STORIES TO TELL:

FAMILIES OF CHILDREN WITH VISION IMPAIRMENT

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for the degree of
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ABSTRACT

This study explored the experiences of ten families of children with vision impairment. It gave emphasis to interactions within families and in relation to wider social, cultural and political contexts, highlighting the impact of medical, educational and social services and their policies on families.

Qualitative, collaborative methods offered techniques whereby ideas, feelings and beliefs ndividual to each family could be expressed within a climate of power sharing and reflection. Designed around a narrative, life history model, stories were accessed through the triangulation of focus group exploration, data sheet information and face-to-face family nterviews. Each story was treated as a unique, personal account, using participants own words as the authoritative statements on their experiences.

Findings were examined within the framework of Bronfenbrenner's (1979) Ecological Model. Issues relating to the educational and health needs of children predominated with educators he professionals parents most expected to support them. Parents sought parent-professional relationships which reflected equality, based on parent as well as professional expertise. Coping strategies used to negotiate both developmental tasks and social systems were identified, with the significance of alliances with other parents of children with disabilities highlighted. Advocacy was deemed to be a central process in bringing about change to social systems which were perceived as largely unchallenged by the great majority of parents.

Implications of the study were detailed in relation to families, professionals and service providers, policy development and future research. They underlined the importance of a society valuing diversity, and empowerment of people disadvantaged by prevailing attitudes, policies, structures and practices, providing a firm basis for actions that could enhance the lives of all families of children with disabilities.

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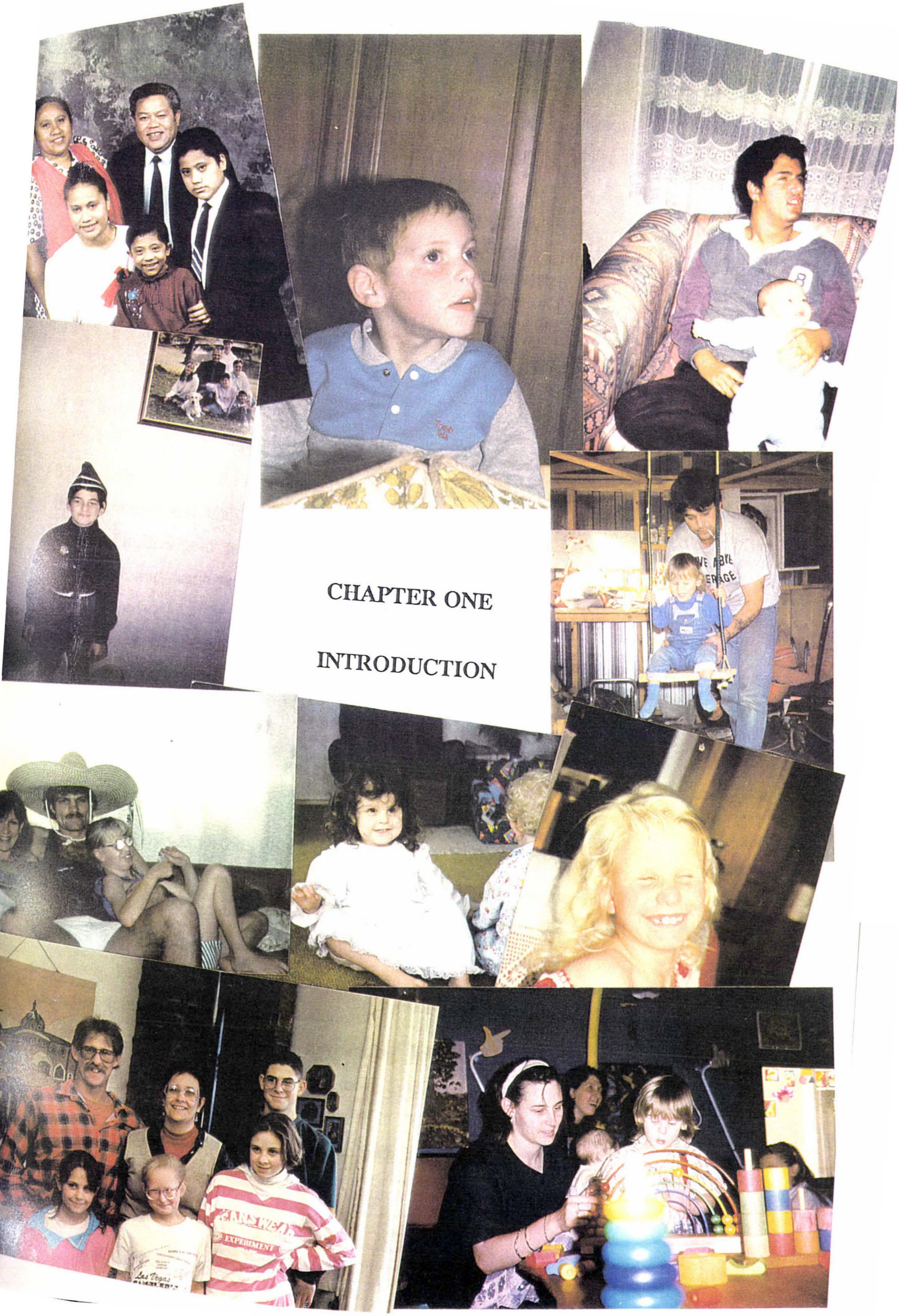

CHAPTER ONE

INTRODUCTION

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INTRODUCTION

> *Stories play a powerful part in a person's life. They paint pictures that give insight, understanding and help to make sense out of what may seem chaotic experiences. Stories challenge the listener to learn new things and to reflect upon his or her understanding of life. To listen is to recognise the value of another, bringing with it acceptance, respect and affirmation.*
>
> *(Hand, 1995, p.1)*

1.1 Introduction

This study presents the experiences of families of children with vision impairment through the recounting and analysis of the stories they shared both individually and collectively. The stories families told provide unique personal accounts of the meanings they received, negotiated and conveyed in relation to the lived experience of having a child with disability in the family. As there is little known research which explores the concerns and coping strategies of New Zealand families of children with vision impairment the present study is both timely and significant.

1.2 Background

Current trends in education in New Zealand espouse such notions as 'Parents as First Educators' (Boyd & Dixon, 1994), the education and support of the child through an holistic approach, emphasis of equality within the parent-professional partnership, and the ideology of a parent-driven education system as frameworked in 'Tomorrow's Schools' (NZ Dept. of Education, 1988). In tension with these trends are the rationalisation of the nation's education, health and welfare services, the move towards genericism, a 'traditional' view of education (currently reflected in the education versus disability support debate underpinning present policy change), discussion surrounding 'hands-on' services as opposed to 'support services', and the more recent apparent move towards the restriction of educational support services to learners with visual impairment in the early childhood and tertiary sectors of education. While some families negotiate such complexities in order to meet the needs of their child and family, others find themselves isolated and powerless. Whatever the involvement there are not only financial costs, but also loss of potential, loss of self esteem for the individual and the family; loss of status; loss of independence and mobility; loss of literacy; loss of identity; loss of vocation; and when the stress level gets too high, loss of family. The costs therefore can be enormous (Kerr, 1994).

One way to gain experience is to share that of other people. Stories are powerful ways of learning which convey knowledge within the complexity of life itself, expanding understanding of others and developing a sense of community within them. Thus learning how some families approach, for example, their dealings with different professional groups, their personal feelings regarding their child, their role as advocate or their negotiation across transition points may assist others in similar situations further to develop coping strategies and approaches.

Ferguson, Ferguson and Taylor (1992), believed that telling stories in the study of disability was valuable because stories show how people experience their social world. They noted that while disability is increasingly acknowledged as a social issue requiring changes, there is still a lack of direct, personal accounts by people who are disabled and their families as a legitimate source of information for policy analysis and service reform. It was their contention that personal narratives constitute a large and neglected source of data for understanding how society and schools could better support children and their families. Such narratives could reveal the personal perspectives in words chosen by the authors, rather than being converted to predetermined categories by researchers.

Seligman and Darling (1989), suggested that professionals who exist to help families achieve their goals must understand, as far as possible, the families' definitions of what their members want and need, and must take a social system perspective. While researchers and policy-makers may think they know how a system operates they may be unaware of the attitudes, power relationships and day-to-day activities that govern people's lives.

Sonntag (1991) wrote from her experience as both a parent and researcher in New Zealand that the women she knew with first-hand experience of disability never experienced feeling powerful in relation to policy decisions. Foucault (1980) focused on how "systems of ideas emerge as systems of power" (p.97) and stressed the need to understand the ideas of those who were disempowered and whose views were rarely heard or used in policy. Ignoring their voices was not because they had nothing of value to say, but rather because more powerful people, including researchers, dominated and controlled ideas, discussion, and the interpretation of reality.

Carhill (1991), together with researchers and writers from the disability movement in New Zealand, urged that the voice of those with disabilities, their families, whanau and caregivers be attended to. This position is supported by Ferguson and his colleagues who described disability as a "social construct of multiple experiences waiting to be recognised" (Ferguson, Ferguson & Taylor, 1992, p.296). What people experience as real is determined by such things as culture, values, beliefs and gender. From this perspective, research as stories can uncover the many experiences of disability and forms part of the rationale for this study.

1.3 Purpose and aims

The study was designed around a narrative, life history research model which focused on the lived experiences of ten families. Collaboratively undertaken, the purpose of the research was to make visible the lives of families of children with vision impairment. The participants themselves determined the focus and parameters of the study. The collaborative approach adopted required that participants were involved in every aspect from the identification of the study's aims and research questions, to determining what information was presented and how it would be utilised.

The following were the specific aims of the study:

1. To reveal the hidden face of disability through the lives of families of children with vision impairment.
2. To explore people's lived experiences of disability in relation to such issues as attitudes, values, minority status, empowerment, disempowerment, and historical, cultural and social circumstances.
3. To identify some of families' coping strategies and the ways in which they have negotiated developmental tasks, information systems, service systems and support networks.

4. To identify the impact of education, health and welfare systems and policies on the experiences of families and to seek positive directions for the future.

5. To present the experiences of these families to others so that their stories might be useful to those with disabilities, their families and whanau in making a positive difference to the overall quality of their own lives.

6. To provide others: advocacy groups, professionals, service providers, policy makers, with the ideas, experiences and emotions of participant families as a basis for critical analysis and action for change (Lather, 1986a).

Participants in the study were the members of the national committee of the Parents of the Vision Impaired Organisation (PVI). This organisation was established in 1986 to advance the educational, health and welfare needs of their children and young persons with vision impairment, by providing an effective parent-based support and advocacy group with an active and informed parent constituency. The philosophy of PVI is based on the belief that children who are vision impaired have the right to an equal opportunity education, access to required services, and community acceptance (Revised Constitution of PVI, 1994).

1.4 Significance

The study gave emphasis to interactions and relationships both within families and in relation to wider interdependent social, cultural and political networks. Thus families described their experiences with medical, educational and social services, and policies which have impacted upon their lives. Their stories aimed to build understanding of aspects of families of children with disabilities as experienced in their homes and communities, by sharing some of "the mechanisms, the experiences, the behaviours, the looks, and conversations which are involved" (Stanley & Wise, 1983, p.167). While some events and statements have been analysed and interpreted by the researcher, first person accounts have been presented in detail. The inherent value of this study lies in the uniqueness of each story and in the reader's ability to integrate meaningfully what is relevant to their own life experience. Families were all willing to talk openly about themselves, if it would help other families to interpret and analyse their world, and to develop plans for action from new understandings.

The aim was to highlight the complexity of the experiences which families of children with disabilities face in an inequitable society and some parts of this study inevitably are somewhat critical of professional practices and policies. What parents remembered and felt about professionals were captured in the stories they told. Their various responses depicted how professionals and their advice might be perceived by families adjusting to life with a child with a disability. Professionals may sometimes believe that parents misrepresent them or fail to take account of their advice and it might be helpful for those of us who are professionals to listen and understand this different perspective.

1.5 The researcher's personal perspective

Personal experiences and perspectives are important elements which a researcher brings to qualitative analysis. The relationship between researcher and participants is important in any kind of research, but particularly so in a narrative investigation. While positivism has suggested that the researcher can stand back from the object of the study and be neutral and dispassionate in the analysis of data, writers such as Oakley (1981) and Stanley and Wise (1983) have criticised such research paradigms rejecting the concept of neutral objectivity in favour of recognising the experiences and knowledge that is brought, either implicitly or explicitly to the study.

It is therefore acknowledged that my background, experience and personality have affected each stage of this research process, from the selection of the participants through to the writing up of the analysed data. I heeded the importance of placing myself within my own experiences and incorporating them into this work. The study therefore has emphasised the inclusion of personal experience and acknowledged the subjectivity of both participants and researcher.

A Pakeha working woman, married, with four sons, teenage and young adult, I brought historical and cultural experiences that differed from those of some of the participants. This required that I examine my own values and assumptions and attempt to put these aside while listening, reflecting and analysing. Court (1989) has stated that while "trying to stand off far enough from my own personal involvement with the issues discussed to 'hear' their experience", I also needed to "maintain the empathy that would open the understanding of their stories" (p.36).

My subjective involvement in this research was multi-positional - as child, parent, professional and academic. My interest in families of children with disabilities relates to experiences as a child with a physical disability. The physical impact of my condition is today rarely apparent and it is largely the psychosocial impacts which remain. Certain events in childhood drew me to this study. For example, an incident over forty years ago had a significant effect on my view of the parent/professional partnership. Briefly:

> *My middle sister and I had been members of the Crippled Children's Society since our birth. From time to time the social worker of this organisation visited our home. To my child's eyes she appeared austere and 'stiff' - not at all like the other women in my life. Perhaps this was also the perception of my mother, a gentle, unassertive person. On one particular day, she caught sight of the social worker approaching. Quickly scooping up the youngest, she ushered her three daughters to the bedroom where we crouched under the bed, remaining there until the knocking on the door had ceased and the footsteps faded away. The safety of our family was restored!*

Such personal experiences have contributed to the depth and understanding that I brought to the research process.

My position as parent of four sons has spanned a period of twenty five years. While some experiences of the study's families were outside those encountered in my role as parent, there were others with which I could more fully identify and which provided meeting points between participants and researcher.

As a professional educator for eleven years at Homai Vision Education Centre I had the opportunity to become familiar with the challenges which face families of children with vision impairment. Responsible for the delivery and administration of services as teacher, adviser, and co-ordinator I was privileged to enter the lives of these families and be afforded a glimpse of both their struggles and achievements. I acknowledge and thank these families for their contribution to my understanding, both personally and professionally.

My career has since led to study at Massey University in guidance and counselling and further immersion in educational, social and political issues for families. For the past two years I have been teaching the Education of Students with Vision Impairment (ESVI) Diploma Course within the Centre for Special Education at Auckland College of Education. Graduates from this course work with learners with vision impairment in various settings. Supporting these learners in relation to families, communities and cultures is of prime importance, since valuing the uniqueness of each family is fundamental to their effectiveness as educators.

