available to families by WINZ. Families are able to make application for a means-tested disability allowance to cover extra costs associated with disability needs. The qualifying income for this support is set at a level where some parents report financial hardship as they are judged to be in the 'middle income' category and thus do not qualify for this financial support (Ministry of Youth Affairs, 2000: Clause 555). Parents also report a lack of co-operation between the health and education sectors where they experience both agencies being avoidant in providing support such as funding for a wheelchair to assist an individual child attend school (Ministry of Youth Affairs, 2000: Clause 556: 97).

Parents report that fractured service delivery and the lack of rationality in eligibility across the health, educational and welfare sectors also lead to feelings of anger, anxiety and hopelessness (Weaver, 1999). The literature confirms that the experience of dealing with fractured and complex assistance and support is an experience that is

consistent across the western world (Marshak et al., 1999; Mukherjee et al., 1999; Read, 2000) and not solely the experience of New Zealand parents.

While many parents report that depending on income support services, health services, educational services, and ACC services is a 'daily challenge' (Weaver, 1999: 129) not all parents report negative experience as carers of disabled high care needs children. Bennett (2002) interviewed mothers of disabled children and some of the mothers she interviewed believe that they have had improved access to professionals and agencies over the past few years, although some attribute this to their increased assertiveness and not to an improvement in access to services (Bennett, 2002: 41, 48).

The Disability Strategy remains, however, a means to address situations such a lack of cohesion in the support parents receive to care for their high care needs child. The aim of the Disability Strategy is to create a community where those who are disabled can 'reach their potential and 'participate fully' (Ministry of Health, 2000: v; Minister for Disability Issues, 2001: 5). Services funded or partly funded by the government must meet guidelines in line with this aim (Health Funding Authority, 1999). An overarching strategy is to be commended but it cannot be considered successful until the issues that Sullivan (1998) raises have been addressed.

There is also a range of other government commitments and statutory measures that impact on social policy and service delivery for children as a group and the individual child and their family. These are now briefly overviewed.

Children's rights

In 1993 the New Zealand Government signed the United Nations Convention on the Rights of the Child. The Convention dictates that any Government who is a signatory to the Convention must aim to ensure that every disabled child

‘should enjoy a full and decent life, in conditions which ensure dignity, promote self reliance and facilitate the child's active participation in the community’
(Ministry of Youth Affairs, 2000: UNCROC: article 23).

The Convention promotes rights and therefore is not a document that guarantees services and support to each New Zealand child, instead Article 23 can be viewed as a template against which all policies related to disabled children can be measured.

The 1993 Human Rights Act is legislation that sets out rights. The Act required that the Human Rights Commissioner examine all legislation and policies for the purpose of reporting to Government any conflicts between all other legislation and the Human Rights Act (Ministry of Youth Affairs, 2000: 10 – 11). This document, *Consistency 2000* (Human Rights Commission, 1998), is part of the Government's commitment to ensure that all children are given access to services they require to experience inclusion within their community.

The Human Rights Commissioner also has a role to hear complaints and follow up any issue where parents feel their child has been discriminated against. Thus when a parent considers that their child has been excluded from full participation in education, the Human Rights Commission can investigate, but cannot act to ensure

that a school is required to enrol a child. The only course of action open to a parent, if they consider that their child has been unfairly excluded from school, is to seek redress by taking court action requesting a judicial review of their child's entitlement under the Education Act. If a school argues that it is unable to enrol a child because of 'special services or facilities that in the circumstances cannot reasonably be made available' (Human Rights Act: Section 3: 6) then the school can claim an exemption pursuant to Section 60 of the Human Rights Act and is therefore not obliged to enrol the child. The situation is similar for every service provider in New Zealand and the Human Rights Commission cannot act to impose a child's right to inclusion in any one programme if the service provider can argue that it cannot reasonably provide a programme for an individual child (Human Rights Commission, 1996: 2 – 3).

The Health and Disability Commissioner Act 1994 allows a health consumer to ask the Health and Disability Commissioner for an investigation if they consider that they have not received adequate service from a health provider. This Act is one that allows health consumers to ask for a review of health services that they have used. It is not an Act that grants a right to access to services.

The New Zealand Bill of Rights 1990 gives a legislative commitment to each individual that they have a right to live in freedom from discrimination. This Act, like as all other Acts, a statute that is a balance of rights rather than a law that grants a child an absolute right.

Ideals that promote inclusion and full access to community are important when providing quality child-focused services for children who are diagnosed as disabled.

However, while policies and services that underpin the delivery of services for each child may promote inclusion and participation, the actual delivery of a fully inclusive world to every child will be achieved only if each individual agency or service is able to access the funds and expertise required to meet an individual child's needs (Sullivan, 1998). This environment is further complicated for parents since in New Zealand, the provision of welfare and social services has been constantly reviewed and changed over the past decade (Sullivan, 1998) and keeping up with what resources are available can be difficult for any parent (Munford and Nash, 1994: 273).

Some New Zealand parents report dissatisfaction with the services that are available to them and their disabled child. They report that services remain inadequate and do not fully meet their needs (Ministry of Youth Affairs, 2000; Munford and Sanders, 2003: 75 – 76). This view also exists in other western countries (Mitchell and Sloper, 2001, 237 – 252; Munford and Sanders, 2003: 75 – 76). While Read (2000: 105) in her research reported that services have improved greatly over the past few years, there still remains a point of friction for many parents as the report to the UNCROC indicates (Ministry of Youth Affairs, 2000).

Support services and high care needs

The exact number of high care needs child is unknown. What is known is that only a very small percentage of New Zealand children who receive services for a physical impairment have high care needs (Carpinter, 1995). However, this does not mean that a child enters a system of support and services where parents want a focus on their child's 'disability'. Information from parents of children with high care needs suggests the focus must remain on the needs of the individual child and their

experience (Ministry of Education, 2002: 4). This view, also outlined in Llewellyn et al., is that the focus for children who experience disability and their caregiver families must remain centred around the services and support required, to enable day-to-day life to proceed as smoothly as possible (Llewellyn et al., 1996: 4 – 5).

Needs assessment, service co-ordination

In New Zealand a child's eligibility for personal care-related support and other services is based on an individual assessment of entitlement. The assessment process aims to identify and prioritise need. The Ministry of Health contracts agencies to carry out needs assessments in specific geographical areas of New Zealand under national standards for assessment and eligibility using a Ministry of Health disability support framework (Ministry of Health, 1999a). Ministry guidelines aim to 'Facilitate the development of the health and disability sector to maximise the potential of people with disabilities and the health of New Zealand people – 'Healthy New Zealanders' (Ministry of Health, 1999c: 28).

Service co-ordination follows this assessment process. Service co-ordination aims to identify the services and support options to meet individual need from the services available in their district (Ministry of Health, 1999a: 6-7, 14). Service planning and the provision of services such as respite care, daily personal care, equipment and home modifications are the face of social policy that individual parents experience.

It is within these processes that the negative environments so soundly critiqued by Oliver (1996: 4) can be seen. Oliver argues that the needs assessment process is one that works to entrench the 'loss' and 'deficit' view of disability and is a process where

the view that medical professionals 'own' and 'control' disability can be seen. Oliver is firmly of the view that assessment focusing on loss, deficit, or lack of, only serve to perpetuate beliefs about disability that do not progress changes in how those who experience disability are supported.

There is a view that assessment and services can only be considered successful when they focus on building a person's control over their environment by enabling a disabled person to gain and maintain control over their life (Hales, 1996: 8 – 11).

In summary, the assessment and service co-ordination processes are often experienced by parents as difficult to deal with, and irrelevant to the actual day-to-day life of the disabled child and their family (Hales, 1996: 6 – 7; Ministry of Youth Affairs, 2000: Clause 556). Sullivan (1998) argues that workers in these services can provide balance if they are clear about their role in the process. The argument is that the professionals who are part of a process that rations services according to qualifying boundaries and available resources must acknowledge when services are oppressive rather than empowering. Thus the needs assessment and the service co-ordination processes have within them the potential to unlock and build personal and family strengths if they are structured to do so.

The parental experience of targeted family and disability policies in the health, education and welfare sectors is reflected in the confusion parents experience as they access multiple services to meet an individual child's needs. As well as experiencing complexity in services and support, parents can also experience exclusion. While policies and legislation promote inclusion, the ideal remains elusive for some

individuals as access to services is not guaranteed as an unqualified right (Sullivan, 1998; Bennett, 2002: 51).

Rights to services

If the principles outlined in Article 23 of the UNCROC are to be met in future years, each disabled child would need to have access local to quality programmes in which any special needs they may have are specifically catered for. Currently parents report having to continually lobby for services for their child (Weaver, 1999). If the situation is to change there will need to be a refocusing of the processes that assess need and deliver service so the process is experienced as equitable. Ballard (1996) makes this clear when he states that children who do not experience disability go to school expecting to see books, desks and other educational equipment, and he asks why the parents of disabled children should have to argue for their child's right of access to educational services when it is every child's right to have an education made available to them (Ballard, 1996: 28).

Professional support

Professional support comes in many forms for families raising a child with disability. These range from medical services available from specialist services within hospitals and community health services, through educational services, to a myriad of home-based services provided by a range of Government organisations and NGOs (Weaver, 1999). Professional support is important for parents, especially in the early stages of a child's life (Bray and Mirfin-Veitch, cited in Munford and Sanders, 2003: 74) but it is often a complex and difficult job for a parent to keep up with the services available to them in their community (Weaver, 1999).

There exists a model for intervention in families raising a disabled child that provides a link between services and a family raising a high care needs disabled child. The model, termed the 'key worker' model (Mukherjee et al., 1999), is a model based upon the understanding that in families raising a disabled child, the family is involved with a complex range of services. In this mix, there is often a professional who takes on the role of key worker, and who assists the family to draw together the threads of services and agency support they must access to raise their child (Mukherjee et al., 1999: 7 – 8). An evaluation of the model by Mukherjee et al. found that having a key worker in place was a unique opportunity to support a family as they took up the care of a disabled child. The role is one where a named person becomes a 'key worker'. A key worker takes on the responsibility to work across services and agencies and they also become the professional a parent can approach about any matter at all (Mukherjee et al., 1999: 26-33). The model assumes long-term contact. The model also sees the key worker taking a range of roles such as initiating contact with a family, providing information about aspects of entitlements and services, acting as an adviser, advocate, and confidant. The role supports a family by ensuring that services delivered to the family are co-ordinated and that all professionals who have a role to play are involved. (Mukherjee et al., 1999: 6 – 7).

The caregiver role

While there is recognition that unpaid care provided by family members is based on reciprocity (National Health Committee, 1998: 9), there is also recognition that the work carries with it an indirect cost of lost opportunities such as lost income due to inability to work, constraints on career development, and personal stress (National Health Committee, 1998: 14 – 15).

Caregivers report that they require practical support for their work as caregiving parent and a major request is assistance in the form of someone to fill in as a carer when they take time out from the role (Weaver, 1999: 94 – 95). Belgrave and Brown (cited in National Health Committee, 1998: 18) found that caregivers also wanted recognition for their work as well as support people to share their experience with.

Caregivers

Caregivers are the people who provide support for adults and children who require extra help with care tasks. It is those caregivers who take on unpaid caregiving as they care for friends and family members who are most effected by policies that do not provide financial recompense for family work (National Health Committee, 1998: 9). While all parenting is a task that is on the whole unpaid, parenting a high care needs child takes on the additional aspect of specialist caregiving that can lead to isolation and hardship (Weaver, 1999; Read, 2000). Weaver (1999: 85 – 90) advises parents to take active steps to put in place support systems to build coping strategies for themselves.

The care role that parents take on when their child requires extra support is one that is viewed by the Government who provide support services as a private family role. The notion of 'private family' as the means to meet all the care needs of the members within family is one that has arisen from a market-based economy (Munford and Sanders, 1999: 83 – 84). The argument is that the idea is promoted as a means of separating out family responsibilities from state responsibilities. Every family in a western society is supported by services in the infrastructure such as public transport, schooling and health services but family support, including support to those who experience disability, has become a private matter where individuals have to qualify for state support (Munford and Sanders, 1999).

Conclusion

Support to disabled children and their families in New Zealand is provided across a range of services in the health, educational and welfare sectors. There is, however, really only one universal support that all disabled children have a guaranteed entitlement to in New Zealand, and this is the Handicapped Child Allowance. All other support services are only available via the needs assessment process. Even then services are only available if there are agencies delivering the service in the community a family resides in. New Zealand has in place a raft of disability policies that promote the ethic of inclusion for a disabled child, and support for their caregiver. This does not provide a guaranteed right to a service or specific support for any disabled child and their family. Parents of a disabled high care needs child find that they take on the role of caregiving parent for their child so that their child's needs are met. In doing so, they often experience fractured service delivery that adds to the stress of their parenting role.

There is a model of support for families raising a disabled child, the key worker model. The model has been evaluated as one that has the potential to provide families with a professional approach that will build their strengths in their role as parents to a child with high care needs and disability.

Providing support to families raising a disabled child remains a challenge for those who put together social policy and for those agencies that provide child disability services in the community. Parental experience in New Zealand mirrors parental experience across the western world, where parents report that they require personal support in their caregiving role; that they experience gaps in service delivery to their child; and that they experience difficulty coping with the complexity of services they must deal with as they parent their child. Why some parents cope in their role, while others do not, remains a question that is not clearly answered. It is not easy to establish exactly what it is that enables one parent to cope while another fails.

Chapter Five

Theoretical lens

Introduction

This research involved interviews with parents who had a minimum of six years experience raising a child who had impairment in physical function as well as high care needs. The data from the interviews were explored to analyse the parental experience related to their child's needs, services accessed and support used. Systems theory, feminist theory and attachment theory provide the basis for distinguishing links and themes related to the parenting experience of raising a child who has high care needs and the services and support that have impacted upon parental strengths.

Taking a systems view brings to the research an understanding of parenting and caregiving as they take place within the family system, a system sitting within a myriad of systems that surround a family in their daily life. This view places the work of parenting at the centre of the ideological, political, community and family systems that exist for New Zealand European parents in New Zealand today.

Feminist theory situates the genderised work of parenting and caregiving in the post-modern western world. The economic worth of the role a parent takes on, the balance between a child's needs, family needs and personal needs, and the multiple roles associated with parenting are seen from a feminist view. When viewed through a feminist theoretical lens, the reality that is parenting in the western world is revealed.