1.6 Structure of the thesis

The study is presented in four main sections. The literature relevant to the study is reviewed next. The characteristics of disability and vision impairment are outlined as a basis for understanding their effects on families. Consideration is given to families as social systems, and models are identified which describe the functioning of families of a child with disability. The nature of social networks outside families is examined in relation to self-perceived need and the current education climate and issues relating to the parent-professional partnership highlighted. Self-advocacy as a means of support networking for families, and as a research process by which experiences may be recounted directly, is also appraised.

Chapter Three gives a detailed account of the methodology for this research. Within a qualitative research paradigm a collaborative emancipatory approach was used to explore perspectives on problem areas for families, to understand both the presenting issues and the coping strategies which helped to solve them. The richness of families' experiences was accessed through group discussion, individual, and family interviews.

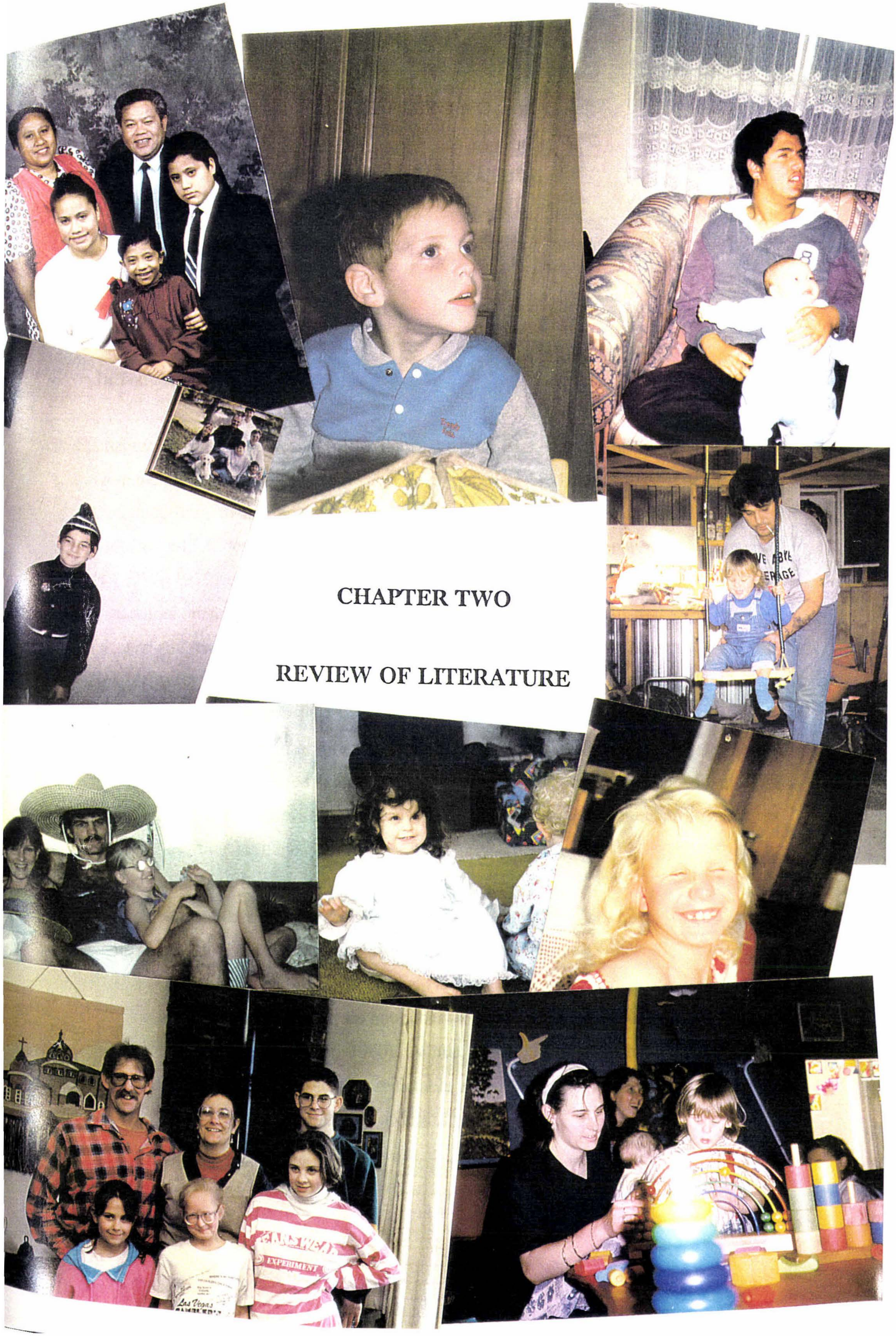
The stories of each family are presented in Chapter Four, ordered according to the chronological age of the child with vision impairment and commencing with the youngest. Where all members of the family participated in the narration, the child's perspective is first, followed by siblings, then parents. The voices of all participants are heard directly. Nine families chose to use their own names and one family requested that they be given other names. Accompanying each story is a profile of the family. Each story is a reflection of the perspectives of the family at the particular point in time that the study was conducted and is not representative of the experiences of any other family.

Data from the focus groups and interviews, as portrayed in the stories, are presented and analysed in Chapter Five. The framework for analysis was influenced by Bronfenbrenner's ecological model (1979) adapted by Hornby (1994) for use with families of children with disabilities. The findings are discussed in relation to their location within the four systems of this model: microsystem (immediate family - child, mother, father, siblings); mesosystem (extended family, neighbours, work colleagues, friends, peers); exosystem (health, education, welfare systems, voluntary agencies); and macrosystem (cultural, ethnic, religious, economic, political, legal systems). A final section in this chapter examines the issues and coping strategies that have been utilised across all system bands.

The final chapter, Chapter Six, summarises the findings of the study and makes recommendations for future research and action.

1.7 Conclusion

This study goes further than the particular stories of these ten families, being an illustration of the daily experiences of many families of children with disabilities in New Zealand. Written from particular points of view, those of the families and the researcher, it presents positions which recognise interests and complexity in everyday life and speaks to families, professionals, service providers and policy makers, who may all find a glimpse of the familiar in these accounts. It may assist in the establishment of policy and the provision of support which may be more fully informed. There are also stories about how already existing attitudes and social patterns of privilege are maintained by society, and about how systems and policies, which have been designed to assist, benefit some but not others. The study underlines the importance of society valuing diversity, and the empowerment of people who have been disadvantaged by prevailing attitudes, policies, structures and practices. As Lather (1986b) proposed, research should contribute to a more just society.



CHAPTER TWO

REVIEW OF LITERATURE

CHAPTER TWO

REVIEW OF LITERATURE

> *It's not only what you know that's important, it's what you don't know or need to find out. If you think you know everything and stop searching, stop questioning, you've lost.*
>
> (*Research participant*)

2.1 Introduction

This chapter considers the notion of the family as a social system. The effects on families who have a child with disability are reviewed with the characteristics of disability and vision mpairment outlined to aid understanding of the issues experienced by such families. Models are identified which describe the functioning of families with Bronfenbrenner's Ecological Model (1977, 1979) chosen to form the framework for the present study. The nature of social networks outside the families are considered in relation to their self-perception of need. Finally, self-advocacy is introduced as a means of support networking in order to access vital services and resources for families.

Families of children with disabilities face unique issues which arise as a result of their specific situation. While some families negotiate issues and systems in order to meet the needs of their child, and ultimately, themselves, for others disempowerment, frustration and unmet needs are their heritage.

It has been observed that a single event has the power to transform not just one life but many lives, and to change not just one stage of life but an entire lifetime (Krauss & Seltzer, 1993). Some events are predictable and occur roughly at the same time for most people. Other events, however, are unanticipated, do not occur to most people, and usually are not wanted or desired (Baltes, Reese & Lipsitt, 1980). While both types of event have the potential to transform lives, the latter do so in less predictable ways. An example of such an event is the entrance into the family of a child with a disability.

The importance of considering the effects on families of one member having a disability has been increasingly realised in recent years (Hornby, 1994; Seligman, 1991). Coping with impairment is a shared experience. Nixon (1994), contended, for example, that coping with vision impairment is not confined to persons who have low vision or are blind. Rather, it is a social matter in which the individual's vision impairment may have a profound impact on the variety of networks of social interaction and relationships in which the person is involved. Not only does this influence individual family members but the family as a unit. Family members often find that the demands and issues of the impairment may influence their interaction with non-family members and their individual and collective opportunities to do things.

Scant attention has been paid to families coping with vision impairment from sociological researchers, and few attempts have been made by researchers and others in this field to write generally about aspects which impact upon families of children with vision impairment. Although there has been some consideration of family factors in the research literature, of the education of students with vision impairment, and of their adjustment as adolescents, relatively little is known about the relationship of family factors to families' means of coping with such impairment.

2.2 Characteristics of disability and vision impairment

It is clearly indicated that the nature and extent of a child's disability has considerable impact on the family (Gallagher, Beckman & Cross, 1983; Shapiro, 1983). The type and severity of the disability is likely to play a significant role in how parents are affected and in turn the nature of the family will impact on the child (Mink & Nihara, 1987). Therefore, in order to comprehend the issues and unique situations with which families of children with disability live, consideration is first given to the nature of disability, and in particular, vision impairment.

Disablement, within the World Health Organisation model, is regarded as a collective descriptor referring to any experience identified variously by the terms impairment, disability and handicap (Wood, 1980). Within this model there is more or less orderly progression from impairment to disability to handicap. Making distinctions among impairment, disability, and handicap is important in clarifying how cultural beliefs and social practices shape the interpretation of impairment and the manner in which persons with impairment are addressed in everyday life (Bowe, 1978; Roth, 1983).

An impairment is essentially a biomedical condition, an organic or functional disorder that may arise as a result of a disease, accident, or congenital abnormality. There is the implication that there is a loss or abnormality in the anatomical or physiological structure (Bowe, 1978; Roth, 1983). There are different ways of categorising impairments, such as physical, organic, emotional, sensory, intellectual and speech.

Disability is considered to be one of the possible consequences of impairment and is described as lack of ability to function in the manner of, or within the range considered normal for, most human beings (Bowe, 1878; Roth, 1983). Although impairments underlie disabilities, the presence of an impairment does not indicate how disabled a person will be. Disability varies across situations, roles, tasks and activities. For example, a blind child who must try to keep up with class peers without the benefit of special devices such as tape recordings, readers and braille, is likely to experience a serious learning disability. However, the same child could have a much less serious learning disability if devices are available that provide access to the same learning materials and information used by classmates. Thus, disability is situational incapacitation and varies to the extent that situations require skills a person does not have or cannot use.

Handicap is a possible consequence of disability. It has a strong social component in the sense that, for the individual, it is a disadvantage which limits or prevents the fulfilment of the role of someone of that age, sex, or social or cultural background (Bogdan & Biklen, 1977). A person with an impairment becomes handicapped when that person is cast into a socially inferior status merely because she or he is impaired or disabled.

Nixon (1991) illustrated this giving an example of a person who is anophthalmic (born without eyes):

> *The inability of this person to travel independently without a cane or a guide dog means that this person will have a disability in trying to get around without these aids in unfamiliar circumstances. The disability may largely or entirely disappear when the devices are available. However, when the regulations of an airline do not permit*

> *guide dogs on an aircraft and the blind person depends on a dog for independent travel, blindness becomes a handicap and the person is a victim of prejudicial and discriminatory treatment that can be called handicapism. (p.14)*

Nixon also portrayed social disadvantage as a result of discriminatory rules, regulations and laws in organisations, communities and societies (institutional handicapism, Sullivan & Gill, 1975). He maintained that institutional handicapism may be difficult to uproot because it is part of the social order or routine way of doing things, and for that reason seems to be rational or justified. Persons with an impairment may also be handicapped by the unwillingness of others, including parents, other close family members, and professional service providers in potentially important networks of social support, to allow them to use their abilities.

The term 'vision impairment' has been most commonly used to refer to those persons who are blind or partially sighted (Hodgson, 1985). Barraga (1976) elaborated on the term, distinguishing between two distinct types of vision. The first, blind, indicated that an individual had no vision, or only light perception, and that their learning medium would be braille, the second meant that an individual had low vision.

Technical definitions reflecting the level of visual acuity also differentiate between levels of vision impairment. Visual acuity is recorded in the form of a fraction, with 6/6 indicating normal vision. Individuals who are deemed legally to be blind are those whose visual acuity is 6/60 or less, or whose field of vision is 20 degrees or less. Partially sighted individuals are those whose visual acuity is between 6/60 and 6/24. In both cases the measure is of the acuity in the better eye with the best possible correction. To give meaning to such measurements 6/60 indicates that the individual sees at 6 metres what a person with normal vision would see at a distance of 60 metres (Harley & Lawrence, 1984). Field of vision refers to the entire area which a person can see while the eye remains fixed upon one point. It includes both central and peripheral vision. When a person who has a severe loss of visual field is left with only central acuity this may be described as 'tunnel' vision (Harley & Lawrence, 1984).

Within education settings technical definitions have been replaced by those that indicate the medium through which the student learns, (Batemen, 1967; Gilmour, 1986). According to Gilmour the blind student

> *is one whose visual loss indicates that he or she uses braille plus tactile and auditory materials whilst the partially sighted student is one who has sufficient visual acuity to use print. (p.3)*

A broader definition of vision impairment has been used in studies of mainstreaming within New Zealand (Mitchell, 1985b; Norman, Sritheran & Ridding, 1984):

> *visually impaired children are those who suffer from some eye defect or disease which limits their activity and requires special provisions or consideration at school.*
> *(Mitchell, 1985b, p.6)*

In the field of disability, vision impairment is the primary responsibility of ophthalmologists, whose medical training enables them to prevent, cure, or reduce the disorders of the ocular system by surgery or medication. It also falls within the domain of optometrists who may be able to overcome a physical abnormality of the eye by the prescription of visual aids to counteract aberrations in the eye. However, when these professionals have done all that they can, there may remain for some people a potentially permanent handicap to their personal, social, and vocational development. In partnership with parents, responsibility for alleviating the effects of these handicapping conditions will rest with the habilitation and rehabilitation professions: counsellors, psychologists, teachers, social workers and technical and mobility instructors.

Vision provides a vital foundation for learning - for organising and synthesising the events that make up the world of sighted children. Psychologists, scientists and others have speculated that as much as 80% of the perceptions of sighted children originate in the visual sense (Hart, 1987). It is the ability to bring meaning to the various experiences of living through incidental learning that is at risk in children with vision impairment.

Leigner (1994) stated that the threat of blindness in today's society ranks among the highest personally frightening conditions, sharing the fear of AIDS, Alzheimer's disease, and cancer. Of these four medical problems, only vision impairment is non-terminal, reflecting the public's deep seated concern about a condition with relatively long term functional impact.

Within New Zealand 10,856 people are registered with the Royal New Zealand Foundation for the Blind (RNZFB), (RNZFB Membership Data Base, July 1995). Of these, over 1,000 are children, adolescents and young adults who receive educational support services from Visual and Sensory Resource Centres and Homai Vision Education Centre. It is from this subgroup that the present study draws life experiences, in an attempt to better understand the issues encountered by its members and their families.