Attachment theory gives access to understandings that take account of the intrapsychic dynamics that make up the parenting process. Attachment theory places the intrapsychic attachment bonding process right at the core of parenting. Attachment bonds situate the child-parent dyad and the child's family right at the baseline of a mix of complex systems that come into play when a concern that a child may have impairment is first raised. Attachment theory focuses the experience when parents find themselves in the medicalised world of specialists, assessments, specialist interventions and home-based support programmes that make up the systems that interact to support a disabled child and their family.

Attachment theory sits alongside feminist theory and highlights the contrasts that arise in the debate around genderised roles, economic supports for 'family work', and the need for a parent to make decisions that balance a child's requirements and needs against the costs for self and others in a family.

Systems theory

Systems theory underpins an understanding of how families operate and develop as systems within an ecological environment made up of systems of influence. The theory provides a basis for understanding how a family will function as they raise a child. The theory places a child with high care needs at the centre of a system of family, community services, social policy, political and ideological beliefs. Systems theory provides the basis for understanding that interaction between a child and their parent does not take place in isolation, but within the core of a system of environments that surround and support each child and their family.

Bronfenbrenner's (1996) theory of systems provides an understanding that each child and their family are a system, situated within set of subsystems and systems, which impact not only upon each individual in the family, but upon the family system as an entity (Luster and Okagaki, 1993; Smetana, 1994). In a social ecological model of systems as outlined by Bronfenbrenner, the microsystem, mesosystem, exosystem and macrosystem form increasingly stepped away systems which are the environments that support a family. Child and parent rest at the core of the microsystem, which in turn rests within a system of increasingly removed environments that influence and define the experience of caregiver parenting (Marshak et al., 1999: 10). Influences from the macrosystem are ideologies and belief systems; influences from the exosystem are political and economic systems; influences from the mesosystem are educational, health, and welfare initiatives and services; and influences from the microsystems are from school, neighbours, grandparents, siblings, parent's partners and others that form parts of a child's immediate life.

A major influence for a parent of a child who requires extra care will be the support and services they use to assist them to parent. Viewing the changing context of family care and community support over the past twenty years from a systems perspective, highlights the importance of the political and economic ideologies, which have been a major influence in the development of the services currently available to parents raising a child who has a disability and extra care needs. Services a parent accesses to assist their child also reverberate across the family system. The support influences relationships between the child, their parent and immediate family and between extended family, neighbours and social and community networks. The systems of inter-relationships and interdependency between child, parent, family,

neighbours, friends, community networks and services make up the infrastructures that are the day-to-day world of each caregiving parent (Blacher, 1984: 411 – 414).

This system of interrelatedness supports and structures the development of parental competence. Systems theory does not make direct causal links between the birth of a disabled child and family function. The theory cannot draw out variables that predict the quality of a parent-child relationship, or the development of the life cycle of a child or a family. Instead systems theory makes it possible to define and explore relationships between variables while understanding that there is a complex network of support impacting on caregiving and parenting (Blacher, 1984: 411 – 414). The theory links how services and support such as family help, respite care, technological support and child health services, all balance and interact to make up the structures that assist a child and their family. This is a key understanding when analysing data to explore the development of parental competency for a child who has extraordinary care needs.

Systems theory also allows a view to be taken that acknowledges the effect a high care needs child has on a family group (Munford and Sanders, 1999: 99). The theory provides a means of drawing links between other family members and the impact of the birth of a high care needs child upon these family members. The impact on other children in the family, on partners of caregiving parents, and on grandparents, is linked and drawn together using a systems model of family life and family development. Not only do the systems in place support each child, their parent and their family, but they also create an environment where balance and counter-balance is a constant process (Blacher, 1984). There is a balance of costs and benefits to each

and every member in a family, to families as a whole, and to communities. Systems theory allows the links between parenting tasks that are extraordinary to be weighed up in terms of benefits and costs without taking a prescriptive view that would see one pathway as the only one for all families.

Systems theory also allows a wider view that considers families as subsystems set within the larger subsystems of community, social policy, political initiatives and beliefs about disability. Systems theory provides a basis for drawing conclusions that bring together the connections between influences that support extraordinary parenting and the support available to parents.

Individually, parents do not always experience the support services they access as interlocking and working in unison. There is considerable reporting by parents of conflict and disharmony in the service provision available to them (Marshak et al., 1999: 197; Munford and Sanders, 1999:197; Ministry of Youth Affairs, 2000: 46, 97). Systems theory allows the contradictions that surface when parents report their experience to be analysed and commented upon. As a parent interacts within the subsystems that interlock, overlap, or at times work against each other, there will be a rebalancing or realignment of family relationships, family responsibilities and family beliefs. Systems theory allows for analysis that reflects on the impact and links between caring for a high care needs child and the influences from the support and services available, even though there is no positivist deterministic relationship between the two (Blacher, 1984).

Feminist theory

In this research feminist theory is the theoretical framework used to establish and discuss the difference between the public and the private worlds of the family. Caregiving is a role that many women report as one that has given them fulfilment even when there is a cost for the 'thousands of hours of hard work, love and devotion that has been energetically and willingly poured into sustaining the activities of loved ones' (Dominelli, 2002: 22). The reality of private unpaid labour in a world that values paid employment means caring for others is often 'invisible' as the caregiving exchange takes place in the private world of family. A feminist view allows the unpaid work associated with being a caregiving parent to a high care needs child to be viewed critically as a process where the rewards are based in the role, the situation, and in the connectedness that comes from the relationships, not from seeing the role as a pathological one where the work is devalued (Dominelli, 2002: 37), and where caring for a 'disabled' child was a 'tragedy' and a 'problem' (Bray and Mirfin-Veitch, cited in Munford and Sanders, 2003:74).

Feminist theory allows for a post-modern view of parenting and meeting the needs of a child in a world where relationships between the sexes characterise caregiving, parenting and involvement with systems that support parenting a child who has special needs. Fook (2002) argues that a post-structural view allows for wider understandings and gives credibility to the view that there is a multitude of influences in a modern world where no one philosophy will provide a full and total explanation for any event or observable fact. The parental experience of raising a child, and developing specialist skills and knowledge as they parent, fits a methodology where there is no one prescriptive explanation for the experiences individuals recall.

Feminist theory sits alongside systems theory as a basis for consideration of the information given by parents in relation to caregiver parenting. The role of caregiver is a role that women take on across the western world (Marshak et al., 1999; Mukherjee et al., 1999). In New Zealand, the situation is no different as it is women who play a pivotal role in providing care for members of their family (National Health Committee, 1998).

The method used to collect data, a qualitative method, is a one that is well recognised as a reliable means of collecting data from the genderised realms of the private world of 'family' (Oakley, 2000: 295). Oakley argues that 'neither methods, or methodology can be understood except in the context of social relations' (2000: 4). For a caregiving parent, the social situation is defined by the genderised nature of the role (Weaver, 1999; Mukherjee et al., 1999) that they as a parent cannot walk away from.

In the western world and in New Zealand disability service provision has gone through an era of privatisation and restructuring that has seen the words 'reform' and 'choice' become synonymous with change in service delivery, multi-agency support, and difficulty in accessing services (Sullivan, 1998).

Early feminist theorists redrew and clarified the experience of women as subjugated and marginalised in a male-dominated world (Dominelli, 2002:19). However, parenting is a partnership between parents and across family, and not a role that women who are parents report as secondary or unimportant (Dominelli, 2002: 22). Feminist theory places arguments relating to genderised care and parenting roles in

the open. Care is women's work in New Zealand and women who take up this role often do so at the expense of paid employment (National Health Committee, 1998: 9). A feminist lens reveals the nature of the work, the 'being there' twenty-four hours a day, seven days a week, and the reciprocity of family work that leaves women taking on this work without question because it is their child.

Taking a feminist view does, however, situate caregiving and parenting in the margins of the dominant world defined by gender. Qualitative research methods are methods that can allow information from private and female worlds to be revealed (Oakley, 2000: 3 – 4). I chose to use a qualitative method because I wanted to access data from this private world of genderised relationships where family life was defined in parenting and caregiving. If in any individual family parenting work is actually undertaken by a child's father, or any other family member, it is still a role that is recognised as one that sits outside the dominant world (Read, 2000). This world is not part of the public world of paid work and public economic exchange, but a world based in the private world of 'home', unpaid care and service to family (National Health Committee, 1998: 9).

Explanations of caregiving parenting, taking a feminist view, situate the experience where meaning is related to the social and historical context of the time and context of the lives of those who are relating their experience. The 'language (and therefore the meaning) must be interpreted in relation to specific contexts (social, historical, political). Discourses are therefore situated (socially, historically and politically)' (Fook, 2002: 12). Fook's argument is that taking a feminist view provides a basis for explaining the links between the experience of individuals and social structures (Fook,

2002: 12; 56-69) that relate to the lives of caregiving parents. The role of parenting a high care needs child is subject to the situation where caregivers find that they can be heavily dependent on family, friends, social agencies and community services for support. Analysing the reality that is this experience of parenting a high care needs child, in the light of support systems; of beliefs about disability; and of beliefs about caregiving, is a means of drawing the links between the private experience of a parent and the support networks that a parent or family has developed.

Other aspects of feminist theory are the issues of power, knowledge creation, purpose, and use of the information. Oakley links feminist techniques of research with the process of thinking about power imbalances, about who defines what knowledge is, and about the need to remember who the knowledge will serve. Research that will make the world a better place and where there is a benefit for those who are in situations of disadvantage or oppression are challenges that Oakley puts forward for all researchers to consider. I hope that in carrying out this research I have achieved some measure of the ethics that, Oakley argues, underpin feminist research.

Another theme significant in feminist theory is the notion of reciprocity (Dominelli, 2002: 37 – 39). Taking a feminist view adds a responsibility to ensure there is clear and transparent process about who the data belong to and whose needs collecting such data will serve.

Feminist theory also promotes the idea of emancipatory and strengths-based intervention in families where assistance is sought from outside agencies (Munford in Munford and Sanders, 1999: 97). The transformatory work that Munford advocates

for practitioners who work with families is based upon an understanding that intervention can be radical and empowering without taking a stance that there is an insurmountable cost to each woman who takes up a caregiving role. Feminist theory values the work that is revealed in the genderised world of social relationships, and promotes the view that supports emancipatory work. The view is based on a post-structural stance that allows analysis from a point based on 'seeing' the individual in their situation, rather than viewing the caregiving role as being a role in isolation. The view is one that can thus connect empowerment and strengths to the role, rather than focus on what a parent has had to give up to raise their child, or the opportunities that they have put aside to work as a caregiving parent.

Attachment theory

Caregiving, parenting and attachment theory are inextricably linked (Howe, 1995; Holmes, 1993). Attachment theory moves the debate related to learning parenting skills into the realm of the interpersonal. How a parent grows into the role of specialist parent taking care of a child in a complex world is rooted in the interactions and relationships that take place between the child and the parent. This research taps at the door of those parents who have been asked to re-draw their hopes and dreams for their child, as they move into a new world of medical services, specialist care and complex systems.

The commitment of each parent to their continued involvement in their child's complex world is linked directly to the attachment relationships that a parent has with their child (Marris, 1991: 77 – 90). Without a viable attachment bond, there will be no foundation laid for the reciprocity of parenting that develops over time, especially

when a family member requires extra care, and adds extra responsibility to a family (Dominelli, 2002: 22).

A secure and viable bond between a child and their parent is essential for development for any child. Bowlby theorised that attachment and bonding between a child and their parent arises out of the experience of care in 'a normal family life' (Bowlby, cited in Holmes, 1993: 39). Attachment theory postulates that in an interactive healthy child-parent relationship, a child develops the attachments that will provide them with a secure base instrumental to their growth physically, socially and emotionally (Bowlby, cited in Holmes., 1993). The cycle of interactive behaviour arises not only from instinctive behaviour, but also from learned behaviour based on a parent's own 'parenting' experience, their beliefs about parenting and the supports that are in place in their society to support them as parents (Bowlby, 1979; Smetana, 1994; Kendler, 1996). It is within this environment, where a parent becomes involved in caring for and responding to their child, that their attachment bond with their child develops and grows.

When raising a child who has impairment there can be extra stress placed upon the development of an attachment bond between a child and parent (Kendler, 1996). When a child has an impairment, communication may be difficult; when a child is chronically unwell, or when a child undergoes long periods of hospitalisation, parenting can have extra dimensions that are related to the child's circumstances and that place a pressure on developing a bond (Kendler, 1996).

Attachment theory allows for a view that gives credibility to the time that parents put into their child's care (Howe, 1995). An attachment perspective over the information from interviewing parents, about their experience, adds a view that enables meaning to be drawn from the actions and beliefs of parents who have actually taken part in raising a child who requires extra care (Marris, 1991: 80 – 81). Marris argues that dealing with uncertainties in life is a human condition and that an individual's action as they seek to control their life is guided by the meanings that have been given to their social world. It is these meanings that lead to actions parents take as they seek to control and understand what is happening in their child's life. Attachment theory grounds the personal relationship between a child and their parent, and that between a child and their family. Extracting data from reflections of parental experience takes on credibility, because there is recognition that attachment is a key factor in why parents react as they do.

The connection between a child and a parent is mirrored in how a parent behaves when confronted with having to take on new meanings and new behaviours, in response to finding themselves in a new role, or at least in a role that has some new aspects.

It is how a caregiving parent grapples with and resolves the challenges that arise as they meet their child's needs, their family's needs and their own needs while seeking to ensure their child is well cared for that forms the basis of the research.

The research method

The research method chosen for the study was one that anticipated exploring the parental view of the support they have received to raise their child in a world that defined their child as 'impaired'. 'Success', 'strength', and 'positive pathways' in parenting a child with very high care needs formed the 'viewfinder' through which the interviews were carried out with parents.

By taking a qualitative view, I set out to reveal knowledge that came not from 'expert' analysis of quantitative data i.e. the numbers of caregivers, their gender, whether they do this because they are a family member, or for pay; but from an analysis that takes meaning from the actual world of being a caregiving parent. Knowledge and meaning, facts and conclusions arose out of a process of knowledge creation that acknowledges a feminist way of 'seeing' and a feminist way of 'knowing' (Oakley, 2000: 22).