2.3 The family/whanau

The family may be viewed as a system in which the members are differentiated, but at the same time merged so that the whole is greater than the sum of the parts (Ackerman, 1958; Barnhill, 1979; Minuchin, 1984; Murphy & Marquis, 1993). Within a family shared history, traditions, rituals, and rules, both implicit and explicit, govern the interactions among family members. Strong emotional ties also bind the family and influence interactions.

The family is the most basic and ancient of all institutions and it remains the fundamental unit in every society (Hand, 1995). An idealised view of a family would describe it as consisting of a mother, a father and two or three children living at home (Murray, 1991). Traditionally stereotypic roles would be assigned to the parents, such as the father being the breadwinner, providing protection and economic support, and the mother being the homemaker, primarily responsible for the children. However, over the past three decades personal attitudes and societal views have changed (Wills, 1994), and in many instances the roles of mother and father are now much more blurred. Views of what constitutes a family are changing.

There are several ways of defining a family. Robertson (1987) defined it as "a relatively permanent group of people related by ancestry, marriage or adoption, who live together, form an economic unit, and take care of their young" (p.348), while Strully and Strully (1989) suggested that the ways of defining families are: biological, adoptive and alternative living. They considered a biological family as a nucleus of one or two adults living together with the children to whom they have given birth. In adoptive families children may be shared, there may be an open grouping or affiliation, or the parental structure may be traditional, one person or a couple. These families make a legal commitment to raise a child as though he or she were the biological offspring. Alternative living families are those that have no formal legal contract but have an emotional, moral and personal commitment.

A comparatively recent form of family, but one that is rapidly growing, is the one-parent family. In New Zealand today, only 34 percent of people live in what was once thought of as a 'typical' family - a household consisting of a husband and wife and at least one child. One in five families is run by a sole parent; one in five households are solo - no partner, no children, no grandparents; eight percent of all marriages are de facto (Murray, 1991).

In June 1993, results of surveys from two voluntary social service agencies, the Marriage Guidance Council and the Council of Christian Social Services, indicated that:

- one quarter of all families rely on New Zealand Income Support for their income, and the children of those families are being brought up below the poverty line;
- one quarter of all families have one resident parent;
- one half of Maori families are sole parented;
- one third of Pacific Island families have one resident parent;
- one in five Pakeha families are sole parented;
- that sole parent is predominantly female, however fathers now occupy the sole parent role in 18% of families.

The prime responsibility of any family is to care for and nurture the young child and to ensure survival. It provides the environment where the physical needs for warmth, food, shelter and care are met. Family members usually form stable, lasting bonds where the need for affection, nurturance, intimacy, and love are fulfilled. The family is recognised as the most significant agent in the socialisation of each child. The provision of a sense of support, stability, acceptance and caring are required for the development of self-confidence and the assurance necessary to promote both learning and social success in school. Families provide the foundation for children to become involved, to be accepted, and to survive and find support in challenging new environments in the school and community. Thus within a secure grouping, each family member learns healthy interaction patterns through which they develop a perspective of who they are and what they may become, enabling each person to meet their fullest potential (Strully & Strully, 1989).

A family also has a responsibility to the society of which it is part to transmit the culture and the values of that society. To small children the family is all encompassing; in addition to establishing their first emotional ties there, they also learn language and begin to internalise cultural norms and values (Hand, 1995).

Havighurst (1972) proposed that each person has to achieve a series of skills or 'tasks' at various stages during life. For example, early tasks expected of all children include learning to walk and to get on with others, while the tasks of adolescence would include acceptance of one's body, a masculine or feminine role and emotional independence from parents and other adults.

In carrying out their function some important characteristics of family networks are: size and stability; cohesion; density; the amount of hierarchy in family relations; the openness of family members to contacts with outsiders; clusterings of subgroups within the family network; and the content of messages and resources that flow between family members (Smith, 1987). A significant aspect of relations in families is the exchange of resources among members (Eggert, 1987; Milardo, 1988; Olson & McCubbin, 1983). Families accumulate, exchange, and use up resources to meet the individual and shared needs of their members. These resources, which may be tangible or material assets, include information, and patterns of belief, feeling and action (Nixon, 1994). The range of resources that a family has or is likely to accumulate and use in the future and how the family uses its resources have an important bearing on how well the family will meet its stresses or tensions, problems, challenges, and needs.

2.4 Families of children with disability

The entrance into the family of a member with a disability usually causes the family to renegotiate the rules and rituals while still attempting to maintain the stability and integrity of the family. The "family coping" may be viewed as the restructuring, compromising, assimilating, and adapting of family goals and functioning that occur in the family as a whole system.

The impact of children with disabilities on parents and other family members has been documented over a period of almost thirty years (e.g. Chinn, Winn & Walters, 1978; Ross, 1964; Seligman, 1991). Over this time, however, the understanding of relationships within families in general has grown considerably. Currently families are viewed as interactive, interdependent systems with individual members reciprocally affecting each other, so that anything which affects one member of the family will have some impact on all other members and therefore on the family system as a whole (Satir, 1967; Marshak & Seligman, 1993).

This change, in which the family is considered as a social unit, is reflected by a trend in the focus of research conducted with families who have children with disabilities. In the 1950's, studies focused on the impact of parents on their children (Hornby, 1994) while in the 1960's they focused on negative effects on parents caused by their children (Bowlby, 1965; Olshansky, 1962; Roos, 1963; Ross, 1964). In the 1970's the impact on marital relationships and on siblings began to be studied (Gath, 1977; Grossman, 1972; McAndrew, 1976). From the 1980's onward research in this area has taken into account the interactive, interdependent nature of these families and much more complex views have emerged of how such families are affected by a member with a disability (Brim & Ryff, 1980; Bristol & Gallagher, 1986; Fewell & Vadasy, 1986; Schilling, 1988).

In considering this progression of trends, a number of models have been used to describe the functioning of families which include children with disabilities. While the parents of children are a broad heterogeneous group, the existing literature suggests recurrent themes and patterns that may be seen to emerge through the adjustment processes that parents face. The most common theories are around the notion that parents and families move through stages of adjustment. Four of the most widely known include: a continuum of stages of reaction (Bicknell, 1988; Gargiulo, 1985; Hornby, 1987; Seligman, 1979); a series of developmental tasks (Mitchell, 1985a); a number of existential crises (Roos, 1963, 1978); and the experience of chronic sorrow (Max, 1985; Olshansky, 1962; Solnit & Stark, 1961; Wikler, Wasow, & Hatfield, 1981). Wills (1995) also suggested salutogenic orientation, in which difference is considered as alternative, rather than abnormal.

The reaction of parents to the news that their child has a disability has been described in a number of ways. Often based upon a psychodynamic interpretation, one theoretical perspective has been to view parental response as equivalent to child loss (the loss of a normal child) which results in grief. Kubler-Ross (1969) described the grief process following a death as a process where the grieving person experiences a variety of feelings such as denial, bargaining, anger, depression and acceptance. The reaction of parents to the birth of a child with a disability may be considered similar to this process by eliciting a range of feelings which more or less follow a similar pattern (Murray, 1991). Such feelings have been reported as shock, denial, guilt, anger, sadness, detachment, reorganisation and adaptation (Gargiulo, 1985; Hornby, 1987). The process may be viewed as a continuum of reactions which together represent a healthy response to the diagnosis of disability. Each parent experiences a different intensity for the various feelings and more than one reaction or feeling may be experienced at the same time. Some may complete the process in a few weeks, others may take years, while some parents may never be able to come to terms with the disability. Gargiulo (1985) advised professionals to guard against stereotyping parents; rather they should regard parents' reactions as "legitimate, normal, human responses" (p.38). The passage through the process may be accelerated or retarded depending on the quality of the support received.

The second major psychodynamic conceptualisation of parental reaction to the birth of a child with a disability is that of chronic mourning as proposed by Solnit and Stark (1961), being the abject loss to which the birth of the child with a disability was equated. This 'neurotic interpretation' of parental reaction was challenged by Olshansky (1962) with the suggestion that a concept of chronic sorrow needs to be accepted by professionals to understand the slow, and at times near static, movement of some parents through the stages of grief, with this being a natural rather than a neurotic reaction. Olshansky pointed to social factors within the culture of the day that may have led parents to feel devalued for having a child with a disability, and to other co-existing factors such as the parental personality, ethnic group, religion and social class, which may inhibit the ability to externalise sorrow in order to dissipate it. Additionally, Olshansky (1962) suggested that all parents would be accepting and rejecting of their child at different times.

Hillyer-Davis (1987) was of the view that a systemic approach needed to be taken to understand the complex relationship between disability and grief and the experiences of parents. Recurrent, cyclical sadness was described and the view offered that "professionals who view adjustment as a time-bound process will view parents who experience repeated sorrow as dysfunctional" (p.353). Damrosch and Perry (1989), determined from gender-based responses that mothers were more likely to experience a pattern of "peaks-and-valleys, and periods of chronic sorrow" (p.25) while fathers experienced a more steady and gradual adjustment.

It was Wills' (1995) belief that much could be learnt when difference is considered as alternative, rather than abnormal; the birth of a child with a disability being regarded as a change in the path of the family and parents, rather than a tragedy. Most models have suggested a finite process, with acceptance as an end point (Bristor, 1984). However, while routine parental expectations may not be met in the birth of a child with a disability, Antonovsky (1993) considered it limiting to focus merely on the immediate problem of the individual and appropriate therapy. Rather, it was suggested that a salutogenic orientation, concerned with overall health, focuses thinking in systems terms. This leads to an understanding of the strengths, not only within the family system, but also in the suprasystems within which the family functions. A salutogenic orientation "may open the way to formulating a theory of overall successful coping and health" (Bristor, 1984, p.115).

A similar point was made by Gallagher and Bristol (1983) when discussing their Family Adjustment and Adaptation Response Model. They considered it useful because it places an emphasis on adaptation over time, is an ecological model which recognises the social and contextual nature of adaptation, provides for the assessment of active coping as well as passive support, and addresses the possibility that "healthy adaptation rather than pathology may characterise the family's response to stress" (p.301). Wills (1995) considered loss and grief experiences within an holistic framework and recognised that such factors have important intellectual, emotional, behavioural and spiritual impact over large segments of a person's life. Initial 'loss' is used as a catalyst to motivate an individual to redirect physical and emotional energy in a growth potential. Wills believed that it may well be possible to create a new metaphor for disability, one that displaces the 'tragic view', by looking at the birth of a child with a disability as the starting point for adaptation and change, and involves a shift in paradigm. A new schema of shared values, beliefs, goals and expectations can emerge to displace the pathogenic view.

Within the developmental tasks model Mitchell (1985a) viewed parents as progressing through a series of developmental stages, each of which was characterised by a set of tasks which must be at least partially mastered if parents were to adapt successfully to the presence of a disabled child in the family. Hornby (1994), categorised the tasks in four broad stages of development: the initial diagnosis; infancy and toddlerhood; childhood and early adolescence; and late adolescence and adulthood. Many of these developmental tasks also apply to parents of non-disabled children (Havighurst, 1972). However, knowledge of the specific tasks which apply to parents of children with disabilities enabled practitioners to be aware of the kinds of issues which these parents might be dealing with, in addition to those of other parents, at various stages of the children's development.

Children with disabilities may be slow to develop in some areas and therefore have life-cycles which differ from those of their siblings (Hornby, 1994). This is likely to create conflict within the family at various stages. For example, the stage of children leaving home is likely to be delayed or blocked totally, because the family is not willing or able to find a suitable living arrangement outside the home for the disabled member. This then prevents other family members, usually the parents, from progressing with developmental tasks necessary to fulfil their own life-cycle demands, such as preparing for retirement. Life-cycle variables also affect family functions and resources, which in turn affect family interaction patterns (Carter & McGoldrick, 1980; Terkelsen, 1980).

The process of change in families is a complex phenomenon. Heller, Rowits and Farber (1992), in a life-span study of families with a child with a disability, focused on how families' stressors changed and how families coped with these through developmental phases and transitions. Younger families were more likely to report problems in obtaining reports on their child's development and in gaining access to family support services. In the pre-school years, major family demands related to securing an accurate diagnosis and accepting the diagnosis. Many families of young children noted their struggles with professionals, their advocacy role within the education system, and their own personal feelings regarding their child. Families of adolescents reported the greatest difficulty of all age groups in finding adequate support. In particular, issues relating to behavioural challenges, sexuality, and transition out of the school system were noted. Families of young adults were likely to face issues centred on the child with the disability leaving the family home and searching for independence. A further key issue affecting families was the lack of sufficient adult services and across all phases it was found that transition points were often stressful periods that brought new demands with which families needed to cope.

Stress for families occurs when family relations are perceived as tense or disrupted and when family members believe that demands on them exceed their available resources (Eggert, 1987). Shapiro (1983) commented that studies on families coping with different impairments generally pointed to the stress and burden that impairment can cause. Stolarski (1991), found that all family members of children with multiple impairment, including visual impairment, experienced a variety of forms of stress that were considered clinically significant and required clinical intervention. She also reported that unimpaired siblings of children who were vision impaired, but who had no other handicapping conditions, showed levels of stress that were almost clinically significant, whereas the parents of these children were not clinically stressed. Three other studies on families coping with vision impairment included a mother's perspective on parenting a child with vision impairment (Hancock, 1987); the coping strategies, emotional issues, and concerns of mothers of vision impaired children (Hancock, Wilgosh, & McDonald, 1990); and the significance of the social support needs and networks of families with children of various ages who have impairments, including children who are deaf-blind (Vadasy & Fewell, 1986). Findings add insights about families coping with vision impairment, with the significance of social support needs and networks emphasised.

Featherstone (1981) and Nixon (1994) both considered it important to understand family difficulties caused by impairment for three related social reasons:

> 1. *Such difficulties may affect the ability of family members to perform their roles effectively and to derive satisfaction from them.*
>
> 2. *They can undermine the stability of family relations and the family unit, causing the family to neglect its commitments and to even break down.*
>
> 3. *When families have a difficult time coping with impairment, impaired and other family members are likely to be deprived of social support.*
>
> *(Nixon, 1994, p.331)*

Nixon (1994) placed family experiences as social constructs which were derived from family members' exchanges of ideas and attitudes with each other and with outsiders. Therefore family members did not experience impairment just as an objective reality but also gave meaning to it by the ways they learned to think about and respond to it and to their disabled child. For example two children might have a similar impairment; the family of one could experience the child's impairment as a severe disability with highly disruptive effects for them, while the members of the second family could experience it as an inconvenience that had only minimal effects on family life. Therefore, the 'reality' of impairment might have different meanings for different families and even different members of an individual family.

The meanings constructed by families are likely to be shaped by a number of factors. These may include: previous exposure to an impairment and its history; the type, severity and onset of the impairment and changes in it; the gender and age of the family member with the impairment; family members' perceptions of their responsibility for the onset or development of an impairment and of their power to change the impairment or its disabling implications; acceptance of the reality of the disabilities associated with impairment; sensitivity to the stigma of impairment; and perceptions of the things that must be done or acquired for a person as a result or his or her impairment (Goffman, 1963; Nixon 1991; Voysey, 1975).