Conclusion

Gaining an understanding of what it is in a parent's journey that has given them the skill and knowledge to parent their child arises from understanding the world a parent lives in. Systems influence how well a parent is supported. Feminist thought defines the private world of family, family care, and parenting. An attachment view provides the connection between the interpersonal world of a child and their parent and their social world. Together these three theoretic perspectives provided a basis for viewing the experience of a small group of parents.

Chapter Six

Carrying out the research

Introduction

Carrying out the research was an exercise in planning, review, reconsideration and replanning. Recruiting research participants presented a challenge that brought me back to the original question then took me out again to re-look at how best to recruit research participants who were fully informed and consented to being involved while at the same time protecting their privacy. In this chapter, I discuss the steps involved in the process of the research and the implications of the method chosen to access data for analysis. I then discuss the ethical considerations of human research and also raise ethical issues that related to child disability. The chapter concludes with a short discussion on bias and limitations of the research.

Research question

This research examines the experience of parents in order to establish the influences that have built parental strength. The objective of the research was to speak to New Zealand European parents of children between the ages of 6 and 16 years who had an impairment in their bodily function and who had high care needs. The experiences of five women who are the parent of such a child were recorded and analysed with the aim of extracting the influences that have built parenting skill.

Recruiting research participants

I approached Mrs Heather Alford, a parent liaison worker at the Parent and Family Resource Centre (hereafter referred to as 'PFRC') about the research proposal. PFRC is an 'information and support service for families of children with congenital and acquired intellectual, behavioural and physical disabilities' based in Onehunga, Auckland (Parent and Family Resource Centre Inc, 2002: 12). The PFRC employs staff who provide individual counselling, facilitate groups, assist with networking, and link parents with support groups. The Centre also maintains community and personal links by mailing out approximately 700 newsletters to organisations, community groups and individuals four times a year. Mrs Alford asked for a copy of the draft application I was in the process of preparing for the Massey University Human Ethics Committee before I met with her. My meeting with Mrs Alford took place after she had discussed the request with other staff members at PFRC.

In approaching the PFRC to recruit research subjects, I commenced a process that ultimately aimed to provide knowledge that would be of benefit to parents who have recently been informed that they have a child who has a disability. I also recognised that the knowledge gained 'belonged' to those who were involved in facilitating access to the research participants, i.e. PFRC, as well as to the women who were interviewed.

In asking for assistance from the PFRC to recruit research participants, I entered into reciprocal relationships with the people who make up the Centre's staff. In response to a request from the PFRC manager, I agreed to provide the Centre with a full copy of the research. I also committed to present verbally, to the group a summary of the

findings of the research. The verbal presentation was based on a document that summarised the findings of the research prepared after analysis had been completed and conclusions finalised. There was also a sense of reciprocity when I committed to taking part in a seminar, facilitated by the Centre, around how Centre staff are supported in their roles.

Process

The recruitment procedure was designed as a two-step process on order to ensure that prospective respondents had fully considered taking part in the research. The first step in the process was asking parents who were interested in completing an interview to make contact using a telephone number listed in the PFRC newsletter. The notice outlining the research was placed in the quarterly newsletter of the organisation PFRC in March 2003 (see Appendix 2). Parents of children aged between 6 and 16 and who had a diagnosis that meant they had limitations in day-to-day life as well as very high personal care needs were asked make contact if they were willing to participate in an interview for research purposes. The next step in the process was to outline the project to the caller and inform them that participation was voluntary. If prospective participants were still interested, an information sheet (see Appendix 4) was mailed to them. The information sheet asked prospective participants to telephone once more and indicate that they were willing to participate in an interview. At that time, an appointment would be made with them to carry out an interview.

The research instrument was the collection of data from parents via a semi-structured interview. The parental view was sought in order to provide an understanding of what

interactions or actions had taken place through their parental journey that had built their parenting strengths.

The research instrument was designed to collect valid and reliable qualitative data from the experience of parents who had been in the 'business' of parenting for at least six years (Patton, 1990: 24, 31 – 32). An interview framework was constructed and followed. The questions were sequenced, with questions that required straightforward responses about experience coming at the beginning of the interview. This sequencing of the questions was put in place to encourage respondents to give full descriptions of their experience, to 'respond descriptively' (Patton, 1990: 294). Only after experience had been verbalised were views and opinions sought. This sequencing in the process of questioning was specifically aimed at eliciting views and feelings grounded in the experience of 'high care needs' parenting (Patton, 1990: 294 – 295).

A decision was made to interview individually to ensure that those parents who participated in interviews felt that they were free to reflect on their experience in private. It had been suggested to me when I first considered how best to research the question of support that had built on strengths, that a group discussion would be an efficient method of eliciting reflections on experience that had been instrumental in the development of parental skills and strengths. However, I considered that it was important for each parent to be able to talk privately and so I opted to interview parents individually.

No telephone calls were received as a result of the initial flyer and the notice was included in the next newsletter of the Centre. There were also no responses to this second notice.

In retrospect, it is clear that the two-step procedure carried with it a risk of being too removed and impersonal from potential research subjects. I cannot comment on the reasons why there was a zero response rate, apart from acknowledging that recruiting research participants must be carried out in a manner that does not set in place insurmountable barriers (Oakley, 2000). It was only after the recruitment procedure was changed to one that involved PFRC staff that there was any success in recruiting prospective research subjects.

The recruitment procedure where each participant was called on to actively make an appointment had been designed to allow the space for participants to be sure that they felt comfortable about contributing information to the project. Given that the cost in the use of such an impersonal process was a zero response rate, the question arises as to how the notice was framed and whether or not a change in the wording or format would have provided the motivation for parents to pick up the telephone and make initial contact. In retrospect, the process was an unproductive method of recruiting busy participants probably because it was too remote and not because of how the notice was presented.

I met with Mrs Alford once more, and also with Mrs Maureen Craven, Centre Manager. An agreement was reached that as the Centre's Community Support Group Liaison Officer, Mrs Heather Alford would ask people attending groups to consider

whether they would take part in an interview. Permission was sought from the Massey University Human Ethics Committee to change the process by which research participants were recruited and this revised process was followed.

Mrs Alford gave information sheets (see Appendix 4) to individuals who were attending support groups and seven women who were parents of children between the age of 6 and 16 responded.

The process of recruitment became a key issue for me when initially no prospective research participants made contact. Asking busy people to take time out to make a phone call in response to a notice they may have read did not work. Acknowledging this means acknowledging that the approach was far too impersonal. A personal approach needs to be taken when asking people to give their time to a researcher. Looking back on this experience, I see that such a distant approach probably made the lack of response inevitable.

Another aspect of the recruitment process was thinking about who the parent carers might be. There is no precise statistical information about who cares. Although we know that it is primarily mothers who take on this role (Mukherjee et al., 1999; Read, 2000), I had not ruled out other family members from being participants in the research. I thought grandmothers who were caring for grandchildren might respond, or fathers or couples who saw themselves as co-parents may have responded. However, all the parents interviewed were mothers.

Once contact had been established, appointments were set up for an interview (see Appendix 3). Two women withdrew after reading through the information sheet, stating that they did not consider that their child met the research criteria. Prospective respondents were asked when they were contacted if they would like the interview to be carried out at the office of PFRC, in their home, or at another venue of their choice. Four of the prospective respondents chose to carry out the interview in their home. One chose to carry out the interview at her place of employment.

Data management.

Interviews were recorded on an audio tape and each tape was then transcribed. The transcriber signed a confidentiality form and transcribed the interviews onto floppy disk. The disk and audio tape were then returned to me.

The tapes and the transcripts of the tapes did not record any identifying information such as a name or address. All tape transcripts of interviews and disks were kept in a locked private space while analysis was completed. Once analysis had been completed, transcripts and disks were placed in secure storage with the audio tapes, for destruction in five years time.

The names and addresses supplied by the research participants were kept separate from the research data and were destroyed as soon as the summary of the research had been completed and mailed out to those who had been interviewed.

Qualitative interviews

Qualitative data has formed the backbone of this research project. As a research technique, collection of qualitative data validates the reflections of the parents as based upon their experience, their social situation and their reality (Sarantakos, 1995: 61 – 62). It is the human experience of the reality of support used to assist with parenting that interviews using a qualitative method of data collection to capture. Information collected arises from social interaction, is subjective, non-deterministic, value bound, and recognises the respondent as being an expert in their field (Sarantakos, 1995: 51-53).

The data taken from the interviews had the potential to reveal knowledge about systems of support and the caregiving parental experience (Sarantakos, 1995: 107). Open-ended questions were asked and flexibility was given to track the respondents in their reflections. The experience of the women who were interviewed made them the 'experts' in the field of caring, support and services.

Reliable and valid data is a prerequisite before any conclusions can be drawn from the information available about the impact of support and services upon the caregiving experience. Parental interviews provide data that lay out the caregiving experience to be viewed, analysed and commented upon so that the conclusions that are drawn have validity.

Analysis of data

The transcripts of interviews were read through for patterns in use of services, views about services, support from family members, impact on family members, events in the life journeys of both the parents and the child to establish universal themes (Sarantakos, 1995: 201). 'Critical appraisal of reality' was used to establish regular trends (Sarantakos, 1995: 299) and to look for common events, common use of terms, and unique characteristics (Sarantakos, 1995: 303). Sarantakos gives the name domain analysis to a technique that sorts and categorises data from transcripts and outlines a method drawn up by Lamnek to draw meaning from data. Lamnek (cited in Sarantakos, 1995: 303) breaks the process down into four steps. The first being transcription on to paper. The second is analysis of individual transcripts and interpretation of the information in each transcript in order to integrate and evaluate the information. The third step is to generalise findings across the transcripts so that differences and similarities can be identified, and to allow for the development of typologies. The fourth step is a control where transcripts are reviewed thoroughly, to verify information and details, before trends and hypotheses can be established or modified. These were the steps that I used to analysis the data that was collected

Limitations of the research

The project was limited in size and no cross-cultural analysis was possible. New Zealand has a unique history where the experience of Maori in the health sector and in disability support services is inextricable linked to cultural and economic issues related to a history of colonisation (Kingi and Bray, 2000). Families in New Zealand can be described in a number of ways, but it is families that self-identify as European that formed the basis for this project. Cultural definitions of family groups outside

this were broader definitions than this project had the scope for. Thus this research does not seek to make analysis across cultural or ethnic family groups.

A review was made of the international literature from Australia, Britain and America around parenting, care and disability. Literature around New Zealand services for children and their families, family policy and parental experience was also considered. The literature review identified models of disability and the themes of child disability, parenting, and services and support. This review provided information about the knowledge that already exists and also provided a base upon which to structure open-ended questions that would allow the free flow of information about parental experience.

Ethics.

This research was carried out under Massey University's Human Ethics Code. The research was set up to adhere to the University's Human Ethics Code and these standards were built into the research proposal submitted to, and approved by, The Massey University's Human Ethics Committee.

Thus, informed consent and a principle that the research must be useful and relevant were primary considerations when designing and carrying out the research. The method of accessing prospective participants was one that aimed to ensure all participants who took part in the research consented to the information they gave being used for the purposes they consented to. All participants were fully aware that their participation was voluntary; they understood what the information was to be

used for, how it was to be stored, and that they could withdraw from the information-collecting process at any time until the interview had been completed.

Research participants were given a commitment that their privacy would be protected and that confidentiality was assured. Keeping in mind that New Zealand is a 'small town' (Tolich and Davidson, 1999), that greater Auckland is smaller still, and families involved with PFRC even smaller, the writing up of the analysis of the data collected from the interview processes does not report any information that is considered to have the potential to reveal individual identity, geographical area within Auckland, or any other circumstances that may lead to the identification of any individual.

For easier contextual reading, all children in the research, both children who were siblings and those who being cared for, are referred to as 'she'. Quotes from parents have been denoted A, B, C, D or E to differentiate them. To ensure that the revelation of a personal circumstances does not lead to the identification of any individual or family, each child's age, specific diagnosis and individual circumstances are not referred to in the written analysis.

Where information from the narratives would have clearly identified a parent, family or child this information was not reported on. Information such as the name of an agency a parent was, or is, involved with, or the name of a service the family used has not been mentioned in the written analysis of the data. The exception is five agencies or services that are named in the report. The PFRC is identified as all participants had been recruited from its support network. Starship Children's Hospital is named as all the children have had contact with the hospital. The Meadowbank Plunket Family

Support service is named, as this is a widely used service that many new mothers use. Maternal Mental Health is also mentioned for the same reason, but the geographical location of the service is not specifically identified. Work and Income New Zealand is also mentioned as all families have experienced contact with the service in relation to the Handicapped Child Allowance or when applying for Disability Allowance.

Only parents already in some type of relationship with a support agency were recruited. This protocol was included in the application to The Human Ethics Committee as a means of ensuring that all those who did complete an interview would have access to support should they experience any adverse consequences after the interview.

This research project also creates an ethical awareness in three separate spheres related to child disability. The first sphere is an individual's rights to access services in a modern market economy and the dilemmas that arise due to budget restraints and limited funds. The second sphere is technology and its impact and the debates around quality of life, and the third issue is related to pregnancy termination.

The first debate is the issue of an individual's absolute right to have access to whatever services and medical intervention they require to support rehabilitation and promote living a fully inclusive life. The number of technologically dependent children has grown as science in the area of birthing and care of premature babies has developed (Read, 2000; Dickenson, 2002). This increases the call on services that are delivered to individual children and their families from set budgets (Sullivan, 1998). The reality of access to services in the medical and support fields for the individual

child and their family is that they are dependent on financial constraints to gain access to services to assist with care and quality of life. Where technological support could enhance function for high care needs children, this can mean that service providers do not have access to the budgets that will fund high cost technological support. The financial cost of services and support then becomes an unspoken factor in the services that can be offered to individual children. (Sullivan, 1998; Read, 2000)

The next debate is that related to questions about cutting-edge intervention in premature births and for births where there are medical conditions that may or may not respond to medical intervention. While related to the debate around the right to services, this question extends to include discussion about the quality of life for individual children (Read, 2000; Dickenson, 2002). For babies born prematurely or with complex medical needs, future quality of life is often an unknown that cannot always be accurately predicated. Precise diagnosis often only comes from tracking development and progress over the first few months of life. Making decisions about invasive intervention when prognosis is unclear, when information about living with pain is unclear and when intervention may result in no change at all becomes more than a medical matter for parents: the decision becomes a moral and ethical one.

Another ethical discussion that has not been fully explored in this research report is one a research participant implied when she stated she had decided to limit her family size and not 'risk' another high care needs child. Another stated 'no more, no more' when talking about the size of her family. This issue creates strong feelings about the rights of unborn children to live in any circumstances versus the rights of women to choose to terminate a pregnancy (Beatson, 2000: 66; Read, 2000: 101). One side of

the debate promotes the view that a disability a child may have to live with must not be a rationale for termination of a pregnancy. The opposing view is that to terminate a pregnancy because of foetal abnormality is a medical procedure that needs to be decided between a parent and their medical consultant. Technology has progressed to a point where genetic screening can diagnose some disabilities and genetic disorders while a foetus is in utero. This technology is available to parents in New Zealand and if there are indications that they may be carrying a child who could have a genetic disorder, or where there are other indicators the foetus may have an abnormality, parents will be offered an option to terminate the pregnancy.

There are no clear answers for any of the issues raised above. What we do know is that medical technology will progress. Medical science will continue to improve the life chances of premature and medically challenged babies. Equipment and services available to support and address impairment will continue to be developed and become more readily available.

What is also clear is that the financial cost of accessing specialist equipment and services will continue to rise. How much funding will be made available to access new technologies as they become available will remain a political decision. The debates around a parent's right to access pre-birth screening for genetic disorders as a tool for diagnosing child impairment will continue as science progresses. The answers to pre-conception and pre-birth screening, and pregnancy termination are ethical issues that cannot be decided by focusing solely on medical science.

The moral issues a parent faces will not go away as scientific progress is made. Individual parents will continue to face ethical predicaments around child disability, the rights of their child to access services, the financial and personal costs of child disability and the use of technologies.

Bias

I do not argue that the research that I have carried out is value-free. Research that explores caring for others as an unpaid family member cannot be value-free. Taking an economic view of the financial cost of parenting and providing care just does not make economic sense. However, parenting and caring for family is not about economic sense. If the extra financial costs such as extra care costs are added to the cost of lost in career opportunities then the equation makes even less sense. This work is not about costs verses benefits, it is about the extra dimension to parenting a child who requires extra time and extra energy that can see parental strength emerge.

History has constructed the discourse where women have a role in care and family. The challenge for this project is taking a parental view of the support and drawing out data from these views. The research does not provide definitive, positivistic answers to questions about services or support and their impact on parents. What the research does is look at the experience of a small group of women and draw conclusions from the commonalties and the contrasts in their experience.

The conclusions drawn from this data cannot be taken as the experience of every parent in a similar situation in New Zealand, as the parents interviewed represent their own experience rather than a universal one. Having said this, there are some

conclusions that can be considered to relate to the whole group of parents who are raising children who require extra parenting.

What this research does not provide are the answers for those parents who do not find the energy and family support that they need to succeed in parenting their high care needs child. Parents who do not engage actively with the medical support systems their child uses, parents who have little or no family support, parents who do not accept their child's disability, and parents who find it difficult to meet their child's needs have not been spoken to, so no data that points to these experiences is included in this report. This alone provides substantial bias in the findings reported on in this thesis.

Conclusion

The process of operationalisation of the research followed a protocol that had been submitted to, and approved by, The Massey University Human Ethics Committee. The process of setting up and carrying out research to seek out evidence of the impact of services and support used to raise a child who has a disability and who has high care needs followed a set pathway. Data collection, data analysis and data management were straightforward processes. Informed consent was also straightforward. Sharing of information was built into the operationalisation of the research and research participants and the agency were provided with research findings when the project was completed.

Recruitment of research subjects, however, had to be reconsidered. A staff member from PFRC took a primary role in supporting me to review and replan the recruitment

process. This staff member had been supportive of seeing the research being carried out and she gave me considerable time for discussion of issues that came up when I had to reconsider the recruitment process.

Ethical considerations for this research are primarily the principles of informed consent and voluntary participation. There are other ethical issues, however, when child disability is discussed and these relate to the experience of financial constraints, technology, quality of life, and medical intervention in pregnancy

The research is a qualitative piece of work and as such does not purport to be value-free. The research set out to report on parental experience but in effect only interviewed women who were actively involved in parent support programmes and thus there is a strong argument that the findings are heavily biased as they report only the experience of parents who have succeeded in building parenting strength.

Chapter Seven

Parental experience

Introduction

In the next two chapters, I report on the data collected from the interviews. Analysis of the data from the interviews revealed that success in the parenting experience is closely linked with support received.

In this chapter, I discuss the experiences with a view to revealing the links between the experience of parenting a child who has high care needs and coping with the extra tasks associated with the care the child requires. In Chapter Eight, I continue the analysis and discuss the influences of family support, parent support groups, and agency support on coping. Then, in Chapter Nine, I present an analysis of the findings with comments about support and intervention that have the potential to strengthen families and build parental skill.

Beginning a journey that is different

The mothers interviewed for this research had commenced their journey in the time shortly after their child was born. Soon after being informed about their child's impairment, they had all been drawn into a complex world involving their child and medical intervention. Following this experience, parents learnt medical care techniques, took this into their homes, learned to monitor and track information, access support, and case-manage their child's life, while building their expertise as a parent of a child who had extra-ordinary needs.

The attachment bond between each mother and her child can be viewed as the base that supported these women and their families as they dealt with the processes involved. As these mothers worked to establish and maintain a balance for themselves and their family, they remained focused on their child. It is this attachment bond to the child and across their family that kept all the mothers focused on their child's needs while seeking to establish some understanding, and subsequently the knowledge and skills, to competently parent their impaired child. The circumstances of these first weeks become a foundation for parenting in the future.

The research participants

All the parents interviewed were women who had given birth to the child that they had become an 'expert' parent for. Their high care needs children were aged between 6 and 16 years old. Four of the children were the youngest in their family and one was the oldest in her family. Four of the women had two children and one had three children.

At the time of interviewing, two of the women were married and their husbands took an active role in their child's care. One participant had separated from her husband in the years after her child's birth and he remained actively involved in their child's life as a non-custodial parent. One participant and her husband had separated shortly after the birth of their youngest child in the time before it was known that the child had impairment in her bodily function. The mother of this child reported that the child's father took no active role in her care. One family was a single-parent family and the father of the high care needs child had no contact with his daughter.

All the women interviewed were primary caregivers who had experienced taking care of a child who was fragile and limited in their interaction with the physical and social world. One of the children had recently undergone surgery and with technological support was now leading a life where her impairment no longer presented any real limitations for her.

One of the children had an intellectual disability as well as a physical disability. Four of the children had histories of undergoing surgery and the other is facing major surgery at a date to be determined in the future. For two of these children, the surgery they are to undergo will not provide a guarantee that the quality of their life will improve or that their prognosis will be positive, but if they are to survive into adulthood, they must have the surgery. For one child the surgery is a procedure to assist with the management of the condition with which she has been diagnosed.

Finding out

When each parent was informed that their child had a serious condition, this switched on a process that started the parental pathway each parent would take. Bowlby theorised that parenting is behaviour where a parent changes their behaviour in reaction to responses to their child and that even though parenting has strong biological beginnings, parenting is a learned behaviour (Bowlby, 1979: 4, 5). Each of the mothers interviewed faced having to change their plans, change the dreams they had for this child, and they moved into a mode where they started to provide the care their child required.

The information that their child was fragile and had special care needs came as a shock to all the mothers interviewed. The information was the beginning of a change in the pathway each mother had envisaged she would be taking as she raised her children.

‘it’s almost like when you have a child with any form of disability it’s just like your dreams are shattered’ (Respondent D)

As well finding out their child was fragile mothers then found they were involved in caring for a child where the work is constant, repetitive, time consuming and at times physically onerous.

‘It’s 24/7 care ... there is real hardship here, real hardship here’
(Respondent A)

In those early days, a mother’s high input into her child’s life is necessary not only because a baby has high care needs, but because a medical assessment process commences that is to be critical in determining how the child progresses. It is known that this time is critical in establishing how well a mother of a disabled child will move on to develop the understandings to successfully parent a child who has special needs (Read, 2000:115).

‘it’s like, where am I, the future is so hard to see when this child has this tenuous grasp on life, ... there might be a future, it helps you to build.’
(Respondent D)

In these early days, any intervention can have a significant consequence for a child's longer-term development. The input required from the mothers during this time drew them into the complex world of medical services and specialist treatments.

'unfortunately we were seeing three different clinics in that first year of life, they were so interested, they don't really know how it's going to go, they throw in all these scenarios and then after a couple of years they don't really want to know you any more. It's not such a big thing to hack. I've heard that the first year is always the worst.' (Respondent E)

After diagnosis was made, all the women moved into working alongside those professional medical staff in the clinics who provide intervention for the medical diagnoses their child had. These early experiences were influential in providing a parent with the basis from which their parenting skills developed as they endeavoured to meet their child's needs. It is within this highly charged environment that a parent takes the first steps in what can be viewed as a layer in a matrix that becomes strengths-based parenting as they work to meet the needs of their child who has extraordinary care needs.

It is known that separation can impede development of attachment between a child and a mother (Ainsworth, 1991; Kendler, 1996) but each of these mothers had family support that enabled them to be with their child.

One research participant knew shortly after her child's birth that the child had an impairment that would influence her physical development. Another child was born at 26 weeks' gestation and for the first months of life, her prognosis was not clear. This child underwent major surgery in her early days, to save her life but her complete diagnosis was not given until she was entering school by which time it had become clear the impairment in her physical function would be with her for life. For the parents of two children, diagnosis came after the children failed to thrive, medical exploration diagnosed circumstances that required major surgery, and the children remained fragile as they grew. The other research participant's child's diagnosis came after postnatal screening. None of the five women had expected to give birth to a child who was going to experience a disabling impairment and all five moved very quickly into a role where they connected with the medical systems that their child was engaged with.

A glimpse of future pathways

One mother was thrown straight into engagement with medical systems immediately after the birth of her daughter. She had experienced a fast birth and was coping with knowing her child was experiencing birth trauma.

'I had her very quickly on the bathroom floor [in the maternity hospital] she wasn't breathing, so she was whisked away to resuscitate her and get her breathing, then she went straight to intensive care. So I knew nothing about it ... my husband came upstairs and told me that she had a small problem ... I imagined she had a birth mark ... later staff told us what her prognosis was ... I think they said "what you see is what you get" ... No one explained it to

me ... later on the next day the surgeon came to see me I was still in shock from the delivery.’ (Respondent B)

For this mother there was no time between finding out about the child’s impairment and being able to understand what this actually meant for her child, for herself and for her family. There is no sense of a process to allow the mother to take in what had happened. Nor did this mother recall any professional support as a means of facilitating access to knowledge around managing the changes that are about to take place in the family’s life. This was then followed by a sense that the parenting was becoming technical.

‘she came home armed with a cot monitor.’ (Respondent B)

For the mother of the child born at 26 weeks’ gestation there was also the experience of immediate involvement with complex medical systems. Her experience was one of critical surgery post-birth while not knowing if the child would survive.

‘the first words I ever heard from a surgeon were “the operation went well but there is a strong possibility of brain damage because of seizures”, and she had only a 10% chance of surviving the surgery.’ (Respondent A)

Here also there was a lack of process to enable the mother to take in what was happening.

The experience of these two women points toward the immediate response of a melding of personal responsibility in an environment that is medicalised. Each mother's attachment to her child drew her immediately into this situation where a parent stands alongside professional personnel or a medical system and where they receive complex clinical information that they have to process and attempt to understand within a short space of time.

In contrast, the other three mothers were given a post-natal diagnosis in the weeks following birth. For these mothers there was a process of adjustment, since the experience was not so abrupt. Reflecting on the process, a mother acknowledged that the life changed dramatically and that adjustment had taken place.

'It's a blessing. It really is. You wouldn't choose it but it really is because your life is just so different.' (Respondent A)

This did not mean that at the time parents experienced assessment and clarification of diagnosis as an easy process.

'I just had a barrage of hospital appointments and that was just too much, especially since every time I saw the specialist the outlook was so dire.'
(Respondent C)

'the specialist says one thing then he contradicted it and so you have spent a few weeks freaking out thinking your whole world was at an end.'
(Respondent D)

For these mothers, being given a diagnosis was not a clear linear process but became a process of multiple hospital appointments, waiting, uncertainty and fear. However, for all these women, this process was the same step into an unexpected environment where they were expected to engage with systems that are medically complex.

The environment described here is one where a parent is taking care of a baby that they know is not settling, and they are becoming exhausted because of the constancy of the need to be with baby. Continuing to care for a child when exhausted places stress on a mother. It is the bond with her child that draws a mother through the experience of tiredness. It is this bond that also drives a mother to seek answers about why her child is not settling.

Both the mothers who has unsettled children questioned if there was a problem, as both had developed a sense that their baby's continued lack of ability to feed was related to something that was out of the ordinary.

For the mother where diagnosis occurred after post-natal screening, baby appeared well, settled, and appeared to meet all expected developmental milestones.

'for the first four weeks we were unaware of anything ... then we got a phone call asking us to come in for tests from my GP ... we went and it was explained to us that it might be a false positive ... so we had that [referring to re-test] and had to wait a long time ... my GP came over and told me ... it was quite distressing [referring to finding out the diagnosis was critical and life long].' (Respondent E)

However, at diagnosis this mother also moved immediately into a close relationship with the medical system.

All five parents entered a relationship with those systems that supported their child as each child had significant impairment that required treatment, rehabilitation, on going monitoring and considerable input from parents in the home.

There was a contrast in the experience for parents who found out a baby had a serious impairment when the baby was critically unwell, and for those who found out when the baby was thought to have no problems. The contrast was in the absence of high stress due to the child's presenting circumstances. This factor does not appear to have any long-term impact on how parents progressed as they took up their new role. All the parents expressed a commitment to find out about their child's circumstances, to look for answers to the question 'why' their child, to work with professionals and lay people to support their child, and to seek specialist assistance. All the parents faced a future that was unknown and all had started to become part of a team with medical professions as they provided care for their child.

Becoming involved

It was from this time on that the mothers had experiences that were different from those expected when raising a child. I will discuss these experiences with a view to discussing the impact upon the development of parental competence.