The examination of just one factor, that of severity, may serve to highlight the potential extent of variables present within each determinant. In considering severity, it is proposed that the presence of some sight makes a difference in parents' responses to their children (Cowan & Bobrove, 1966). Partial sight allows or encourages parents to delay their acknowledgement of impairment and disability longer than does near or total blindness. However, when the marginality of their children's impairments makes the impairment seem relatively invisible in some situations, parents can become confused and anxious. Previous studies have found that blind adolescents coped better than did partially sighted adolescents with perceptions of pity and acceptance and that parents found blindness less difficult to accept than partial sight (Cowan & Bobrove, 1966). Parents of blind children have expressed relief that they were free of the uncertainty about the future of their children's visual condition and that the certainty of irreversible blindness was preferred to the ambiguity and uncertainty of partial sight (Fewell & Gelb, 1983). Such uncertainty can be a major dimension of parental emotional coping. In addition, persons with low vision who find themselves between the world of the sighted and that of persons who are blind, may experience difficulty in developing self identity and self esteem. As a second example, the onset of vision impairment, and its impact, it has been considered that early diagnosis is generally easier to come to terms with than later diagnosis (Hornby, 1994). In addition, if onset occurs during the adolescent years it is likely to be experienced as a particularly traumatic event. Thus it may be seen that each factor has many variables, bringing implications which both individually and collectively impact upon the functioning of the family.

Models have been developed which describe family functioning. Three such models which have had an impact on work with families who have children with disabilities are the Transactional Model (Bell, 1968; Mink & Nihira, 1987), Family Systems Theory (Berger & Foster, 1986; Chilman, Nunnally & Cox, 1988; Coopersmith, 1984; Turnbull & Turnbull, 1986), and the Ecological Model (Bronfenbrenner, 1977, 1979).

In the Transactional Model development is believed to result from the interplay between a changing organism and a changing environment (Bell, 1968). Therefore, families are considered both to be affected by their disabled members and to have an impact on them (Mink & Nihira, 1987). The type and severity of the disability is likely to impact on how parents are affected, and the kind of people the parents are will have an important bearing on the child's behaviour and development. The different developmental stages that the person with disability passes through also affect their family in different ways.

Family Systems Theory suggests that the behaviour of a family member is a function of the family system of which they are a part (Berger & Foster, 1986; Skynner, 1982; von Bertalanffy, 1968; Walrond-Skinner, 1976). A change in the family system will inevitably lead to a change in the behaviour of each family member. Likewise, a change in an individual's behaviour will cause the family system to change. However, the functioning of the family system is considered to comprise more than just the total of the contributions of its members; interactions between family members and the organisational structure of a family also play a part in family dynamics. Intervention at the level of the family system has been perceived to have more impact than intervention aimed at one of its members (Berger, 1984; Coopersmith, 1984). The family systems conceptual framework developed by Turnbull and her associates highlighted the various elements of the family system with particular relevance to children with disabilities (Turnbull, Brotherson & Summers, 1985; Turnbull & Turnbull, 1986). The framework consisted of four components: family interaction, family resources, family functions, and family life-cycle.

Bronfenbrenner's (1979) Ecological Model posits that human development and behaviour cannot be understood independently of the social context in which they occur. The social environment influences behaviour and this occurs at several levels. Thus, the effects on a family of a child with a disability are strongly influenced by the social environment in which they are living, including the extended family, available services and community attitude. The model, adapted by Hornby (1994) to apply to families of children with disability, encompasses four different levels of influence on the family: the microsystem, the mesosystem, the exosystem, and the macrosystem. This model has provided the framework for the present study.

Lonsdale (1978), and Philip and Duckworth (1982), highlighted the restriction on the social life of the family with Gallagher, Beckman and Cross (1983) concluding that the extent of the social restriction was greatest when children were young, when physical disability or behavioural problems were present and when the degree of the disabling condition was severe. Additional expenses, often for medical care, clothing and transport (Lonsdale, 1978; Murphy, 1982), and reduced family income (McAndrew, 1976), due to the daily care requirements of the disabled child, were likely. While most countries have various financial benefits available to assist such families, surveys have shown that many parents did not receive the benefits to which they were entitled (Hornby, 1987; Philip & Duckworth, 1982).

Much has been written concerning the potential marital difficulties faced by parents of children with disabilities (e.g. Featherstone, 1981; Max, 1985). These difficulties were considered to be related to the additional demands of caring for a child with a disability, and other factors including disagreement about the child's care or treatment, insufficient time to resolve conflicts, and the need to consult with professionals. It was often the mother who attended appointments with professionals and who then had to re-interpret the meetings for the father. It was suggested by Featherstone (1981) that because of their greater involvement, mothers sometimes moved through the adaptation process more quickly than fathers, thus creating another area for conflict. She also identified that difficulties in sexual relationships might result from a lack of privacy, fatigue, a sense of isolation on the part of each spouse, and the fear of producing another disabled child.

Several studies have investigated the prevalence of marriage breakdown in such families. Overall, the results have been inconclusive, with reports of high marriage breakdown and low marital satisfaction (Gath, 1977; Murphy, 1982; Tew, Payne & Lawrence, 1974) being balanced by findings of average marital satisfaction and breakdown in other studies (Furneaux, 1988; Gath & Gumley, 1984; Roesel & Lawlis, 1983). One result consistently found was that a stable and satisfying marriage appeared to reduce the stress experienced by parents in coping with a disabled child (Gallagher, Beckman & Cross, 1983; Minnes, 1988). These findings have led some researchers to suggest that having a child with a disability in the family tended to strengthen strong marriages and weaken fragile ones (Brotherson, Turnbull, Summers & Turnbull, 1986).

Many studies have shown that most of the child care in families with disabled members was carried out by mothers (Fewell & Vadasy, 1986; Parke, 1986). Despite the increased demands which a person with a disability made on this aspect of family life, fathers generally did not make a bigger contribution than they made in ordinary families (Gallagher, Scharfman & Bristol, 1984; McConachie, 1986). Another fairly consistent finding has been that mothers of disabled children exhibited higher levels of stress than mothers of non-disabled children (Minnes, 1988). Some studies reported that this led to such mothers suffering a higher incidence of stress-related physical and mental disorders than mothers in ordinary families (Gallagher, Beckman & Cross, 1983; Philip & Duckworth, 1982).

Fathers, as well as appearing to play a smaller part than mothers in the day-to-day care of their disabled children, also had less contact with professionals. These factors have been perceived as leading to fathers experiencing greater difficulty than mothers in coming to terms with their disabled children (Hornby, 1994). Alternatively, as fathers generally work and have other interests outside the home their mental health may be less threatened than that of mothers. However, fathers were often said to use denial to avoid admitting the full extent of the disability or to hide their true feelings about the situation (Featherstone, 1981; Lamb, 1983). Other reported negative effects on fathers included particular difficulty in accepting disability if it occurred to a son, or if the child was severely handicapped (Lamb, 1983); and higher levels of depression, personality difficulties and marital problems than fathers of non-disabled children (Brotherson et al, 1986; Meyer, 1986). However, by contrast, a more recent study by Hornby (1992), found that there was little evidence for such effects.

It has been suggested that several factors can contribute to sibling adjustment (Seligman & Darling, 1989). Siblings might be given excessive caretaking responsibilities or might feel the need to overachieve, to compensate for perceived parental disappointment with the disabled child. Children might also wonder whether parents would expect them to care for the sibling in later life and worry about finding a spouse willing to share such a responsibility (Featherstone, 1981). Other concerns were anxiety about 'catching' the disability or about the future possibility of producing handicapped children themselves (Crnic & Leconte, 1986; Simeonsson & McHale, 1981). Reports of the positive effects on sibling adjustment of having a disabled family member included the entry of many siblings into careers within the helping professions such as teaching or social work (Furneaux, 1988). Other researchers have suggested that siblings of children with disabilities tended to be more insightful and tolerant of others' difficulties, more certain of their goals in life, demonstrated greater social competence, and developed a maturity beyond their years (Crnic & Leconte, 1986; Ferrari, 1984; Grossman, 1972).

A source of support for the family might be the child's grandparents or other members of the extended family (Hornby & Ashworth, 1994). It was indicated that grandparents might provide emotional support, guidance about child care, access to community resources, as well as help with shopping, baby-sitting and financial support (Sonnek, 1986; Vadasy, Fewell & Meyer, 1986). However, other reports have suggested that many grandparents had difficulty adapting to the situation and either attempted to deny the reality of the handicap or to reject the child (George, 1988; Seligman & Darling, 1989). A further problem reported by Pieper, (1976) was the paternal grandmother's resentment of her daughter-in-law for not producing a normal child. Such difficulties might lead to a breakdown in the relationship between parents and grandparents, which in turn, was likely to affect other family members.

2.5 Networks outside the family

2.5.1 Social networks

There are certain events in the life of a child with a disability which have been recognised as times when there is a particular need for support (Marion, 1981; Hornby, 1987). These include: birth, or when a disability is first detected; entry to school; the approach of puberty; the transition from school to work; as the child leaves home and moves into the community; and as parents age.

While an assumption of family counselling is that a family is connected to a larger network of social relations outside it (Broderick, 1988), studies of families coping with vision impairment have rarely incorporated this important aspect. However, a number of studies of family and parental coping in general, and of coping with specific impairments, have indicated in a limited way how family and social support factors might relate to family functioning when there is a child with vision impairment (Cogswell, 1976; Darling, 1983; Darling & Darling, 1982; Eggert, 1987; Featherstone, 1981; Fewell & Vadasy, 1986; Gottlieb, 1981, 1988; Milardo, 1988; Nixon, 1991; Seligman, 1979; Thomas, 1982).

Nixon (1994) suggested that families and parents differed in the types of help they sought and that the types and sources often changed over time. Outside help likely to be sought by family members might include practical resources, guidance, understanding or encouragement. Two networking sources utilised by families were identified: informal social networks composed of extended family members, friends, neighbours and others who were in the same situation, or acquaintances at work; and formal networks such as providers of disability services, education, medical care, and general social services, or peer-support and self-help groups. Families also might seek help from both networks.

Overall, the literature suggested that the extent to which families were likely to seek outside help varied according to their perceptions of need and stress. Whether families approached informal or formal networks for help was likely to be influenced by the nature of their subjective and objective experiences of impairment; their socio-economic status; where they lived; their sense of power, dependence, and familiarity in dealings with outsiders; their understanding of the resources they needed to cope with impairment; and their perception of where they would be able to obtain such resources.

The provision of appropriate and useful services to persons with vision impairment in relation to understanding their families has been addressed by some writers. Erin, Rudin, and Njoroge (1991) emphasised the importance of taking cognizance of the religious beliefs of families to gain their trust and co-operation, while Orlansky and Trapp (1987), and Correa (1987), emphasised the need to understand the culture and family structure of persons from minority groups. Only in this way could culturally relevant and effective services be provided. Likewise, Bishop (1986) found that family and community factors, along with the availability of support personnel in the school and acceptance by, and interaction with, peers, were among the factors perceived to be important components of successful mainstreaming.

2.5.2 Education of children with vision impairment

A formal network of prime importance to society is its education system. The history of education of children with vision impairment is almost as long as education in New Zealand itself and mirrors the shifts in philosophy and practice over the past 120 years. In 1877 both a national system of free, secular and compulsory primary education was established and the first efforts were made to provide formal education to persons with vision impairment (Mitchell & Mitchell, 1985). In 1891 a school was established which formed part of the Jubilee Institute for the Blind, later known as the Royal New Zealand Foundation for the Blind (RNZFB). In a joint undertaking which remains today, the Jubilee Institute was funded by a charitable trust and public subscription, while the government, through the then Department of Education, financed the education of its students (Catran & Hansen, 1992).

In the years up to 1949 the Jubilee Institute School was the only form of education to which children in New Zealand who were blind and partially sighted had access. However, the following period saw the emergence of two separate systems of service delivery, that of the RNZFB and the Department, later Ministry, of Education (Havill, 1972). This dual service provision remains, with the education of learners with vision impairment embedded in the RNZFB Act (1963). Today the large majority of students with vision impairment attend their local school. This had been brought about by the trend towards inclusive education with an emphasis on regular school settings and community-based opportunities, the development of regional support services and the advocacy of parents for a range of educational options for their children.

The philosophy underpinning the education of students with vision impairment is the same as that for all education: the right to equal opportunity and equal access to all parts of the educational programme, both curricular and co-curricular. Today the responsibilities which arise from such philosophy take place against a background of change, both in the education system itself and in wider society. The impact of influences such as the Human Rights Movement, international trends and internal political, economic and social reform are evident. Recent educational reform in New Zealand has followed similar general directions to that occurring elsewhere: school administration has been decentralised; former bureaucratic structures have been dismantled and schools have become independent, self-managing units competing within a deregulated market environment (Codd, McAlpine & Poskitt, 1992).

General education reform in New Zealand has focused on both administration with 'Tomorrow's Schools' (1988), and curriculum and assessment. Changes to the latter were heralded early in 1991 with the New Zealand Government's 'Achievement Initiative' followed by The Draft National Curriculum (NZ Ministry of Education, 1991). In March 1991 another agency, the New Zealand Qualifications Authority, released a discussion document about restructuring national qualifications entitled Designing the Framework (NZQA, 1991). Current policies reflect a direction towards a market-driven perspective.

Over recent years attempts have been made to introduce a more cohesive national policy for special education. In the past decade initiatives have included: The Task Force for Education of Students with Multiple Handicaps (Pole, 1986); The Draft Review of Special Education (1987); Special Education in New Zealand : Statement of Intent (1987); Special Education Policy Implementation Team (SEPIT) (1992); Special Education Policy Guidelines (1995); and Special Education 2,000. While progress has been made, a comprehensive special education policy is still in the process of development. Health reform in New Zealand has also impacted upon special education provision with the establishment of the Regional Health Authorities, the development of the Disability Support Service and initiatives in the disability-education interface.

2.5.3 Parent-professional partnership

In education, as in other formal network systems, it is considered important that professionals provide appropriate support and advocacy for parents. Positive support has the potential to enskill parents so that they develop the ability to advocate for themselves and their child. Murray (1991) indicated that in the past some professionals tended to have negative attitudes toward parents of children with disabilities. Likewise, Lipsky (1989), in summarising attitudes toward parents of children with disabilities, reported that some parents were considered to be unwilling or unable to work with their child; to have unrealistic expectations; to be overprotective; to need professionals; and to be unco-operative and unrealistic. Clare, however, in 1981 noted how professionals had moved away from excluding parents from schools; from telling rather than consulting; and from considering parents to be in need of psychotherapy. She considered that parents and professionals had moved toward partnership.

The changing attitude of professionals toward parents of children with disabilities has come about through several significant trends. Legislation such as the Education of All Handicapped Children Act (USA Public Law 94-142, 1975), and the Education Act 1981 in Great Britain, have given legal force to involving parents in decisions affecting their children. In New Zealand, the 1989 Education Act gave all children the right to attend their local school and in 1993 the United Nations Convention on the Rights of the Child was ratified. The Human Rights Amendment Bill bans discrimination on the grounds of disability and Commissioners have been appointed for Health and Disability and for Children. Professionals have recognised the value of parents participating in their child's education and consultation has increased as a result of the philosophy of normalisation with deinstitutionalisation and the trend toward community living.