As the mothers were drawn into the world of medical clinics and home-based care, they were at the beginning of becoming an 'expert' parent for their child. Each

mother's commitment to be there with their child while they were hospitalised, to work with a range of people, and to take the time to learn the techniques required to meet their child's needs, demonstrates that each mother had moved into the world where systems support a parent to take on a new and challenging role (Marshak et al., 1999: 10). Another measure of feeling able to take on new tasks is that some mothers moved into the role of advocate.

'Squeaky wheel, squeaky wheel, there's nothing more motivated than a group of parents, it don't matter if it's the health care system, the school or the library there is nothing more motivated than a group of parents doing something for their children.' (Respondent D)

Motivation is based on the personal relationship with a child (Bowlby, 1979) and a sense of family responsibility (Dominelli, 2002: 22) and this relationship is the platform upon which all future parenting strengths rest.

Taking a child to appointments at the heart clinic, kidney clinic, neurological clinic and/or the orthopaedic clinic places a parent at a point where they also become managers of time, transporters, appointment keepers and monitors of information from multi-clinic appointments. This experience places a parent directly at the hub of the medical support their child receives. All the parents had to take their child to more than one specialist clinic and all experienced a lack of co-ordination or cohesion in the clinic system. This experience placed all the mothers on a course where they became holders of information about their child's medical treatments and the care systems being put in place to treat, rehabilitate and assist their child.

Getting someone to listen

The first weeks spent caring for a child who is fragile are weeks where the experience of support received leads to the experience of becoming involved and being part of the solution. Once again, the support systems available are seen as strengthening a mother's resolve to find an answer to what is happening for her child. Part of this support comes from the experience of being listened to.

'I actually had a very good midwife, who picked up that something was not right with baby so she referred me to a paediatrician and we were referred on to Starship and that's where the diagnosis was made.' (Respondent D)

'you know my Plunket nurse literally saved my life, she saved my life, she referred me to the Meadowbank Day Centre and the Nurse at the Centre arranged for her to see a visiting paediatrician when she was four or five weeks old.' (Respondent C)

Support for these two mothers was available and their concerns for their child were looked at and acted upon. This is but one more strand to the building of competence as a parent.

One mother still found that her questions could not be fully answered.

'getting someone to listen that there was something wrong ... it's hard to accept that it's random and no one can tell you why ... they can't actually tell you ... it still comes back to you.' (Respondent C)

That this mother felt there were important questions that remained unanswered did not mean that she became stuck. Not 'knowing why' became secondary to building the expertise to meet the baby's needs.

Wanting to know why

The question 'why' came up in all the interviews. When there was no genetic basis for the condition, the question of 'why' has no answer. This was reflected through the interviews at all stages of a child's interaction with medical staff. One mother recalled questioning why her child required treatment soon after diagnosis.

'where had this come from ... why me ... why my child.' (Respondent E)

Later, the experience of wanting an explanation for what was known to be a random event still persisted.

'There is in fact no answer to the "why" this specific child has been born with impairments. The fact that you have other children who have no impairment brings you to ask why this child, even if you have been told there is no answer to this question.' (Respondent D)

That there was not rational answer available did not reduce the stress or anxiety and the 'wanting to know' that parents experienced. Dealing with the information that a child has a condition that will be with them over time and for which they will require medical-intervention is the beginning of a process that ultimately combines with other processes to develop parental competence. The fact that there is no answer as to why

any particular child has been born with impairment does not appear to impact on the development of competence to parent.

Taking control

After their babies' birth all the mothers experienced becoming actively involved in extra care required by the child. The experience of being expected to cope was one all parents reported and is one that other mothers of disabled children emphasised too (Read, 2000). For one mother, this was immediate and sudden once a diagnosis was given, after she had been dealing with a fractious child who was difficult to feed for some weeks.

'your other child was fine, this child has got something wrong with her, something hasn't happened right, something hasn't grown right or whatever and you're thrown out the door with all this stuff it's just a blur really.'

(Respondent B)

The experience of this mother was that she found herself at home taking care of a fragile child when she felt that she was being left to cope on her own. Knowing that there is a problem in a child's expected developmental pathway early in a child's life leaves a parent at a point where they have to commence parenting while still feeling overwhelmed. Professional assistance and support is provided initially but in the end it is a parent who has to pick up the skills to continue the expert care a child requires if they are to support their child to live with their impairment.

'one or two lessons from a physio at Starship then you are doing them at home ... you're doing your medications and doing treatments, doing them at home.' (Respondent E)

Another mother's view was

'and you get on with it' [talking about coping once a fragile child is sent home from hospital] (Respondent D)

The four mothers who were caring for a fragile child at home in the first months of the child's life were all using new skills to provide special care for their child. These were techniques and procedures they had been taught by medical staff, and the techniques were essential to maintain quality in their child's care.

The parent of the child born prematurely recalled spending considerable time with her baby in those first few months, but she recalled no experience of a professional giving her time to talk through the possible consequences of early birth on a child's development.

'nobody told me, nobody told me ... it would take me two hours to tell you the whole story about that.' (Respondent A)

This mother has no memory of anyone revealing to her that her child could eventually experience major disabilities but she recalled considerable experience with technology and special care techniques. The child required specialist care in the form

of technology that became part of her daily life. This mother, as had some of the other mothers, learnt to deal with a range of specialist procedures such as clearing and maintaining a tracheotomy, managing diet, physical exercise, massage and personal cares such as nappies, bathing, and supported feeding.

Having a baby in a critical condition, or a baby that has undergone critical surgery, places a parent at the core of a highly charged situation and is known to be a source of great stress of mothers of high care needs babies (Read, 2000: 54). The situations described by four of the mothers that they experienced in the first few weeks were such that they were coping with high levels of stress because of critical factors in their child's life. Beresford (cited in Read, 2000: 67) reported that a common response was for mothers of high care needs children to become involved and actively work to manage the situation. For all the mothers interviewed, seeking information, knowing what assistance was available, and becoming involved in the care of their child were a first step in taking control.

The 'choice' of surgery

A major choice that was experienced by some of the mothers in the first few weeks after a child had been medically assessed as having life-threatening circumstances was the decision whether or not to go ahead with critical surgery. For one mother the choice had to be made immediately.

'we had to sign for them [the consent to operation], if the decision went wrong whatever operation we signed for went wrong it was our fault. We

okayed it even though they couldn't foresee what was going to happen and they didn't know.' (Respondent C)

This experience contrasts with the experience of other mothers who were given full information about surgery, who had time to talk to professionals about the medical information they had been given, and who experienced medical staff as extraordinarily supportive.

'she works at Starship and she's great.' [talking about being able to pick up the phone at any time and contact her] (Respondent E)

'because I was breast feeding I was up and down all night ... He'd be there at 1 am and he's be there at 5 pm ... I probably saw more of him than his family did.' [talking about a specialist surgeon] (Respondent D)

'and she came every single day, every single day.' [talking about a support person who visited mother and child every day while they were in a process of specialist assessment over a short period of time] (Respondent D)

Making a decision to surgically intervene to ensure that a child survives involves a parent giving their consent to the operation. This becomes a point in time where a parent moves into taking responsibility while becoming involved in making what can only be described as complex decisions. As these choices are made, there is a sense

that control over what is happening in the medical field must be maintained. The information can still be overwhelming, even when given time by professionals.

'always take someone with you to appointments, you don't always hear what is said to you and you don't always ask the right question.'

(Respondent C)

The experience of knowing and understanding what is happening for the child supports a sense of competence for a parent (Read, 2002; 48). Just being there when critical decisions are being considered draws a parent into the process of being involved in an extra-ordinary situation. There is a sense that hearing what is said and asking the right questions ensures that knowledge and understanding is not lost. The experience of seeking knowledge and understanding becomes a strand in the skill a parent takes through into the future, as they work to ensure their child has all possible support.

Avoiding blame

At times, dealing with a child's presenting behaviour caused mothers to question their competence as a parent.

'when she was born she was "failure to thrive" ... There were lots of questions asked about my mental state at that stage ... they thought I was contributing toward her failure to thrive.' (Respondent D)

'this child was not putting on weight so it was my fault as a mother.'

(Respondent C)

When a baby does not follow expected developmental guidelines, a mother can feel that she is in some way responsible. This only changed when mothers gained access to information that allowed them to understand there was a clinical reason why the child was not progressing.

Understanding was what took each mother past feelings of inadequacy as they moved into understanding that their child had needs that required medical assessment and treatment. This brought each parent back to the process discussed previously where parent involvement becomes part of the solution.

Depression

Three mothers experienced depression after the birth.

'I was actually badly depressed ... and yeah I think her diagnosis was a sort of a shock process.' (Respondent E)

The feelings of depression were mixed with the knowledge that their child had a life-changing condition that would have major implications for that child. That depression arose for some of the mothers is not unexpected. Their circumstances were a mix of struggling to understand what was happening for their child, at a time when post-natal depression can be expected to occur.

'my doctor identified me as a candidate for depression ... I was referred to maternal mental health ... I ended up doing therapy if that's what you like to call it ... deal with the fact that I'd had a baby and things weren't normal with the baby.' (Respondent C)

Professional support rather than speaking with a family member was identified by this mother as important in assisting her come to terms with the child's birth and the depression that was being experienced.

Feelings of depression led in one case to referral to a maternal mental health service. Nevertheless, all the parents, regardless of the experience of depression or shock went on to parent their child without any major break in the sequence of care.

Making new plans

An initial sense of failure is deeply felt and this cannot be minimised. Overcoming this feeling is difficult.

'I was a total failure as a mother. I guess I am goal orientated ... and she didn't even get into the yellow shading [growth chart] when I read the words "failure to thrive" ... I mean as a mother I couldn't even feed my baby.' (Respondent D)

When a child does not do as well as expected after birth and the reason is unknown, some mothers express feelings that they have failed. Overcoming this was related to taking steps toward understanding a child's condition, seeking support from other

parents, practical support and assistance from professionals, although this was often from professionals associated with baby care and babies' needs.

The key was rebalance to restore a sense of being in control. Even when a child is fragile and the child's prognosis is unknown, the sense of being back in control leads to a situation where a parent can accept support. The restoration of balance in the child-parent dyad and across the family is another strand in the matrix of strengths-based parenting.

'Plunket Family Centre (*Meadowbank*) dealt with baby's feeding problems, they were brilliant. They would sit there with a teaspoon and I would express milk, and they would feed her and let me go to sleep. It just gave me the break I needed ... they let me have a sleep and did the practical things like getting her fed.' (Respondent D)

Control also is felt when a parent acknowledges they have achieved a balance in the care of baby and where family needs are being met.

'No, I think I am very lucky with what I've got ... No, I'm not pushy at all I am quite relaxed, it all comes to me. I have found out that I haven't had to go out there and push for anything, it's been really good. I suppose it's the services involved.' (Respondent A)

A sense of control is established when skills have been mastered and services engaged. This contrasts with the sense of being overwhelmed in the early days when a parent faces the unknown.

Spending the time

Time sitting in hospital, time spent in clinics and time spent in parent support group coffee mornings subsequently lead some of the women to becoming actively involved in voluntary support services closely associated with their own child's diagnosis.

'I joined the committee after three or four years, I mean I went to most support meetings which were morning teas, then I took a job as a volunteer, so it sort of went from there.' (Respondent E)

'I say for me it's been paramount being involved with children ... I've gone from being on a support group to being on the Auckland Committee ... then we established a national board.' (Respondent D)

Support groups are a known factor in building parental competence when a mother is raising a high care needs child (Read, 2000: 56; Bennett, 2002: 29). Experiencing the reciprocity of informal support has become a platform for all the mothers interviewed to become involved to some extent in support groups at one level or another. Two of the mothers had become involved in parent-controlled organisations that worked to lobby at a regional and national level for funding for services, support for local families, and political lobbying.

Conclusion

There is a complex mix of experiences that a parent has over the immediate period post-birth that provide a basis for the building of competency in extraordinary parenting. The combination of being drawn into complex medical care, seeking information, setting aside blame and understanding what is happening, all provide strands that develop into competency to parent a child who has extraordinary care needs. Competence arises out of the experience of becoming involved and becoming an expert in the care of your child. Contact with professionals was part of this journey but in the end it was the 'being there' that lead to becoming actively involved in the child's care. It is through becoming involved that competence develops.

Chapter Eight

Parental skills

Introduction

In the course of the journey of parenting a high care needs child, a parent interacts within a mix of family experience, support and services (Weaver, 1999; Bennett, 2002; Read, 2002). For the mothers interviewed for this research, it is the experience of support that freed them to become fully involved in their child's life. Involvement by each of the mothers continued as her child went through the processes of assessment, treatment and rehabilitation and continued as her child grew. Involvement saw each of the mothers interviewed become expert in ensuring that her child's needs were met.

Family support

Family support was a critical factor in how parents coped during the initial period when they were caring for babies who were taking up a lot of their time. Some of the mothers interviewed had extensive support in the time shortly after their child's diagnosis and all still continue to have some form of family contact that supports them in the care of their child.

'absolutely all my life my Mum and Dad have travelled the pathway ... in and out of hospital.' (Respondent C)

The 'being there' by family members reported by mothers took the form of practical support such as child care, caring for siblings, being at clinical appointments, learning

personal cares, providing transport, providing after-school and school holiday care, and being there emotionally for the family.

Not all the families had grandparents that could accept a child's serious condition, but all families regardless of their acceptance of the child's fragility and impairment, took a role in providing respite care. None of the women interviewed used agency support for respite care currently, although one mother had in the past used half days in a day-care programme when her child was a preschooler. This mother reported using Family Day Care (where a child is cared for in a family home by an individual who is registered as a caregiver with an agency). All the women interviewed trusted family members to provide care for their child where the child's special needs would be taken care of. The mother who used Family Day Care used two different schemes consecutively, but in both cases chose placements for her child where the caregiver was an older woman whom she trusted to carry out her child's special cares.

Mothers, mothers-in-law, fathers and sisters were all involved in providing respite care. Each mother interviewed identified her child as having high care needs that required training in dealing with technical equipment, complex medications, or personal care techniques that were specific to providing personal care for her child. The children had differing care needs but a common factor was that their care needs required a level of expertise well beyond what would usually be expected from a parent.

Four of the children's families were receiving respite care hours and all were currently using these hours with family members whom the mothers considered could

be trusted to care for the child properly. The parent not receiving formal respite hours used grandparents as carers for her children.