In part, because parents have united to form support groups, they have expected and requested more from professionals. Parents have also felt more confident about claiming their rights and advocating on behalf of their children (Murray, 1991). Murray and Shaw (1984), reporting on a local workshop lead by Milton Seligman of the University of Pittsburg, recorded the following responses from parents when they were asked how they would like professionals to be:

- to listen with empathy;

- to consult parents more;
- to consider the whole family when setting up programmes to be carried out in the home by professionals for the child with a disability;
- to resist labelling and be more prepared to focus on the child's strengths and deficits;
- to adopt a more open attitude and be willing to say they don't know, rather than become defensive;
- to be more sensitive about assessment, giving value to reviews of progress rather than administering too many full psychometric assessments;
- to develop greater co-operation among the professionals involved with an individual child, using a key worker, or 'named' person, to co-ordinate services;
- to administer services and provisions flexibly so that they can be adapted to meet the needs of the person rather than the person needing to fit into the system.

Murray and Shaw (1984) suggested that if a meaningful parent-professional partnership was to exist there needed to be open honest communication in all interactions. The ability of professionals to focus on positive aspects of an interaction, by affirming parents and validating what they contribute was likely to enhance the relationship. This meant professionals needed to be integrated people with adequate self-knowledge (Murray, 1991).

An important aspect in the parent-professional partnership is the professional's attitude to families with disabilities. Gargiulo (1985) suggested the child with a disability can only be seen and fully understood in the context of the family unit. There are many similarities between families with a member who has a disability and families of children without disabilities and mutual respect is the basis for successful interactions between parents and professionals in both. Murray (1991) signified that a professional who has an understanding of the various stresses a parent may have experienced at different stages of their child's life, of the extra demands experienced in parenting a child with a disability, of the anxieties a parent may feel when thinking about their child's future should not find it difficult to communicate regard, respect and acceptance. For Murphy (1982) listening was the critical element in human relationships. He believed it crucial that all professionals endeavour to develop the skill of listening to the highest level possible, as well as demonstrating a caring attitude and a positive interest in the person with a disability.

2.6 Peer support and self-advocacy

A professional's ability to offer support to parents experiencing stress may be restricted by their level of skills and their availability. Hornby, Murray and Jones (1987) therefore suggested that often the most appropriate person to provide support to the parent of a child with a disability is not a professional but another parent of a child with a disability. When help is given by other parents, who may be regarded as 'being in the same boat', the support is seen as truly genuine. The best form of support a professional may be able to offer is to link a parent with another parent whose son or daughter has a similar disability or need. As noted by Gargiulo (1985), professionals need to be knowledgeable about local parent and professional organisations as well as community resources and services.

While many relevant resources and services may be accessed through the parent-professional partnership, it has been necessary for many parents to enter the role of advocate to ensure that the needs of their child and family were met (Kendrick, 1996). A major growth area in recent years has been the proliferation of self-help, or self-advocacy groups (Gitterman & Shulman, 1986), in which parents have united to give mutual practical and emotional support, to provide a forum to enskill each other in assertion and negotiating skills, and to influence each other about their expectations of professionals. Such groups are world-wide and range from those in which a small number of parents get together regularly, to others which have become national organisations (Hornby, 1994). Universality and group cohesion work to promote personal growth and self-advocacy skills. Parents develop their own personal coping strategies and increase their social support networks (Hatch & Hinton, 1986). Parents of the Vision Impaired (PVI) is such a group in New Zealand.

Two recent New Zealand studies and an edited book have provided direct accounts by individuals and families of their own perspectives on aspects of disability. In the Otago Family Network Project study, parents of children with disabilities worked with professionals to impact on policy and practice in health, education and welfare (Ballard, Watson, Bray, Burrows & MacArthur, 1992). Information, advocacy, and support networks were established with family, and disability issues introduced into seven professional training programmes. Within this study nine families gave first-hand stories of their lives. Issues which emerged included the importance of parents' clarity about their own values, the need for advocates to be independent of service provision, and the role of advocacy in developing parents' own skills. In addition to the recommendations made, the report discussed specific implications for researchers and funders of research.

Timutimu-Thorpe (1990) presented the thoughts of Maori caregivers who recounted their experiences raising children considered to have intellectual disability. The findings suggested that Maori families share similar experiences with other families of children who have disabilities, but that difficulties they encounter may be exacerbated by the lack of recognition extended to Maori culture in community and institutional settings.

Ballard's edited book (1994) 'Disability, Family, Whanau and Society' provided description and analysis by writers such as Brown and Wills of their experiences as parents of a child with intellectual disability. As the title suggests, the focus is on family and whanau, and the impact of society.

2.7 Conclusion

This chapter has defined the 'landscape' from which issues for families of children with disabilities arise. It has focused on the family as a social system and the ways in which a child with a disability may impact upon it. Characteristics of disability and vision impairment have been described with their social constructs emphasised. Issues affecting the family, both as a whole and its individual members, have been reviewed and networking sources outside the family identified. Finally, the recent progression towards self advocacy has been explored. Bronfenbrenner's model has been identified as the basis for the discussion in the present study, because the research findings suggested that such a framework would best give them contextual meaning. The model is attended to in greater detail in the ensuing chapter on methodology.

There remains much to be explored about families of children with disabilities. A shift has been discerned to considering the family as an interactive, interdependent system and a developing awareness has given rise to research which has considered the impact of disability on others. To date much of the research however has focused on the mother in the family with minimal attention given to the coping of other family members such as fathers, siblings, or grandparents (Meyer, 1993). Further, family coping with vision impairment itself has received relatively little direct attention from sociological researchers and few attempts have been made by researchers in general to write about the sociological implications for families.

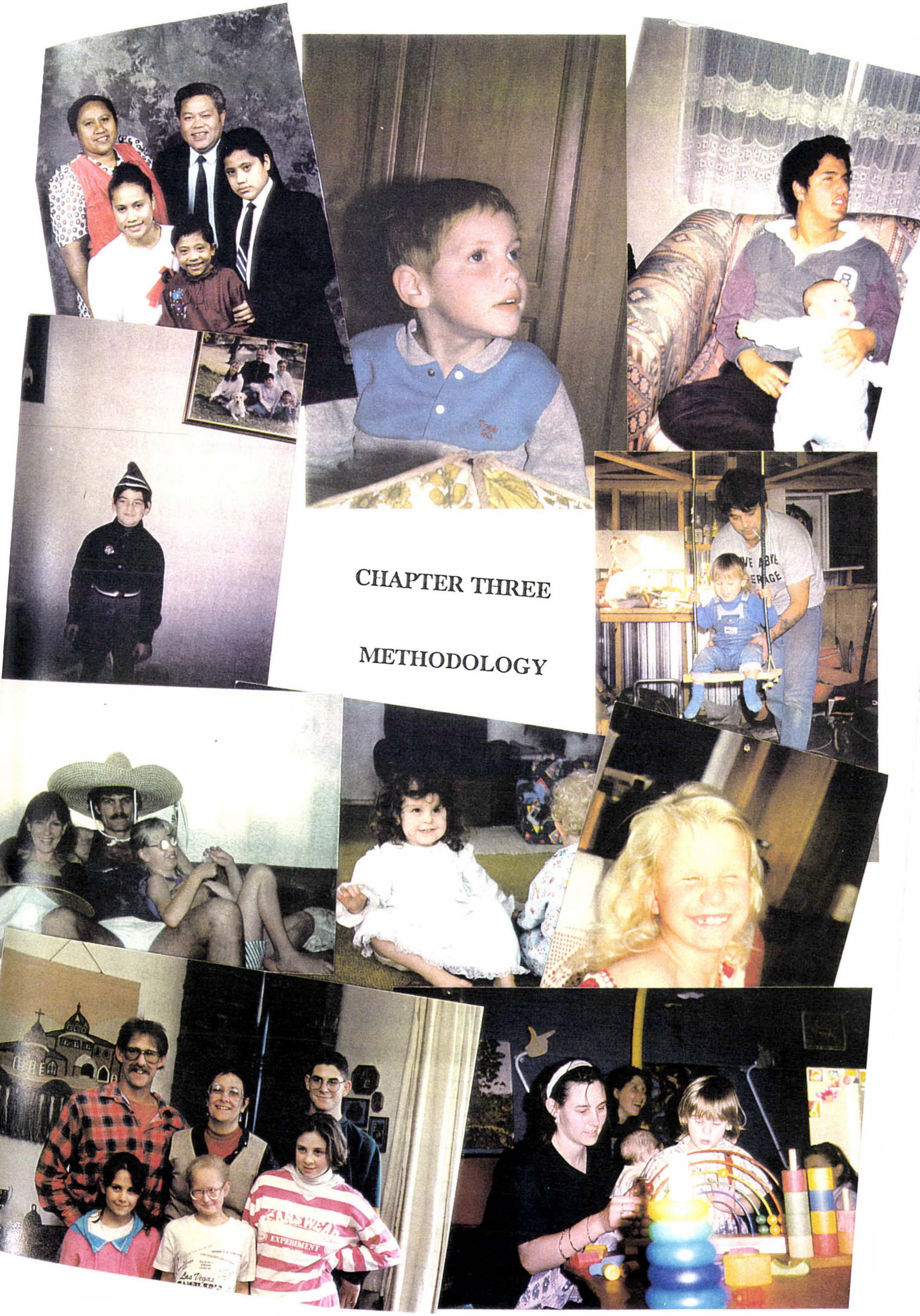
While some information is available from literature emanating primarily from Britain and the United States of America, to date scant family-focused research has taken place in New Zealand examining the impact of disability or the strategies families have developed to negotiate development tasks and fulfil family needs. No known research has explored the concerns and coping strategies of New Zealand families of children with vision impairment.

In concluding, Nixon (1994) highlighted seven potentially important questions for further study concerning the relationship of vision impairment to family function. These included the impact of families' social and cultural backgrounds; their residential location and mobility patterns; how family relations are affected by the use of family resources to cope with vision impairment; how relations with outsiders affect a family's support resources; and how the family is affected by the status in the family and in society by members who are vision impaired.

Nixon's questions suggest the possibility of a much longer list addressing family issues and family coping with vision impairment. The process for individuals and families is "complex, dynamic, ongoing and different under various social conditions" (Nixon, 1994, p.335). Additional research has been needed to clarify and add to existing knowledge, by using new methodologies that enable the unique lived experiences of families and their visually impaired children to emerge. In the end it is their expertise and intimate knowledge that can best guide the work of researchers, policy makers and service providers.

CHAPTER THREE

METHODOLOGY



CHAPTER THREE

METHODOLOGY

> *I think you will find we (as parents) do know what we are talking about. ...And you might even become demanding of what we know.*
>
> *(Research participant)*

3.1 Introduction

This chapter describes and justifies collaborative research as an appropriate methodology for exploring issues surrounding families of children with disability and for accessing family stories in order to make visible their lived experiences. Research questions are defined and methods used to collect data specified. The chapter is presented in four parts. The first part provides the rationale for the overarching methodology and the approaches used within it. The second section appraises ethical and cultural considerations, while the third section details the processes by which the experiences of each family were drawn out. Finally, the method for analysis is described with Bronfenbrenner's (1979) ecological model identified as providing an appropriate framework for this section of the study.

Research questions arose out of the general aims and purpose of the study (ref. Appendix 1). They were determined collaboratively over two initial focus group meetings, taking regard of the experiences of the participants and the researcher and issues arising from the literature. Broad-based in nature, the questions were open-ended and intended to provide some focus for the stories of the families.

The research questions probed four areas. Firstly, attention was directed to the locus of the family itself with issues for the child, parents and siblings explored. Families were asked to consider their various stages of development and identify areas of difficulty. The effects on the family of the attitudes of others, such as extended family, community, professionals and policy makers, were also examined.

The second topic area was directed to finding out how families organised themselves to provide self-support and the manner in which they negotiated issues. Coping strategies were considered with identified support networks and service systems. This question was aimed at highlighting services families found of most value and identifying those needs which remained unmet. The third question sought to find the strengths which families drew upon to meet their needs and goals, while the final inquiry centred on what was needed now and in the future to provide adequate support to families in order to fulfil their role in relation to their own expectations and those of their communities. The research questions were explored sequentially across three focus group meetings and also provided the basis for the interview schedule which was carried out face-to-face with each family.

Because of the nature of the experiences of families of children with disabilities the research was a multi-site, multi-method, multi-data study linking different research methods. Within qualitative methodology the collaborative, emancipatory paradigm lent itself well to the purposes of this study in its attempt to develop perspectives on areas which are problematic for families. It involved the key participants, ten families and the researcher, throughout the various stages of the research process. Designed around a narrative, life history model, stories were reproduced using participants own words, with their experiences accessed through the triangulation of focus group discussion, family data sheet, field notes and face-to-face family interview.

3.2 A theoretical perspective: rationale

3.2.1 Qualitative methodology

Qualitative methods offered techniques whereby ideas, feelings, beliefs, values and understandings individual to each family could be expressed. It offered a means of power sharing, group interaction and story telling. Opie (1992) has advocated the use of "qualitative research methods which can lead to an empowerment of participants on a personal and broadly therapeutic plane and which incorporate the voices of marginal and hence previously silenced groups into the text" (p.64). The study also encompassed one principle of action research in that, in addition to understanding being valued for its own sake, it was also valued for its capacity to guide and reform strategic action in the future (Carr & Kemmis, 1986).

Qualitative research as a theory of knowledge is underpinned by the philosophical, theoretical and sociological perspectives of phenomenology and symbolic interactionism (Chenitz & Swanson, 1986). Both are concerned with the inner experience of a person and how this is expressed. The importance of an individual's understanding of the world and the influence that their particular perceptions have on their actions is emphasised, with reality regarded as independent of a person's subjective perception of it. These perspectives argue that the values within any particular society create a context within which people live, with what is said and done, and how individuals relate, defining their world. Meaning is conferred by others and this, in turn, influences a person's perception of themselves. The interrelatedness that textures people's lives is highlighted, individuals being influenced by, and influencing, the social organisation, cultural setting and historical context in which they live.

An advantage of the qualitative approach is its responsiveness to meeting the needs for much data in a short span of time. It captures the daily processes that contribute to adaptation and the richness of family processes as they unfold over time (Tennen, Suls & Affleck, 1991). The approach also reflects that of Lather (1986b), in that through the dissemination of findings participants can provide opportunities to others. For example, through sharing their own coping strategies they may assist others in developing appropriate coping strategies for themselves. It is by such a progression that families may be empowered and motivated to change the shape of policy and practice, so that their needs might be better met in the future.

The study, therefore, used qualitative methods to present the participants' point of view and to reveal how they have constructed meaning in their lives. The families told of their realities within their own natural contexts, in order for the reader to understand them as they were experienced by the families (Sherman & Webb, 1988; Ely, Anzul, Friedman, Garner & Steinmetz, 1991).

3.2.2 In collaboration

Within the qualitative paradigm the collaborative approach promoted the use of research as a means rather than an end and was aimed at making a positive difference in the overall quality of family life (Turnbull, Turnbull & Senior Staff, 1990). It enabled the study to take its direction from the participants. Collaborative, or participatory research, involves theorists, researchers, service providers and family members collaborating in the research process by together defining questions, designing and implementing methodologies, analysing and interpreting data, disseminating findings, and using results (Whyte, 1991). Ballard et al (1992) supported this position, indicating that if research took its direction from the participants it would become a dynamic experience accommodating to the life circumstances of the families it served.

Four principles for participatory research adopted by participants at the Consensus Conference of Principles of Family Research held in 1989 were:

- Research is a means, not an end. Its goals are to develop information and to test strategies and interventions that themselves are designed to accomplish certain goals.
- Research should be a collaborative endeavour based on mutual respect, trust, potential benefits, and acceptance of each party's responsibilities.
- Research should be sensitive to cultural, socio-economic, ethnic, lifestyle, and life span pluralisms.
- To achieve the foregoing purposes, research should allow for a combination of paradigms and methodologies.

A strong commitment was made to adhere to the collaborative model at every stage of the research process, from defining the parameters of the study through to the dissemination of findings. Overall this resulted in a climate for power sharing, reflection and the telling of stories. The participatory approach also extended to the reader of the study. Lather (1986b) proposed that the initial step in critical enquiry was to develop an understanding of our own and others' world views. Through the direct accounts of the families the reader could become involved in the ideas, experiences and emotions of others. Such participatory knowledge forms a firm basis for critical analysis and action for change. The aim then of the methodology was to involve the key participants - individuals, families and researcher - in every stage of the research process.

3.2.3 Triangulation

Triangulation involves combining different techniques for collecting data in the same study (Reinharz & Rowles, 1988). Its purposes are to highlight different dimensions of the same phenomena, to compensate for the shortcomings of each method and to increase validity of the findings by examining them from several vantage points (Burgess, 1984; Campbell & Fiske, 1959; Phillips, 1985; Webb, Campbell, Schwartz & Sechvest, 1966). Triangulation capitalises on the individual strengths of methods utilised (Blaikie, 1988) and can be used to overcome the problems that stem from studies relying on "a single theory, single method, single set of data and single investigation" (Burgess, 1984, p.144). It is also regarded as a means of decreasing possible bias. Techniques for data collection included focus group interviews, family data sheet, face-to-face family interviews and various materials offered by families in support of their stories (ref. Figure 1).

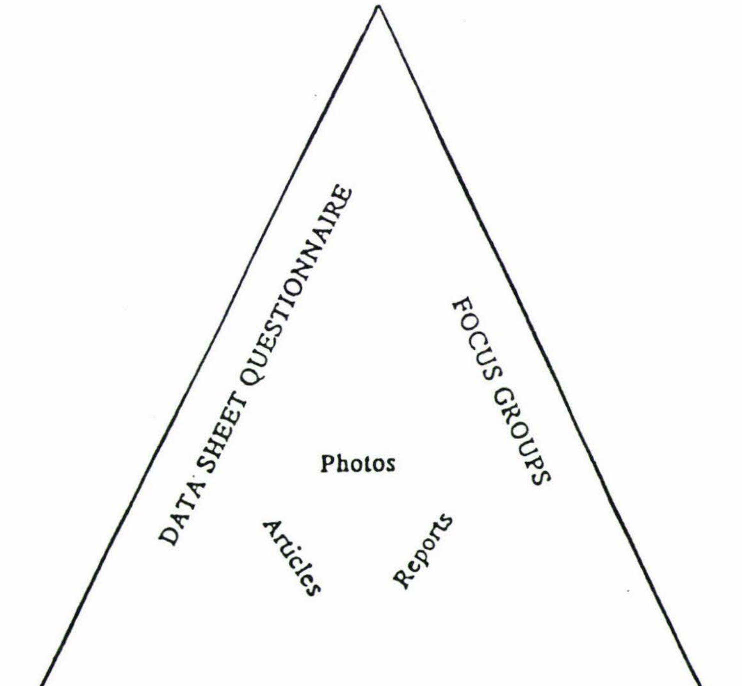


Figure 1 Triangulation

3.2.4 Focus group interviews

The focus group technique was selected as a method of data collection for this study because it disclosed what was important to individual participants and attempted to provide a situation where the synergy of the group could provide additional depth and insight. Its approach to gathering information is both inductive and naturalistic. Particularly useful in developing specific research questions and issues for future exploration, the focus group provides a setting in which individuals are likely to be comfortable in self-disclosure and where the group dynamics create a chain of reactions designed to fully explore the issue or problem. The technique is the result of a movement away from interviews of individuals towards group discussions as a means of getting more diversified information (Mies, 1983).

The technique was developed after World War II and had its origins at Colombia University in 1941 with an evaluation conducted by Lazarsfeld and Merton, resulting in publications outlining the methodology (Merton & Kendall, 1946; Merton, Fiske & Curtis, 1946). Over time it became disseminated and used widely in group interview settings. Goldman (1962) defined focus group depth interviews as a group being a number of interacting individuals having a community of interest, depth involving the search for information that is more profound than is usually accessible at the level of inter-personal relationships, and interview as implying the presence of a facilitator who uses the group as a means for eliciting information. The term focus in the title implies that the interview is limited to a small number of issues. The importance of the group as a source of information has also been emphasised by Smith (1987) who defined group interviewing as one which is limited to those situations where the assembled group is small enough to permit genuine discussion among all its members.

Today focus groups or group depth interviews are among the most widely used research tools in the social sciences (Stewart & Shamdasani, 1990) and are used in a variety of situations. Their purpose is not to teach, to provide therapy or resolve differences, or to achieve a consensus, but rather to obtain information in a systematic and verifiable manner (Krueger, 1994). Focus groups are conducted with the collection of qualitative data as their primary purpose. Their advantage is in producing a rich body of data expressed in the participants' own words and context. There is a minimum of artificiality of response, and participants can qualify thei responses. This results in a certain ecological value not found in traditional survey research (Albrecht, 1993).

Stewart and Shamdasani (1990) outlined the more common uses of focus groups as being to obtain general information about a topic of interest, generate research hypotheses, stimulate new ideas, diagnose potential problems and generate impressions of programmes, services, institutions, or other objects of interest. Researchers may also learn how respondents talk about the phenomenon of interest in order to facilitate the design of questionnaires, survey instruments, or other research tools or to interpret previously obtained quantitative results.

Advantages of the focus group technique include its socially orientated research method which captures real-life data in a social environment, its flexibility, high face validity, speedy results and relatively low cost (Stewart and Shamdasani, 1990). The researcher is able to interact directly with participants with opportunity provided for clarification of responses, follow up questions and probing, as well as observing nonverbal responses which may carry information. Participants can qualify responses or give contingent answers to questions. Focus groups allow respondents to react to, and to build upon, the responses of other group members. This synergistic effect of the group setting may result in the production of data or ideas that might not have been uncovered in individual interviews. Focus groups may also be useful in obtaining data from those who have difficulty formulating and expressing their ideas in an individual context. A final advantage is that the results of a focus group are easy to access. Researchers and decision makers can readily understand the verbal responses of most respondents while such is not always the case with more sophisticated survey research that employs complex statistical analysis. However, while focus groups are valuable research tools they are not without limitations. Areas for consideration in utilising this method include difficulty of data analysis, the skill level of the facilitator, opportunities for the group to meet, and developing an environment conducive to discussion (Krueger, 1994). Because of the particular sequence in which procedures were utilised for this study, the focus group approach provided a valuable lead-in to the family interviews.

3.2.5 Face-to-face family interviews

Face-to-face interviews were carried out with each of the participant families. As for focus groups, a primary focus of in-depth interviewing is to understand the significance of human experiences as described from the participant's perspective and interpreted by the researcher (Minichiello, Aroni, Timewell & Alexander, 1990). This requires that the researcher has personal interaction with the individuals and their context to enable their perspective to be heard.

A conscious attempt is made to tap into people's experiences by telling their stories and presenting analyses based on their descriptions.

In-depth interviewing may be considered to be conversation with a specific purpose between researcher and participant focused on the participant's perception of self, life and events and the means by which the researcher can gain access to, and understand, the private interpretations of reality that individuals hold. While there are a number of definitions of interviewing, the common elements were expressed by Bogdan and Taylor (1984) as:

> *face-to-face encounters between the researcher and informants directed towards informants' perspectives on their lives, experiences or situations as expressed in their own words. (p.77)*

There is the implication that roles will be equal as far as possible within the interview, with the participant's, not the researcher's account which is sought and valued. The researcher tries to retrieve the participant's world by understanding their perspective as it is expressed in their own language. In-depth interviewing is not typically used as hypothesis testing, but as theory-building, based on both the data gathered and the experiences of the actual interaction in the in-depth interview, the model of grounded theory developed by Glaser and Strauss (1967).

3.2.6 Research stories

Within a qualitative methodology, research stories have the potential to uncover the many experiences of disability and as such were the prime framework selected as an organiser for understanding the unique characteristics, patterns of interactions, and functions inherent in the families in this study.

Thompson and Janigian (1988), proposed that each individual has a cognitive representation of his or her life, much like a story, that organises world views, goals in life, and events relevant to these goals. These life schemes may be changed by a traumatic event to accommodate the new experience. The research story approach enables personal insight to people's lives. It gives control back to the families involved because they tell their own story, rather than being produced through another's observations and professional expertise (Schwier, 1990; Bogdan & Taylor, 1982). Stories are valuable in that they describe significant experiences, views and calls for justice. For example, the voices of people with disabilities themselves and their parents' voices have contributed to their inclusion in schools and to the closure of institutions.

An example of a story telling approach which includes direct accounts from people with an intellectual disability is Ballard's (1994) Disability, Family, Whanau and Society, where individuals told of issues that impacted upon their lives and conveyed their hope for more equitable treatment. A case was made for attention to the voice of those who have authentic experience of disability, and for using their stories within emancipatory models of research.

There are ways to evaluate critically whether stories can be the basis for action. This may be done in terms of the values held regarding human needs and rights, or by considering how a story relates to others previously recorded (Barton, 1986), that is, people in different contexts making similar findings. In this way structures that seem associated with oppressive experiences and those that seem typically to occur when people with disabilities and their families feel supported and valued should be able to be identified.

Arguments that the 'average', 'typical' or 'representative' picture is not ascertained do not invalidate this research methodology. Each place, group of people, and their development over time, represents a context that may vary in some aspect or another. Although information arising from research stories is not directly generalisable, because of the small number of participants and the valuing of subjectivity, it has the potential to offer insights to others through developing their own understandings, interpretation, application and evaluation. Validity is gauged by the extent to which readers of the stories are able to relate its content to their own experience (Stainback & Stainback, 1991). It is anticipated that other families, and those associated with them, such as ophthalmologists, paediatricians, early interventionists, teachers, psychologists and therapists, may all gain useful information as a result of this study.

One way to gain experience is to share that of others. With respect to this, Donmoyer (1990) highlighted the value of stories to professional practice, identifying novels, oral accounts and written narratives as a powerful way of learning because they "can create a virtual reality, that is, a reality that exists within our imaginations" (p.191). He emphasised the value of personal knowledge in professional practice, and personal experience in applying new knowledge or working in new settings. People did not just apply research findings, but also used their knowledge, feelings and intuition. The more experience, and the more diverse the settings experienced, the more complex were the thoughts, feelings and tacit knowledge brought to a new task or setting. Stories convey knowledge within the complexity of human affairs, expanding understanding of other people and providing a sense of identification with them. They are accessible to the general reader and increase the range of interpretations, knowledge, and experiences available to those who would use research to inform action, either as lay people or as professionals.

3.3 Ethical and cultural considerations

3.3.1 Ethical considerations

A number of ethical issues required consideration both prior to, and during the study. Some, such as the dissemination and use of the findings, are ongoing. Qualitative research makes demands on participants. Researchers and participants have rightly become increasingly alert as to who is to benefit from intrusions into the lives of children and families. Parents of children with disabilities have questioned researchers about both the credibility of their methods and who will benefit (Turnbull, Blue-Banning, Behr & Kerns, 1986). The participatory approach was selected to address such concerns through collaboration (Bogdan & Biklen, 1982; Patton, 1990) and there was a deliberate attempt throughout the study to ensure that the research design was transparent and clearly articulated. It was also essential to consider ways in which the research might affect participants and what the implications of their participation might be.

To ensure informed consent, emphasis was given during the first focus group meeting to conveying the purpose and nature of the research to each participant, the methodologies likely to be employed and the commitments required by participants and researcher. The rights of participants were outlined, including the right to withdraw at any stage of the research. A Research Information Sheet was provided which outlined the considerations discussed. All those present agreed to participate and signed a consent form. Endorsement of the research study was given by the RNZFB and the Homai Research and Development Committee.

At the commencement of the study an undertaking was given to participants by the researcher that any information provided would be confidential and that participants' identities would be protected. However, as the research progressed, nine of the ten families chose to use their own names. This, then, is how much of the information has been presented.

The research process was an enriching and humbling experience for the researcher, given the families' own interest in, and responses to, telling their stories. These were often frank, and specific incidents were related, both past and current. While some data has been aggregated, for example where there was consensus in focus group discussion or several participants shared views on sensitive issues, there has been a genuine attempt where possible to reflect the stories of individual families and to convey findings that are meaningful to participants themselves.

Participating in a research study is in itself a form of intervention and throughout the study attempts were made to ensure participation was worthwhile. The interactive nature of interviewing can change behaviours and give rise to further ethical issues. Although it is unlikely participants will choose to tell an interviewer things they do not want to have known, people may inadvertently go beyond information with which they are comfortable. Returning transcripts, the drafts of the stories, and the presentation of the study's findings at the fifth focus group meeting ensured that the participants had the opportunity to withdraw any information they did not wish to be used, to modify, and to comment as desired.

Throughout the research a participatory model was used. Participants and researcher acted collaboratively during data collecting and analysis procedures, with feedback and discussion at every phase. Participants were invited to comment on findings - individually, as families, and collectively within the context of the focus group setting. Information obtained was shared sensitively and respectfully with nothing withheld. An attempt has been made in the final presentation of the study to make its style easily accessible and each participant family has been provided with a full copy.

In the future, participants and researcher will make a collective decision as to the nature and extent of the dissemination of the findings. This will probably include oral feedback and reporting, the thesis itself, conference presentations and academic publications, a 'story' book, and a proposed informational video. The goal will be to seek together creative ways in which these stories may best be utilised to benefit those for whom they have been told.

3.3.2 Cultural considerations

The researcher's own culture is New Zealand Pakeha, differing in this regard from four families who participated in the study: one Maori, one Maori/Pakeha, one Samoan, and one Dutch. Cultural practices and background experiences which are not shared or which have different constructed meanings are therefore acknowledged where they were identified. The same questions or responses might have had different meanings to respondents of different cultures. For example, patriarchal western cultures value autonomy, independence and self-sufficiency for all, including those with disabilities. However, some cultural groups value group solidarity above independence (Lynch & Hanson, 1992). The qualitative methodology of this study assisted in providing reliability and validity for persons from diverse backgrounds. Story telling in particular, is similar to the oral traditions of Maori and other indigenous Pacific peoples.