Grandparents also took a primary role in providing transport, care for siblings while a child is in hospital, accompanying a mother to hospital appointments, providing after-school and school holiday care, as well as being the person who takes a child for periods of time to give a parent respite from the care work.

For some families, this has meant that grandparents, as well as parents, have had to learn to clear tracheotomies, administer medications, complete catheterisations and other specialist care techniques that were required to be carried out on a regular basis. The mastering of special care techniques is essential both for a child's family and for their respite caregiver. It is in this becoming involved in quite complex care that a sense of family attachment is seen.

'I wouldn't institutionalise her for the simple reason she does better at home.' (Respondent A)

Attachment is not a bond that exists only between a parent and child. Attachment is a bond that extends across family members to others such as grandparents.

'my mum is a real wise woman, she has been there since the beginning.'
(Respondent C)

These are the bonds that make family support a constant. In the mix of appointments, contact with a range of services and anxiety about a child's health, the continuity of family support is a direct counterbalance to the flux and change of experience in the medical world.

For some families, support extended across the family and had done so since the child with high care needs had been born. Two of the siblings of children with high needs have their own room at their grandparents' homes. This arrangement had been put in place when the siblings were very young and parents were spending a lot of time in hospital with their other child.

Family members

Support received from partners varied. Some of the research participants reported husbands becoming and remaining actively involved in their child's care. There was also the contrasting experience where no practical support was received from a child's father.

The role of parent was a role that fathers undertook as well. Three of the mothers spoke about how early breastfeeding placed them in a role of primary carer when their child was a baby and thus fathers did not always become immediately involved in care. Fathers also took time to come to terms with a child's impairment and care needs.

‘There definitely is a difference in the male and female response ... you know my husband’s way of coping was to become very busy at work.’

(Respondent E)

The distancing that one father used was seen as a way of coping with information about the child’s diagnosis. However, this turned around and he became involved as he took up a co-caring role, which built until he now takes a full dual parenting role.

‘we started to take turns, he would stay at the hospital and I would go home to sleep.’ (Respondent E)

Three of the mothers reported that their child’s father parented to a point where they now take joint responsibility for parenting. (Respondents B, D, E)

There was also the experience where a mother reported that her husband could not accept that their child had an impairment.

‘he basically wanted nothing to do with it ... he was more of a hindrance ... he couldn’t believe there was anything wrong with this child.’ (Respondent C)

This continued over the years:

‘even now after her recent surgery he still doesn’t see her as needing extra care.’ (Respondent C)

Even today, many years on, this father still has difficulty accepting the child is fragile even though the child still requires special care.

The experience of support received by a mother from her husband and the child's father varied. Three fathers remained actively involved in their parent role. One of these fathers no longer lived with his wife but he maintained a parenting role to support his child and his ex-wife in her role as primary parent. Of the two other fathers, one played no role whatsoever in his family's life, and the other took no active role as parent or support person for the child's mother.

Siblings

For siblings the experience of family life was different but not negative. The women interviewed reported that even though their disabled child was the priority in the family, and their other child/ren missed out on time and activities, they considered that their other child/ren had gained from the experience of having a high care needs sibling.

Mothers reported that their other children experienced a more difficult life because they lived in a family where one child took so much time.

'it can be very hard on the other children, especially when she is in hospital, as she got older it impacted more and more on them, they worried about what was actually happening to her.' (Respondent B)

'I think that we have never hidden anything from her [sibling], we have never forced her into ... you know you have to do this ... and there were times when her sister took priority.' (Respondent C)

There was the one variable that all the mothers identified as being important for their other children. They all reported that open, honest information was important in giving their other children a sense of belonging and understanding.

Three of the mothers identified that their other child/ren was stronger and was likely to contribute in a positive manner later in life because of the skills they had developed living in a family where there was one child who required extra care.

Setting aside time

The unique situation of the link between a child who is vulnerable and fragile and their parent ties a parent into a space where making time for oneself as a mother is difficult.

'I just love to lock the door, my friends tend to want to organise my time when I am on my own ... I just want to lock the door take the phone off the hook and have no one ask me for anything.' (Respondent B)

The constancy of the work involved in parenting a high care needs child can leave a mother feeling there is no time for her own needs.

'No, I just don't want anyone, I just want to be by myself. Because you are on constant demand 24 hours ... it just doesn't stop.' (Respondent A)

There is acknowledgement from the mothers that time must be set aside and support must be used if a healthy balance is to be kept in the family.

'having that support so you need to get a break, you need to get a break.'
(Respondent D)

Accepting that a child has high care needs means that a parent must make adjustments to how they care for themselves. All the mothers interviewed identified that they took time out for themselves and that this was important.

Time was not seen as a commodity that stretched and the mothers interviewed all spoke about very busy lives. Setting aside time for oneself is a step toward competency in parenting; however, this meant that a parent must have a process for taking time out. All the women interviewed used either the formal needs assessment respite care, or informal care, to ensure that they had a break from the constancy of the work in parenting their child.

'It is important to ask for help, something that I found quiet hard. To actually stand up and say to your friends and your parents ... I need help and to receive it that is quite a hard thing to do.' (Respondent A)

Asking for help is not easy but identified as essential. Part of asking for help is also associated with seeking advice and support from parents in a similar situation, and in this the parent support group was reported by all the mothers to be important for them.

Advocacy

Becoming assertive and gaining a sense of competence comes from facing challenges and overcoming them (Read, 2000: 48). There were no shortages of challenges for the individual mothers.

‘I think that every time we go to hospital nothing has gone smoothly, every time she has had surgery nothing is straightforward.’ (Respondent D)

On top of all this, a parent has to live in a world that does not change greatly for their child.

‘when you’ve got a child with a disability that doesn’t go away, that just keeps going, and going and going ... understand that with a child with a disability you never actually get to a finality.’ (Respondent B)

A role that all the mothers reported was keeping track of medical reviews, initiating them if they considered it was necessary, and keeping up to date with information about technologies and support available for their child.

‘To get her into the programme to be monitored to find out what she needed medically ... the other problem is the recall system [talking about the system

to recall for clinic appointments] hasn't been working very well for us we seem to be dropping off that and it's only because I keep saying we should have had an appointment in six months and it's been seven months now and ring up.' (Respondent B)

Advocacy and case management was a role that all mothers played to some extent. The role had grown over the years and for some of the mothers had extended to the work they did in parent support groups. Each mother to some extent was a case manager and holder of information for their child.

Agencies and services

The current experience of support received from agencies and services was also a positive one. After the difficult experiences of medical services and dealing with new circumstances that some of the mothers reported in the period after diagnosis (discussed in Chapter Seven), all the mothers moved into a position where they had comfortable and controlled relationships with medical services and support agencies. All the mothers interviewed were still involved with specialist medical teams for their child, and all reported the medical support they currently received as exceptional.

Agency support was identified by some of the mothers to be essential as the contact was experienced as a non-conditional support that allowed a mother to separate it out from family issues.

In an environment where a child is very fragile and undergoing intensive medical intervention, there were times when talking to family was just too close and independent professional help was sought.

'it was better to talk to independent professional help about her.'

(Respondent E)

Taking this step away from personal support to professional support provided a space to see more clearly what the reality of a child's situation was. In the early days, support came from Plunket Nurses, the Meadowbank day-based Plunket programme, Starship and Greenlane Hospitals, maternal mental health, general practitioners, La Leche and parent support groups.

It is important that the person in the service or agency that a mother uses is someone who she is comfortable with (Sloper et al., 1999). For the mothers interviewed, this experience was not a given and some mothers reported stress when professionals they had been engaged with had to be replaced. One mother talked about her despair at finding someone to replace a worker who has been coming into the home for three years to assist with personal cares such as bathing.

'we have lost her, we have lost her ... she hasn't got the time.' (Respondent

A)

For this mother there is the experience of engaging with a worker from an agency. It is the worker who made the difference, who had become a friend and who now has to be replaced.

Support was also experienced when professionals gave parents a sense of being there and available to talk. This experience was an important experience in feeling secure in the support available.

‘being able to pick up the telephone at any time.’ (Respondent C)

There was a question of how to ensure that support is optimised. One mother spoke about her uncertainty when being assessed for services.

‘should we leave the house like a pig sty and look like we can’t cope?’

(Respondent E)

All the mothers interviewed were aware that services were limited and assessment based on need was really quite subjective. By the time mothers had been in the business of special care needs parenting for a few years, they were had all left aside any hesitancy about asking for help and had become assertive.

‘I’m quite a determined person ... it is important to ask.’ (Respondent C)

This sense of the importance of services also came through in the role that three of the mothers have taken in parent support organisations.

The one exception to supportive agency contact was contact with WINZ. This was not reported as a positive experience. There is one universal entitlement that the parents of all children with impairment that meets the definition of a disability can claim (Ministry of Health, 1999a: 1). This allowance, HCA, is paid out by WINZ and some of the mothers reported that contact with this agency had been fraught with misunderstanding and misinformation.

One mother had recently been informed her child's entitlement to HCA had been reviewed and she that was no longer entitled to receive the allowance. This child has a chronic and permanent debilitating condition that will only deteriorate. One mother had never applied for the HCA and she had only recently become aware of her child's past entitlement to this allowance. This mother could recall applying for assistance with costs when her child was younger and when she was in receipt of a domestic purposes benefit from WINZ (actually from the agency that preceded WINZ) but her application had been refused.

'I was on DPB we looked at whether they would cover extra costs, it was a nightmare in itself, it was a great delight to tell them where to stick their DPB.' (Respondent C)

This mother had no recall of anyone ever talking to her about an entitlement to a HCA. The child had an impairment that lasted for many years and only recently was corrected with a procedure that involves the on-going use of technical equipment.

Two of the mothers interviewed spoke out about the use of the term 'handicap' for the allowance. One remarked that she could not believe the term was still used for the allowance. The other commented that she had not talked to her child about the allowance because of this label, even though she knew that when her child was 16 she would be eligible to transition to an invalid benefit. This mother spoke about her distaste for the words 'handicap' and 'invalid' as labels that portrayed a negative image of the circumstances of her child's impairment.

Parent support groups

A parent support group is a powerful agent for parents of high care needs children. Parents in informal support groups experience less stress and a sense of support (Bennett, 2002; 29). All the mothers interviewed had involvement over time with a parent support group.

A parent support group provides a process focused on 'sharing'. The group based experience is one of reciprocity of emotional support, advice, advocacy and practical support.

'Being in a new mothers' group [with mothers where child had a similar diagnosis], that was like coming home.' (Respondent D)

Once involved with a group, the role of participant became more than just a reciprocal one of providing advice or being a listening ear. Parental involvement in the early days took the form of coffee mornings, advice and leaflets, someone to talk to. There seems to be a dynamic at play in the support group arena that encourages

more active participation from parents. Three of the women interviewed have gone on to take more involved roles in the parent support organisation they belong to. They have extended their involvement to the wider roles of lobbying for services and funding both at a regional level and at a national level. At a regional level, the groups promote and actively work to ensure that support is available to new parents. This support ranges from provision of nappies and parking entitlements, practical home help such as gardening, visits from specialist medical support staff, and funding for specialist equipment.

The reasons for more active involvement are acknowledged as being related to a child's diagnosis but in terms of the commitment made, such as in time put into group work, each mother's involvement cannot be seen as selfish.

'in reality my motive is selfish because in helping others I am helping myself, in helping others I am making sure my child is looked after.'

(Respondent D)

All the while, the mothers involved in these groups at a regional and national level maintained their role as parent support group members attending local coffee mornings and made themselves available to families who had recently been given information that their child had a diagnosis.

The role that parent support groups play as self-help groups seems to be a very powerful one. Mothers who become involved at any level all report positive contact and acknowledgement of self in the mix of roles as ordinary special parent, adviser,

assertive person and lobbyist. Belonging to a group appears to have a benefit that goes beyond building skills and finding ways to cope with new and different realities in the sharing of the group.

Reflection by some of the mothers saw that initial involvement with a parent support group was a means of moving more readily into a position where a parent approached their role with a sense they would be able to achieve success.

‘to get into a parent support group ... so then you know you are not alone and that it’s not something that you caused and its okay not to know what to do.’ (Respondent D)

There is, however, a process of facing the reality of their child’s situation that must be overcome. The mothers recalled that there was a fear of seeking support initially that was related to accepting there was a problem for their child.

‘I think that admitting you need a support group, then that is admitting there is something really wrong here. You pretend there is nothing wrong by not associating, you just try to keep life as normal as possible and that was something out there.’ (Respondent E)

‘but it can be a scary thing to get into that group but you still want to pretend that it is not as bad as it is.’ (Respondent C)

Another mother viewed the support from parents as important for her as this helped her cope with the personal stress of the initial influx of information from medical services and worry about her child.

'I have met wonderful people through [the support group] I've become quite involved. It was really helpful because that has given me a whole different bunch of skills, it has made me realise that children are pretty precious as well.' (Respondent D)

The step into a parent support group is not easily taken, but once it has been taken a parent is able to access both emotional and practical support from other parents, who are people who have a working knowledge of what is happening for a parent new to a situation.

Conclusion

Becoming a competent parent means that the whole world is re-evaluated. This came about partly because parents had been freed up to concentrate on being involved with the world that they found themselves in with their child. When other family members put themselves forward to take care of siblings, to transport, cook and provide an alternative home for siblings, a parent was able to invest the time in becoming involved in the complex world of assessment, treatment and rehabilitation.

The focus of parents and families has continued to be on seeking services for their child who experiences impairment. Parents have remained focused on accessing the

support they require from agencies to enable their child to live in their home. This has meant that family members have learnt specialist medical and care techniques.

In this journey, parents have continued to engage with specialist medical services, have maintained a role at some level in a parent support group, and have continued to work to maintain balance in family life for themselves and for other family members.

Agencies have also provided support that frees a parent to become involved in their child's complex life. However, a primary initiator of parental change toward the role of expert parent is the support received from those who share the experience, the parent support group.

In some families, fathers took an active parenting role, while in others the father took no active care role and in one case a father no longer has any contact with his child.

Parental competency has developed directly out of being involved with seeking to ensure that a child has available the optimal services they require for rehabilitation and a quality in their life. In setting out to lobby for their child, a parent enters a world where they become aware that time is a very scarce commodity, but where, in keeping up an active involvement in the work of parenting their child, they must make time for themselves. This is but one of the balances that a parent who is moving toward building on the strengths in their lives must seek to resolve.

Chapter Nine

Discussion

Introduction

In this chapter I discuss the factors the interviews highlighted as having some bearing on the growth of parenting competence. I draw these together with the theories grounding parenting in a family that is caring for a high care needs child. I then discuss professional support and the influence that such support may have on the development of parental skill. The information in the stories of the five mothers interviewed revealed a view of parenting competence developing as parents negotiate their way through a maze of systems to support their child. At the same time, each parent kept a focus on their child's needs and maintained a balance in the family. I briefly discuss this experience in relation to systems theory, feminist theory and attachment theory before I move on to discuss professional support.

This project set out to find out what it was in the mix of support and services that supported parents to build the competence they need to parent a high care needs child. The reflective stories of the five women do not answer the question about which services and support were instrumental in building competence in all parents raising high care needs child. What the stories revealed was that five ordinary women were in fact quite exceptional. They led ordinary lives with one exceptional circumstance as they raised their families. This circumstance was that they were parenting a child under circumstances that they had not planned or prepared for.

One common factor for these mothers was, and still is, that none of them were, or are, parenting in isolation. Some had support of husbands even if they did not live with them, and even if the father did not fully accept their child's impairment. For some, support from grandparents was available, and for some there was also support from other family members. Each mother had a mix of family support that was present from the time their child was diagnosed.

The family support system

Parents of disabled children who have family support report that such family support is an important source of strength for them (Bennett, 2002: 35) and support from grandparents, if it is available, is invaluable for parents of disabled children (Mirfin-Veitch, cited in Bennett, 2002: 38). All five parents interviewed for this research reported some form of family support. Early support was in the form of actions that freed the parents, whose child was admitted to hospital for assessment and or treatment, from the need to ensure their other child/ren was cared for. The impact of having a grandparent to organise child care for an older sibling, transport, providing a home, making meals or doing washing is a demonstration of the rebalance that took place in the family systems of each of the mothers interviewed.

When each parent was faced with the choice of being with their baby when the child was admitted to hospital for assessment or treatment, they were supported by a partner or a grandparent or, in some cases, both. It was in this time that the mothers interviewed learned the practical skills required to care for their child. Marshak (1999), Weaver (1999) and Read (2000) all highlight family support as important for a parent when they find themselves having to take on the responsibility of a child who

requires extra care and extra time. Bronfenbrenner's systems theory (Luster and Okagaki, 1993; Smetana, 1994) ties the experience that the five mothers had in with the understanding that support from people in familial relationships supports the rebalance and readjustment of individuals in the family and thus the family system as a whole.

In practical terms, this meant that each mother was able to be with her child when they were in hospital because grandparents stepped in and freed the mothers to do this. As well as the practical assistance, there was the 'being there' to talk to, or to accompany a mother to appointments. Other family members took up tasks to support mothers as well. Family support also allowed husbands to start becoming involved and two mothers reported that their husbands started to take turns with the child in the hospital and that they also took up learning the care tasks. This is the practical side of family support that enabled parents to fully attend to their child's needs during investigation, assessment and initial treatments.

A situation where a parent is able to be present during assessment and initial treatment phase has three consequences. Firstly, a parent is present when medical staff who are involved in determining what is happening for a child call and see the child. The professionals meet the parent and they discuss their child's situation with them. While assessment proceeds, information is tested and shifts. Options are explored and ruled out and new options are explored. By being present with their child, a parent is placed in a situation where they are drawn into their child's treatment. Even if intervention is complex and technical, and specialist decisions are made outside the clinic room or away from the child's bed, just being present with their child places a

parent on the pathway to gaining some understanding of what can happen for their child. The importance of parental involvement in the process becomes clearer as a child grows and a parent steps in to take an active role as advocate for their child. All five women identified having to lobby for services, push for medical appointments and be assertive about their child's needs.

Secondly, becoming a holder of information places a parent in a unique situation where they are the one person involved in all clinics and all interventions. Through this process they gain confidence and competence as an agent who understands their child's situation.

Thirdly, a parent is placed in a situation where they have had to learn the skills to carry out procedures related to their child's care. To be able to suction a tracheotomy tube, replace a tractotomy if it becomes dislodged, provide care to ensure a child's skin does not break down, that their pain is addressed, to understand infection control, or ensure that a diet meets special needs are some of the skills that a parent may be required to learn and carry out at home as soon as their child is discharged from hospital. Learning these new skills is not a solitary academic task but one that arises out of their child's need for competent specialist care to develop and maintain their well-being.

All five parents were placed in the situation where they became, in a very short space of time, a competent and knowledgeable parent who had the time to attend to their child's needs. They had come to know the specialist medical professionals working with their child and had discussed their child's circumstances with them. They had

learnt to administer specialist personal cares to a baby, and had been there through periods of crisis as well as periods of uncertainty. This was the grounding for the building the knowledge and skills to become 'expert' parents.

Bronfenbrenner's theory of systems (Luster and Okagaki, 1993; Smetana, 1994; Marshak et al., 1999) provides a means for understanding the impact of such influences as a hospital system, the belief systems that have underpinned the definitions of disability, and policy initiatives such as Disability 2000 where an inclusive world is promoted.

The initial experiences of the five mothers interviewed took place in an environment where family support provided a basis for the growth of skills and competencies to meet their child's care needs. Their skills also developed across the systems of support within their wider world where inclusion and family care were ideals that underpinned the agency and service support provided to their family. Even though some experiences such as those with WINZ (discussed in Chapter Eight) were negative, all the mothers interviewed had developed into 'expert' parents for their child.

Taking responsibility

Caregiving parents of high care needs children move beyond what is normally expected in a reciprocal relationship. Twigg and Atkin (cited in Read, 2000: 86 – 87) report that caregiving is grounded not only in responsibility to the person being cared for, but in the sense that caregivers develop that it is up to them to ensure 'that things are made to happen' (Read, 2000: 87). Responsibility is reinforced when a parent is

placed into a situation where all intervention to address a child's critical situation occurs via full consent. The mother who expressed her anxiety in being asked to give consent, not only was facing a reality, but she was acknowledging her responsibility as the parent.

Responsibility arises from the attachment bonds that exist between a child and their parent. The attachment bond places a parent in the situation where responsibility and personal relationship come together. This is a critical difference between parent and professional. A professional may have empathy, is likely to have sympathy for pain and suffering, but there is no familial attachment bond. It is the attachment bond between the parent and their child that keeps a parent centred on their child's care. This bond becomes more than an anchor, it becomes a catalyst for change.

Responsibility and attachment

To immediately absent yourself from your home and move into hospital with a child calls for considerable stamina and resilience. When caring for a disabled child it is, as Read (2000: 86) notes, about more than the situation, it is about 'love'. The opportunity to spend the time was given by family support, but it is the parent's bond with their child that will not allow them to leave their child unattended. Each of the mothers interviewed for this research went with their children when they were required to be admitted to hospital.

Case manager

Caring for a disabled child can be complex (Sloper et al., 1999; Read, 2000). Dealing with medical systems, with educational systems, with family needs, and with public perceptions of impairment are all aspects of parenting a child who has high care needs (Weaver, 1999; Read, 2000). The five mothers interviewed all went on to take up the role of case manager to some extent for their child. Mothers tracked appointments and when they were overdue, followed this up, they kept investigations going when medical professionals reported that nothing was amiss, they used the needs assessment service to access support for themselves and for their family, they kept a focus in the family on their child's needs while balancing the needs of their other child/ren, and they became actively involved in promoting their child's needs in a way that mirrors the role of case manager.

Parent support group

All the women interviewed were accessed via an organisation that actively promotes parent support groups. Thus all were involved to some degree in a parent-controlled group that focuses on services and support for children and their families and is centred around their child's impairment and diagnosis.

For some of the mothers, their involvement in parent support organisations has developed until they took active roles at a regional and national level. Isolation is a critical factor in caring for a disabled child and informal support from other mothers is recognised as a counterbalance to isolation (Read, 2000: 56). Read found that mothers of children with very high levels of disability often could not access informal support. The parent support groups that each of the five women belonged to centred

on their child's impairment and in fact may be a bridge across the isolation that Read reports. All of the parent support groups were supported in some way by PFRC but the groups were controlled and driven by the parents who made up the group.

Professional support

The five mothers all reported positive experiences with the professional support they were currently receiving. Some had reported negative contact in the early days after diagnosis but all now received what one mother termed 'exceptional support'. Support from professionals is recognised as a factor that does impact on parental competence (Mukherjee et al., 1999; Read, 2000; Bennett, 2002). The support can come from anyone who is in contact with the family, since what parents report as being important is that they receive support from someone who is accessible and whom they feel understands what is happening (Mukherjee et al., 1999; Sloper et al., 1999).

One type of support that is known to promote active change in families caring for a high care needs disabled child is the concept of 'key working' (Mukherjee, et al., 1999: 32). Parent's spoken to by Mukherjee et al. (1999: 26 – 27) identified a 'key worker' as being a successful concept for them. For those parents who had experienced an 'unsuccessful' key worker experience, the idea was seen as a desirable construct that 'should be a, *integral* part of services provided to families with a disabled child' (Mukherjee et al., 1999: 27).

None of the mothers interviewed in this research identified anyone who came near to taking a formal key worker role in their family but all had contact with a professional involved with their child who fulfilled some aspects of this role.

Success

Is there a link between the support that a family receives when they are under stress and becoming a successful parent to a high care needs child? Finding that they were faced with a future caring for a child who has high care needs was stressful for all the women interviewed. For all five, the information that their child had a major impairment was a shock. All five of these mothers were involved in the process of supporting their child through periods of investigation and assessment. All five were also further involved in processes of treatment and rehabilitation and all five had come to be part of a dedicated parent support group that was proactive in seeking to promote the group they were involved with.

This research does not provide a definitive answer to the question of links between support and parental competence. Interviewing five parents who were recruited via an active parent support programme cannot answer this question fully. What the research finds is that the mothers interviewed had the same experience as that outlined in Read (2000: 48). That is, they met challenges and built competency.

What stands out in this research was that all five families were supported by wider family to the extent that they were able to become fully engaged with the process of assessing and treating their child right from the time when their child was a baby and diagnosis was new.

Another common factor was that all five families were involved with a parent support programme that linked them with a group where children in the families involved had a similar diagnosis. Support programmes are known to be important for building competence (Weaver, 1999; Bennett, 2002).

Interviewing five women who have a close relationship with a parent support network has revealed the experience of parents who remain engaged with active parent support programmes. Discussion highlighting their experience creates a question about what happens to parents who are isolated, to those who do not have family support, and to those who are not coping. This work does not address those questions but suggests that it can be argued such parents are likely to be the parents and families for whom some active professional involvement may make a positive difference.

In New Zealand, services and support have been provided to families by the state and by non -Government organisations over the past 50 to 70 years. In that time, there have been changes in service delivery from one of purely medical intervention and treatment, to a model of family-centred care that is in place at this time. Families are now supported to care for their disabled and high care needs children in their home (Ministry of Health, 1999a; Weaver, 1999) and this process has the potential to provide all families with access to professionals who can play a role to actively ensure a parent is supported and has access to information.

Home-based care does come at a cost to families as parents report dealing with complex and, at times, inadequate services to support them as they care for a high care needs disabled child (Mukherjee et al., 1999; Weaver, 1999; Ministry of Youth

Affairs, 2000). A model of intervention where a professional works across professional boundaries has the potential to facilitate change in a family system (Mukherjee et al., 1999). Individual change, change in how an agency works with families, change in social policy that drives programmes or change in other services available to a family is a wider role than that of a 'key worker', but is a role that social work can take on (see Appendix 1). Munford and Sanders (1999; 221 – 223) advocate such a role for social workers supporting families who are caring for a disabled child.

When a family faces an unexpected and unplanned pathway that disrupts family life in a major way, there is a role for intervention that will assist a family rebalance and adjust to circumstances. The dynamics of support and experience in the early years reported in this research indicates that there is an opportunity for intervention to promote an environment in which parents are given the space and time to take on what is happening for their child and for them. When parents are first told that their child has a disability, they may not be able to absorb what is happening around them (Bennett, 2002: 23) and this was the experience of the mothers interviewed in this research. Intervention has a role in reinterpreting experience and reframing this. Anger, sadness, perceptions of disability as pathology and blame are issues that can be reworked (Munford and Nash, 1994).

Professional intervention can become one mechanism to move a family toward regaining balance and building strengths after the 'initial hurting' on being told a child has an impairment. The role is one that is not exclusively a social work role, however. The interviews with the mothers in this research highlights that the

important factor is that the person who supports a family is available and that the family trust them. A model of intervention can work across all the environments that support a family (see Appendix 1) and does not necessarily need to focus solely on the family. However, a first step in this is supporting a family to gain a sense of control (Fewell and Vadasy, 1986; Alpher et al., 1994).

Knowing when a family is being overwhelmed and understanding the reasons why the situation is being experienced can be a time when intervention can make a positive difference in a family. The skill lies in knowing when a family is in need of advocacy, when it is in need of support, when information or clarification is required, or when techniques based on intrapersonal needs are required, and having the insight and ability to work across a number of these strands at any one time. (Munford and Sanders, 1999; Thompson, 2001)

A first step to success

Having to 'get on with it' leaves a parent at a point where they take that extra step and become the parent their child requires. There is a gap created by the needs of a child and a parent steps into this to ensure that their child's needs are met. This 'step' arises directly out of a relationship based on attachment and is a precursor to strengths-based parenting. Proactive intervention at a time when a parent is on the verge of change has the potential to unlock family strengths that will build positive pathways in the family.

Understanding how services are delivered, why parents may experience grief and loss, how the bond between a parent and child operates, and aspects of family function in a

system of managed services, can allow a professional to intervene in a manner that frees up potential in a family in such a way that a family gains some sense of control over what is happening.

Setting aside the potential for professional intervention to make a positive difference in families, there were two aspects that stood out in the research and that could easily be addressed.

Negative images

The first is the continued use of the term 'Handicapped' when parents apply for a disability support entitlement from WINZ. The message was clear from some of the mothers interviewed that the title 'Handicapped Child's Allowance' by WINZ needs to be reconsidered. Entitlements that continue to negatively label contradict the forward-thinking policies that promote inclusion and participation.