A further cultural dimension was that of disability, reflected in language that was distinctive, often punctuated with abbreviated forms or acronyms but with meanings clearly shared and understood by participants. There were also particular coping strategies employed, such as shared humour in the group. Participants drew a strong sense of support from each other, in part as a result of shared experiences, in part from shared ongoing struggles to meet the needs of their child and family. While the researcher was able to identify with some aspects of the culture of disability from a personal perspective, this was not from the perspective of a parent of a child with disability and care was taken not to claim entry or make assumptions on this basis.

At all times the researcher endeavoured to demonstrate a positive attitude and show sensitivity and respect for others' ways of thinking, feeling and acting.

3.4 The participants

The study focused on families of children and young people who were blind or vision impaired, some of whom had multiple special needs. The participants chosen were an opportunistic sample, beginning with the ten individuals who comprised the National Committee of the Parents of the Visually Handicapped (PVI) organisation at the time the study started. For parents of children, adolescents and young adults who are vision impaired, this organisation promotes support and advocacy and engages in some political activity. The ten members are elected annually representing geographical regions throughout New Zealand, the Tangata whenua, and Pacific

Island fanau. All ten agreed to participate in the study and in collaboration with the researcher, determined the focus, aims and direction of the research and participated in the focus group meetings when attending the PVI national committee meeting. While not all participants were able to attend every focus group session, there were at least seven present at each discussion.

The decision to select this group as the participant sample was influenced by Clay's (1982) approach to reading research. To identify strategies and approaches which would assist readers with difficulties, she focused on the strategies and approaches employed by 'able' readers. Likewise, the ten individuals elected to the PVI National Committee were people who had offered themselves as resources to others likely to be experiencing similar issues and concerns. Because of the nature of PVI it was likely that its members would have knowledge of, and be involved in, issues relating across a wide range of practices and systems.

The composition of the PVI National Committee is provided in Table 1, outlining details of the target participants and the pattern of overall participation.

Table 1 **Participants of the target group**

Participant	1	2	3	4	5	6	7	8	9	10
Gender	M	F	F	M	F	F	F	M	F	M
Ethnicity	P/Ma	P	P	D	P	S	P	P	Ma	P
Spouse Particip	Yes	Yes	Yes	Yes	-	Yes	Yes	Yes	-	No
Chn Particip	No	No	Yes	No	Yes	Yes	Yes	No	No	No

Key: F - Female
M - Male
Ma - Maori
D - Dutch
S - Samoan
P - NZ Pakeha

The wider participant group was determined by extending involvement to the families of the ten committee members. Most of the in-depth face-to-face interviews took place in the families' homes. Eight spouses, three children and adolescents with vision impairment, ten siblings, and one extended family member chose to participate. A profile of each family accompanies their stories.

Of the participants involved in the study the researcher had had previous contact with five families through Homai Vision Education Centre and earlier contact with PVI. With the five families not previously met, there was an opportunity to build a rapport with the PVI member during the focus group meetings prior to the family interviews. This assisted considerably in developing a level of trust and credibility between participants and researcher and the climate for all face-to-face interviews was one of openness and facilitation.

While the common element of the participant group was its children and young people with vision impairment, it was not intended that the study focus upon the impact of a single disability in isolation for two reasons; first a large number of people are affected by multiple disability (for example vision impairment and physical disability or developmental delay), and this was reflected in the children of the participating families; second there is the additional general disabling effect of social attitudes, values, and ideologies which lead to discrimination and disempowerment.

3.5 Procedure

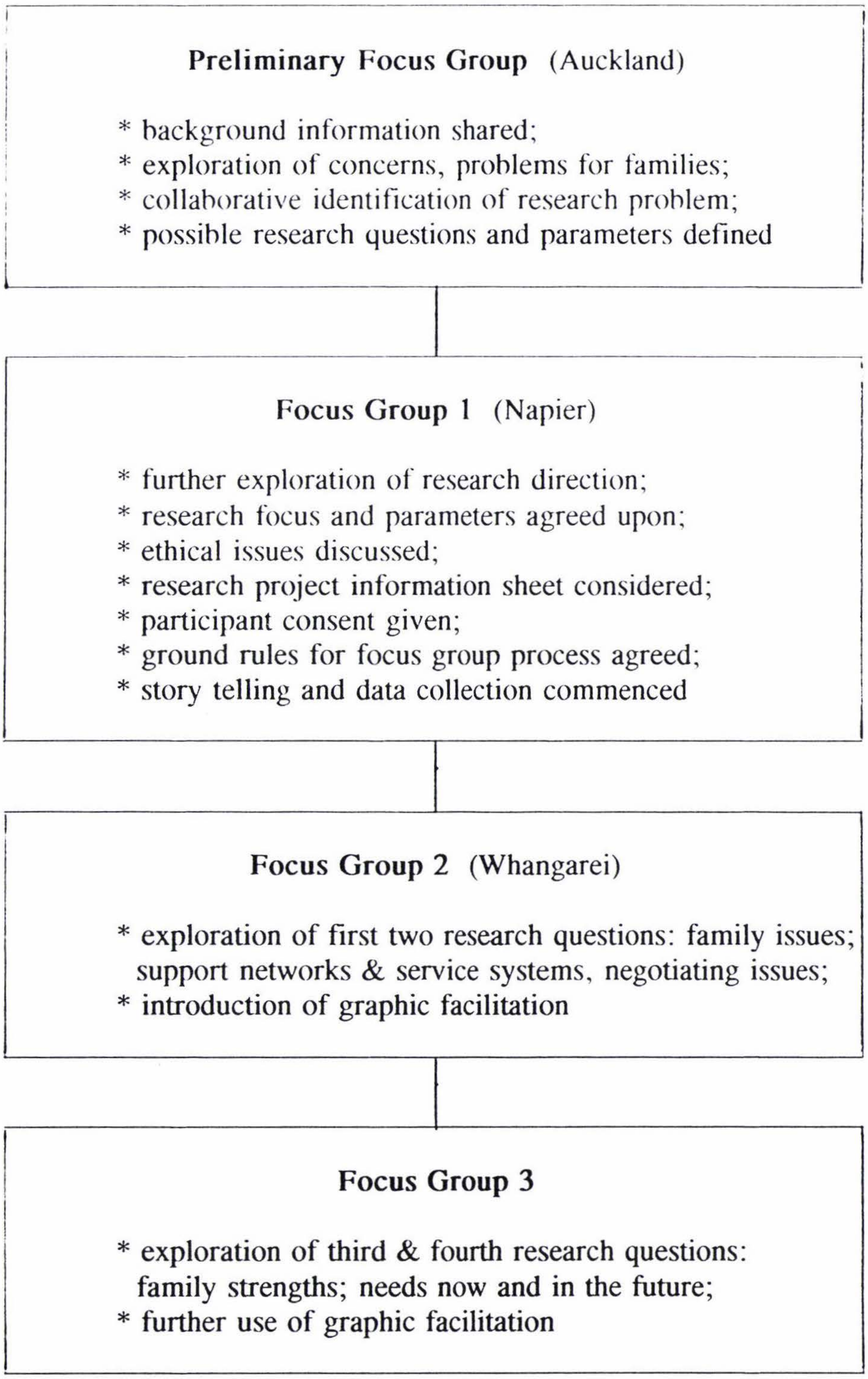
3.5.1 Introduction

This section describes the processes by which the stories of the families were provided with a view to relating them as unique and personal accounts of the experiences of each family, and analysing some of the recurring issues. The richness of the stories is 'mined' through the triangulation of focus group exploration, family data sheets, field notes and face-to-face interviews. Supporting material, such as anecdotal writing, photographs, articles, reports and submissions, was also accessed.

The initial focus groups enabled the locus and design of the research to be established and the issues arising influenced the formulation of the family data sheets and interview schedules. Likewise participation in the focus groups by a member from each family and the communication with families via the data sheet provided an entry point to the family interviews. The final two focus groups provided an opportunity for validation of data obtained and feedback to the community of interest.

Each process built upon, and was complementary to, those proceeding. Figure 2, the research procedure, outlines the processes of the study from the preliminary focus group through to the presentation and dissemination of the research findings. In all, six focus group interviews involving the 'target' participants were carried out. The first, preliminary to the study proper, was exploratory in nature and designed to seek to identify concerns and areas problematic for families which in turn led to the collaborative identification of the research problem, defining research questions and agreeing on parameters. The second, third and fourth focus groups and the family interviews focused on implementing methodology, story telling and the systematic exploration of each of the research topic areas. The final two sessions were devoted to giving feedback, validating, analysing and interpreting data, editing, reporting and making decisions about the use and dissemination of the findings.

Figure 2 **The research procedure**



Preliminary Focus Group (Auckland)

- * background information shared;
- * exploration of concerns, problems for families;
- * collaborative identification of research problem;
- * possible research questions and parameters defined

Focus Group 1 (Napier)

- * further exploration of research direction;
- * research focus and parameters agreed upon;
- * ethical issues discussed;
- * research project information sheet considered;
- * participant consent given;
- * ground rules for focus group process agreed;
- * story telling and data collection commenced

Focus Group 2 (Whangarei)

- * exploration of first two research questions: family issues; support networks & service systems, negotiating issues;
- * introduction of graphic facilitation

Focus Group 3

- * exploration of third & fourth research questions: family strengths; needs now and in the future;
- * further use of graphic facilitation

Postal Contact

- * letter of invitation sent to families to participate in face-to-face interviews
- * data sheet questionnaire sent

Interview schedule sent to families

- * schedules either posted to families or given personally at time of PVI Annual Conference

In-depth face-to-face interviews carried out with 10 families

- * stories told & supporting data presented

Stories written, data frameworked

- * stories written
- * themes identified and analysed
- * checking by researcher with individuals and families to confirm data and check on analysis

Focus Group 4 (Dunedin)

- * feedback, checking, confirming
- * editing and adding to data and draft report

Focus Group 5 (Auckland)

- * presentation by participants and researcher to the 'community of interest'
- * dissemination of findings
- * initial planning for the possible making of a resource video and 'story book' based on the study

3.5.2 Group exploration

The present study commenced with a preliminary Focus Group meeting. Following an initial approach to the Chairperson of the PVI National Committee who expressed interest in the proposed research, the researcher was invited to facilitate a session at the PVI Annual Conference in Auckland to outline a proposal and discuss possible ways forward. Ideas for the study were shared and some current trends and considerations which might impact upon families noted. Interest was expressed by those present and the foundations laid for the study.

The focus groups which followed were dynamic, colourful and at times cathartic. The participants attended PVI meetings five times during the year over a weekend, usually gathering in a motel or conference centre. The Friday nights of these occasions were allocated to participating in the research. Previous to the study this would have been a time of reunion and socialising and, to a degree, this climate pervaded the focus group sessions with their vitality and friendship. Most of the individuals in the group were well known to each other and their sense of purpose and connectedness in relation to their children meant that an environment of openness, trust and support was already present.

Following the preliminary group interview, four data-gathering focus groups were held over a period of nine months (ref. Figure 2), located in different cities. Sessions lasted from three to four hours and were audio taped. Settings were varied with the group adjusting according to the restrictions of the physical environment and resources available. Meeting places ranged from a spacious, specifically designated conference room with overhead projector, whiteboard and pin boards, to the small lounge in the motel unit of one of the participants. Both settings had their advantages and animated discussion was certainly not stifled by restricted accommodation.

Due in part to the timing and circumstances of the focus groups, a pattern emerged in relation to the group dynamics. Following the initial introduction of the focus for the evening a period of intense participation followed, often punctuated by light hearted banter and 'letting off steam'. There was much to share and the liveliness was often accompanied by several participants wanting enthusiastically to contribute at the same time. While such interaction promoted debate and generated ideas, at times transcription of the tapes proved difficult. This period would characteristically be followed by more serious reflection as the data generated in the earlier stage was explored in its fullness in a sensitive, impactful way.

Because of the wealth of information, the transcription difficulties, and the desirability of all participants contributing it was decided to introduce graphic facilitation for two focus groups where the research questions themselves were explored. With the consent of participants, a research assistant was brought into these sessions to facilitate the graphic process. The person was selected because of her training and experience of group facilitation and ability accurately to represent graphically the data generated. Examples are portrayed on the following pages (ref. Figures 3, 4, 5 & 6). The rationale for group graphics (Sibbet, 1983) was discussed during the second focus group session. The outcome of this technique was a creative outpouring: group members participating enthusiastically, both individually and collaboratively, in what was a new experience for them. Opportunity was then given to discuss graphics and explore themes which emerged as a result of this process. The focus groups, in addition to their inherent worth as a technique for information gathering and gaining an understanding of those aspects of the participant's lives which were a focus of the study, proved to be a valuable forerunner to the face-to-face interviews with the families.