The second is the needs assessment process. The process of accessing services and support by measuring failure does nothing to build on strengths that already exist in families. Munford and Sanders (1999) raise this point and this research found that the families who go through the assessment process are well aware that the process is one with the potential to react to pathology rather than strengths. The remark 'do I leave the house a mess' so as to 'look like I am not coping' (Respondent E) illustrates a perception of the needs assessment process as a process where receiving support services is triggered by pathology rather than potential.

Conclusion

For the mothers interviewed for this research, family support has been critical. The support has given each mother the time and the space to become involved in their child's life from a time immediately after diagnosis. Being able to attend fully to a child's needs appears to have a strong influence on laying the groundwork for future competency and future success as a parent.

This support has continued over the years and the mothers interviewed reported that the continued support they received was seminal in allowing them as a mother the space to become fully involved in their impaired child's situation in times of crisis.

Active involvement does not arise solely from the opportunity to be involved. Another factor in a parent's involvement with their child is related to a sense of responsibility and connection based upon a sense of love and reciprocity that balances a family's responsibilities.

One major influence that stood out in the data from the interviews was that all the mothers interviewed had contact with a parent support group. For all, involvement in the group they belonged to had some influence on their lives. For some, involvement was local and involved meeting with other parents of a child with a similar diagnosis. For some, involvement had taken them out of the family into a wider area where they played a role as support person to other families. Support-group involvement appears to have a correlation with parental competency.

Professional support was a given that all the mothers interviewed considered to be a positive factor in their lives. This area contains the potential to deliver an intervention that may trigger the development of competence in parenting a high care needs child. A model of support to families raising high care needs disabled children already exists in the 'key worker' (Mukherjee et al., 1999) model but this is not a model that is currently in use in New Zealand. The model is a well-researched one that is considered to have the potential to support families caring for disabled children in focusing on the strengths that are present in the family.

The research cannot provide a definitive answer to the question of which type of support the mothers who were interviewed received had built their competence as a parent. What the data from the interviews revealed was that the five women interviewed had family support, a connection to PFRC via a parent support group, and that they all took an active role in some form of parent support group.

What was further revealed from the data collected in this research is that all the mothers were drawn into a complex medical world of assessment and treatment very early in their child's life. The process of being drawn into expert fields of parenting came from having to act because of their child's situation. In all cases, the mother — and in some cases the fathers — eventually became involved in specialist cares that had to be carried out for each child.

The analysis suggests that parents who succeed in their role as a high care needs parent are likely to be parents who take up a role where they become involved without waiting for someone to assist them. A parent reacts to their child's needs. Skills are a

flow-on effect, and they develop out of this interaction, given the necessary support and information. It is this message that comes through in the interviews that I carried out.

Chapter Ten

Conclusion

Summary

In New Zealand, the way children who have a disability and high care needs have been supported has developed to a point where family-centred care has become a norm. Last century, children with disability were often placed in residential facilities for treatment and rehabilitation. In the latter part of the 20th century, awareness grew that it was not in children's interests to be separated from their family, even though they required a high level of specialist care. A move to family-centred care followed.

There is no social policy related specifically to the care of disabled and high care needs children, instead children are covered in the wider range of policies that have been implemented following legislation which promotes inclusion and rights for adults who are disabled.

In New Zealand, influences in legislation and the provision of services have been a focus that defines disability as a social construct arising from how individuals or specific groups are excluded from participation in the community because of structural constraints. Even so, the model of disability that underpins assessment for services provision remains one that is based on a medical diagnosis that defines loss of (or lack of) an individual's abilities.

Family-centred care for a child who has high care in reality means care by the mother. There are costs associated with taking on this role. The hard physical work, the

emotional stress, the isolation of the private world of family caregiving, the loss of potential family income and the extra financial costs associated with a child's care can take its toll of a parent. A parent also takes on the role of keeping a balance in the family for self and for other family members.

This research accessed data from five mothers who were engaged in the work of raising a child who had impairment and who also had high care needs. Analysis of the data from the interviews revealed influences that may build strength in a parent as they take on the role of parenting a high care needs child. The influence of becoming involved and taking responsibility for specialist care from an early age in the child's life the influence of family support, the influence of peer support and the influence of professional support were all discussed.

Recommendations

The research raised three points that need further consideration. The first is the question of how parents raising a high care needs child cope when they lack family support. This requires further research.

The second point is in the response of the research participants to the branding of the support available from WINZ to families raising a high care needs child. The branding of entitlements such as HCA and IB can promote and sustain negative beliefs about personal impairment. This branding flies in the face of social policies that promote inclusion and full participation. The categorisation of benefit and allowance entitlements needs to reflect the social policies that advocate inclusion and participation.

The third point is that current needs assessment process requires improvement. Consultation with the stakeholders related to family-centred care needs to be undertaken to determine a more 'family friendly' process of accessing services required to support family-centred care. The needs assessment process should be widened to remove the focus from a loss or deficit assessment, to a focus that builds family strengths.

Conclusion

The recruitment process used to access research participants has meant that there is a strong bias in this work. The group of women interviewed was small; all participants were recruited from a parent support organisation, and all had built up some form of working relationship with a support group. Thus the findings of this research cannot be extended to the total population of parents who are bringing up a disabled child or a child who has high care needs. What the research reveals are variables that have influenced the parenting of a discrete group of mothers who have had support from immediate family members from day one, who became involved in services that interacted with their child, and who have engaged with, and maintained, a relationship with a parent support group.

The preparation for becoming an 'expert parent' began as soon as a mother commenced involvement in her child's life. A trigger for meeting a child's needs is the parent's response to their child, but it is the ongoing involvement that builds expertise. All the women interviewed for this research described a journey that saw them becoming heavily involved in medical systems to ensure that their child's needs were met. As parents 'become involved' expertise arose out of the partnership

between a parent, their family and the dedicated services that exist to assess, treat, rehabilitate and care for a high needs child.

All five mothers interviewed could be described as having developed competency and parental strength because they have had the support and means to become involved in all aspects of their child's life from the very early days. They have also shared information with parents in similar circumstances, and in some circumstances they have moved into working with a parent support organisation to provide other parents with support.

Coping with an overwhelming situation, where a child has a chronic and life-long condition, presents a challenge to those services that interact with families in the very early stages of a child's life. It is here that those families who do not cope are likely to engage in intervention that has the potential to facilitate change in the family. Such change is likely to promote understanding, control and a sense of being able to cope with potentialities rather than pathologies.

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Appendix 1: Ecological social work practice and disability¹

Children with disability and their family: social work intervention

A map of an ecological model for working with families where a child has disability

Critical theories, sociological theories

Political environments: Family care

Ideological Environments: Inclusion

Definitions of disability Models of disability

Power and oppression

Systems: Structural analysis

Feminist thought; racism; colonisation

Psychological and behavioural theories

Attachment and loss

Human development

Behaviour

Family systems

Family needs – Agency mandate: Managerialism – Contracted service delivery

Family capacity and resources

Consent

Privacy

Respect

Citizenship, rights and entitlements

Empowerment

Inclusion

Advocacy

Change

Change in family system

Change in agency mandate

Change in policy

Change in medical, educational, welfare services

Social worker professional practice

Education – models of social work intervention

Supervision Professional body

¹ Ecological social work practice and disability. Designed by P Tucker. Drawn from Prasad, R., Model for Ecological Practice, course work Massey University, 1996; Munford, R., Sanders, R., 1999; Thompson, N., 2001; in consultation with Wendy Greenwood.

Appendix 2: Notice about proposed research

RESEARCH PROJECT: RAISING A CHILD WHO EXPERIENCES DISABILITY: A PARENTAL VIEW

My name is Pauline Tucker and I am a student enrolled at Massey University, Albany. I am carrying out a research project about parenting a child who experiences disability. To collect data for the research, I would like to talk to parents about their experience of the support and services they have used to care for their child. The research will form the basis for a report that will be submitted to the University in partial fulfilment of the requirements toward a Master of Social Work degree.

The research project I am undertaking looks at the experience of New Zealand European parents who are raising a child who experiences physical disability, is aged between 6 and 16 years old, and who has high personal care needs. The process would involve a 1 to 1½ hour interview for any parent who took part.

If you think that this is a project that you would be willing to take part in, could you please phone me on (09Auckland) 5278327.

This research has been approved by Massey University, Albany Campus, Human Ethics Committee, protocol 02/060

Pauline Tucker
09/5278327

Appendix 3: Letter to prospective interviewees

7 Parata Street
Glen Innes
Auckland

December 2003

Dear

Thank you for taking an information sheet from Mrs Alford and contacting me about the research. The information sheet gives you information about the research that I talked to you about on the telephone.

I confirm that I spoke to you today and that we have made a time when I can talk to you about your view of raising a disabled child with high care needs. Our appointment is on (date) at (time) at (address)

If you have any questions about the research you can phone me or contact me by email. My contact details are on the Information Sheet.

As I said when I spoke to you, it is important that you feel comfortable taking part in this research and that if you do change your mind please phone me and we will cancel the appointment.

Thank you very much for taking the time to talk with me.

Regards

Pauline Tucker

Appendix 4:

RAISING A CHILD WHO EXPERIENCES DISABILITY: A PARENTAL VIEW

INFORMATION SHEET

1. My name is Pauline Tucker and I am enrolled in the Master of Social Work programme at Massey University. I am being supervised in this research by Mrs Jill Worrall and Mr Neil Lunt. Mrs Worrall and Mr Lunt are both lecturers at Massey University, Albany.
2. This research seeks to explore the experience of New Zealand parents who are raising a child who has a physical disability that requires a high level of extra care from their parent or parents.
3. If you have any questions about the research you can contact Pauline Tucker on 09 5278327. Alternatively you can contact either Jill Worrall on 09 443 9700 ext 9084 or Neil Lunt on 09 443 9700 ext 9041 with any questions or queries.
4. I hope that parents will be willing to talk about their experience of accessing services and support that has assisted them in raising their child.
5. For this research I am talking to parents who identify ethnically as New Zealand European. I consider that families who identify ethnically as being Maori, or Pacific Island, or Asian as possibly having differing family structures that provide identifiable support that is directly related to their family histories. This study is limited and as such has only the scope to interview parents who identify as New Zealand European.
6. For this research I will be interviewing parents who are New Zealand European and caring for a child who is: aged between 6 and 16 years; has a physical disability; and requires a high level of personal care.
7. I hope that people who take part in an interview will welcome the opportunity to talk about their experience of what have they found helpful, what help they would have liked but didn't receive, what advice from friends, family or professionals was of value to them.
8. The interview will take between 1 hour to 1 ½ hours. You can choose the venue to where the interview can take place. I can call at your home, we can meet in an office at the Parent and Family Resource Centre in Onehunga, or we can meet at a venue of your choice.
9. The information gathered from the interviews will then be considered and analysed to gain a greater understanding of what support is important for parents. The information will be compiled in a final report that will be

submitted to Massey University for the completion of a Master of Social Work qualification.

10. The interviews will be recorded on an audiotape and will then be transcribed. The person who transcribes the tapes will sign a confidentiality statement. The audiotapes and the written transcripts of the interviews will then be stored securely until after the final report is completed. No one, other than the people named as the supervisors for this piece of research, and the transcriber, will have access to any audiotape or transcript once the audiotapes have been transcribed.

11. When the project has been completed the researcher will store the audiotapes, interview transcripts, the list of people interviewed, and the list of people who have requested a summary of the findings of the research in a secure place for five years. After that time all the audiotapes, transcripts and lists will be destroyed.

12. Confidentiality. No names or other identifying information will be used in the final research report. No names or personal information will be passed on to any other person or organisation.

13. Participants who take part in an interview have the right:
 - to decline to participate
 - to refuse to answer any particular question
 - to withdraw from the study up until after they have completed the interview
 - to ask any question about the study at any time during participation
 - to provide the information on the understanding that as a participant your name will not be used
 - to be given access to a summary of the findings of the study when the study is concluded

Pauline Tucker
09 5216050
email: karioi@xtra.co.nz

Appendix 5: Consent form

RAISING A CHILD WHO EXPERIENCES DISABILITY: A PARENTAL VIEW

CONSENT FORM

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand I have the right to withdraw from the study up until the completion of the interview process, and the right to decline to answer any particular question during the interview.

I agree to provide information to the researcher on the understanding that my name will not be used without my permission.

I understand that the information will be used only for the research and publications arising from the research project.

I agree to the interview being recorded by an audiotape.

I also understand that I have the right to ask for the researcher to stop recording the interview at any time during the interview.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signed:

Name:

Date:

Please write your address below if you wish to receive a summary of the research findings when the research has been completed.

Address

.....

.....

Appendix 6: Statement of Confidentiality

STATEMENT OF CONFIDENTIALITY TRANSCRIPTION OF TAPES

RESEARCH PROJECT: RAISING A CHILD WHO EXPERIENCES DISABILITY: A PARENTAL VIEW

Researcher: Pauline Tucker, student, Massey University, Albany

Supervisors:

- Jill Worrell, School of Social Policy and Social Work, Massey University, Albany; Ph: 09 4439700 ext 9084.
- Neil Lunt, School of Social Policy and Social Work, Massey University, Albany. Ph: 09 4439700 ext 9041.

I understand that the information contained in the tapes that I am to transcribe is confidential and not to be discussed with any person.

I understand that if I have any issues I wish to discuss I can contact either the researcher or her supervisors.

I have undertaken to transcribe each tape on to a floppy disk.

When I have transcribed the tape, I will return the tape and the floppy disk to Pauline Tucker.

I will keep a copy of the information on my computer drive until Pauline Tucker confirms with me that she has received the transcript and was able to access the information; or for no more than five working days. I will then delete the information from my computer drive.

Signed:

Name:

Date: :.....

Appendix 7: Glossary

Definitions and terms

Caregiver: Parent caring for a child who has high care needs

HCA: Handicapped child allowance. A non means tested allowance provided by Work and Income New Zealand, available to the parent of a child who had a diagnosis of disability from a general practitioner or a paediatrician where the disability will last for more than six months.

Key worker: a named person taking responsibility for co-ordination and/or facilitation of services when a family has multi agency and/or complex contact with support services

NGO: Non-Governmental Organisation

PFRC: Parent and Family Resource Centre, P O Box 13-385, Onehunga, Auckland

UNCROC: United Nations Convention on the Rights of the Child

UPIAS: Union of the Physically Impaired Against Segregation

WINZ: Work and Income New Zealand