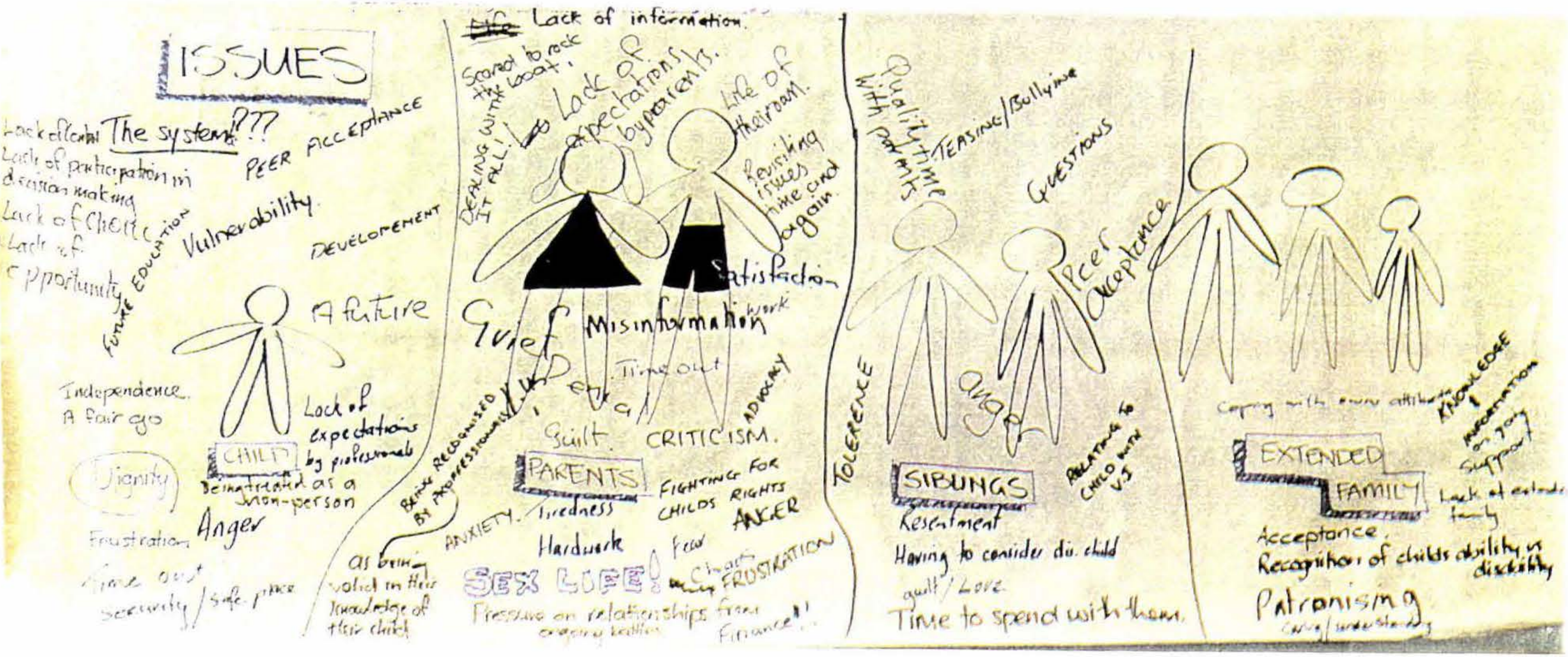


Figure 3 Group Graphics: Issues

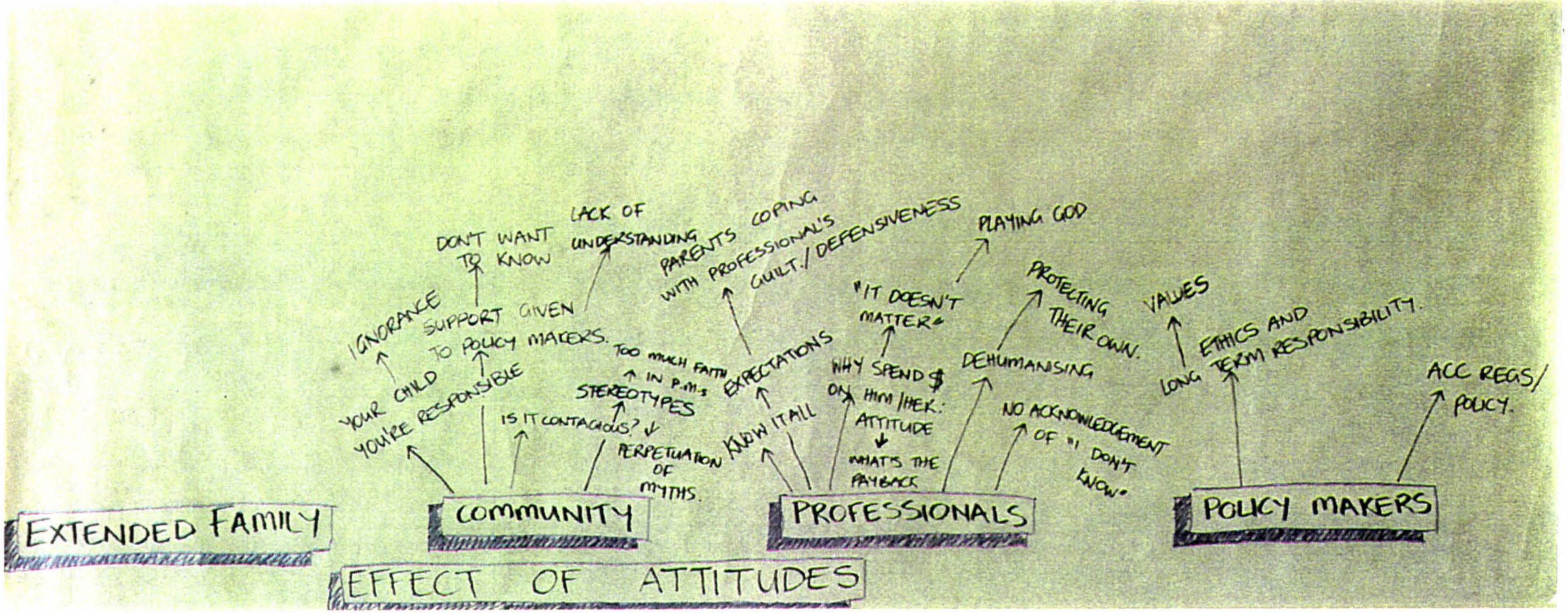


Figure 4 Group Graphics: Effects of attitudes

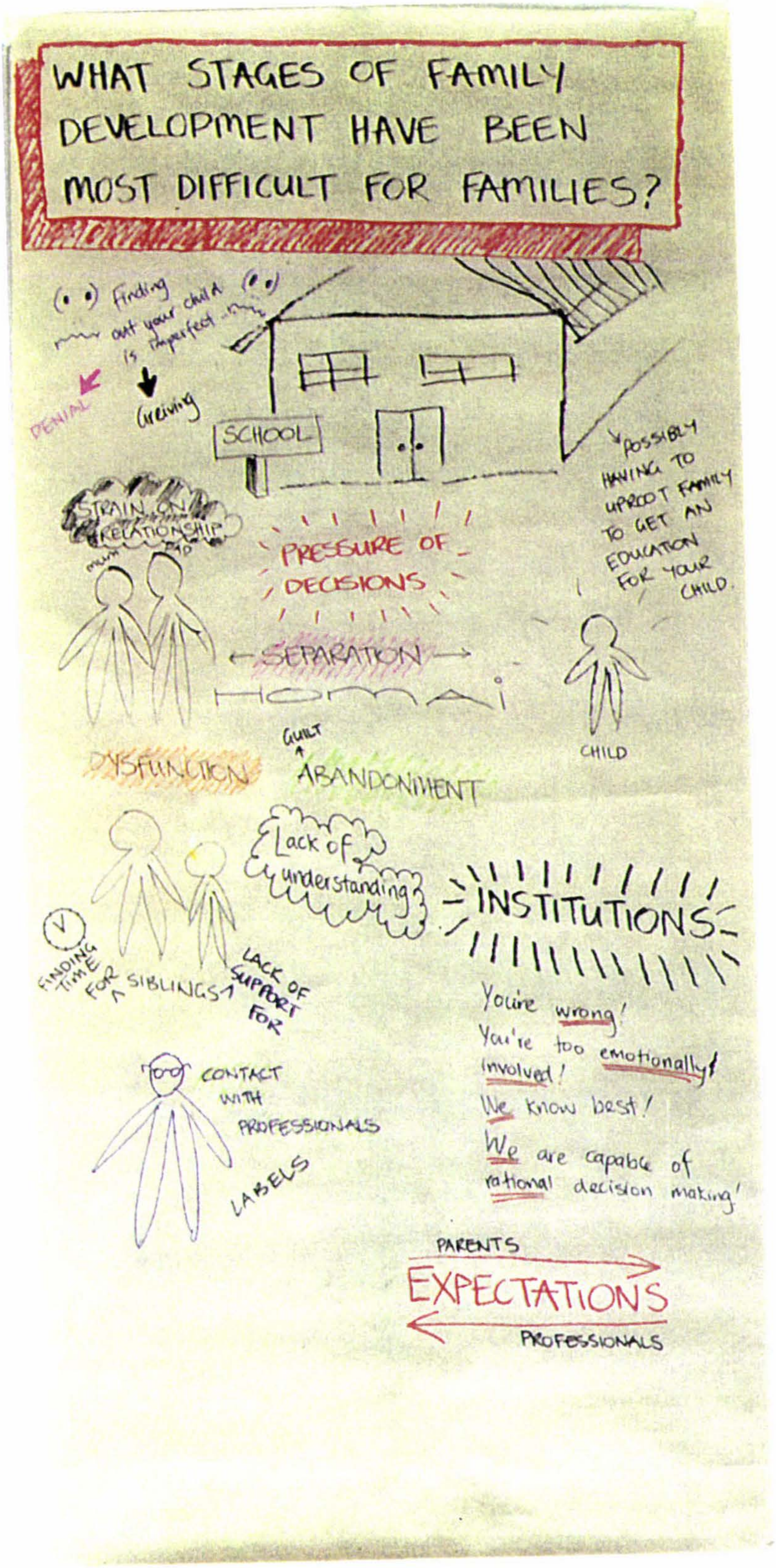


Figure 5 Group Graphics: Stages of family development

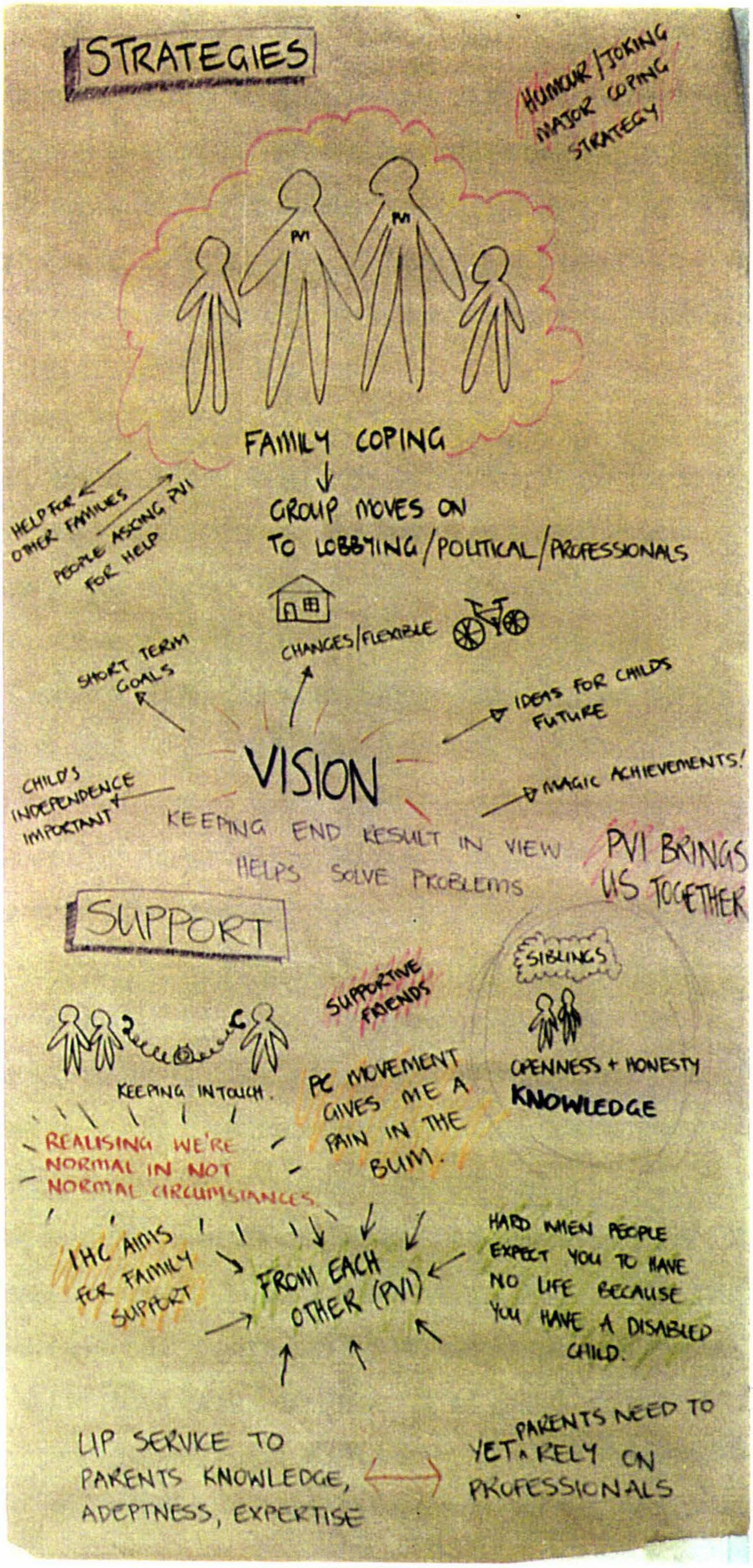


Figure 6 Group Graphics: Strategies

3.5.3 'Mining' the stories

The families of the ten participants of the focus groups were invited to participate in face-to-face interviews. A letter of invitation was sent in which the purpose of the interviews was outlined, and a date and time previously negotiated with families, confirmed. A data sheet questionnaire (ref. Appendix 2) was enclosed with the letter to families. This was designed to elicit personal and demographic details and to facilitate attention to the areas which would likely be a focus in the face-to-face interviews, since these had arisen in the previous focus group discussions.

Because of time, locational, and financial restrictions, one interview only was undertaken with each family. To give all those who wished to participate the opportunity to do so, and to set participants at ease, it was agreed that the interviews take place, where convenient, in the families' homes. At least one member from each family indicated that they wished to take part and so ten interviews took place over a period of four weeks, two at Homai Vision Education Centre at the time of the PVI Annual Conference, and eight in the homes of participants. The number of participants at each interview varied, with two of the focus group participants being interviewed individually. Four interviews consisted of parents only and four interviews included children. The duration of the interviews ranged from one and three quarter hours to five hours, with most interviews lasting approximately three hours.

A semi-structured interview approach was used for the family interviews. To aid the interviewer in maintaining the focus and to ensure that certain issues, topics, problems or ideas were covered by each participant, an interview schedule was developed around a list of open questions (ref. Appendix 3). Its content was drawn from three sources: those issues and questions which arose as a result of the preliminary discussion and first two focus groups; questions arising out of the literature; and the previous experiences of the researcher. The interview schedule was arranged in five sections which were: family background; the special needs of the child with the disability; issues; family self-support, the negotiation of issues and self advocacy; and meeting family needs. The sequence of the schedule moved matters from the family itself to the outside world. It was explained that the schedule was a guide only which could be worked through in sequence, one section or question only could be focused on, or, if questions did not reflect the family's experiences and issues they could be set aside in favour of what the family preferred to share. For the first two interviews families received the schedules immediately prior to the interview, however the first participant indicated it would have been helpful to have seen the schedule earlier, so it was sent to all other families in advance of the interview date.

The researcher was warmly welcomed into the homes of participating families. Often interviews were preceded by an informal chat with family members and a cup of tea or a meal. Links with the families both outside the study and through the focus groups contributed to the level of rapport and trust.

While the topic area guided the types of question asked, the recursive model of questioning used during the interviews enabled the researcher to follow a more conversational model and by doing so, to treat people and situations as unique. As Minichiello et al (1990) pointed out, the role of the interviewer was not simply to record and process responses but to participate in a conversation. This meant responding, commenting and attending sensitively, as well as thinking about each verbal interaction and its theoretical direction. Listening was the means of engaging in the conversation while at the same time being able to sustain that critical inner dialogue which monitored the progress of the interview. There were times for commenting, reflecting back, encouraging, and of just being present as words, silences, laughter and tears were shared.

Story telling was encouraged in the interview process by asking questions in such a way that the participants would respond with a story. Stories were edited in relation to the presentation and arrangement of the material. To elicit responses open-ended questions were used. These allowed respondents to use their own words, and to clarify meanings. A range of question types were used, both in the original interview schedule and as part of the recursive process. Examples of ypes were background/demographic, descriptive, knowledge, values, opinions, feeling and probing questions.

Tape recording was used to obtain a full and accurate record of the interview. Participants did not appear to be inhibited by this process, for which they had given their permission. It enabled rapport to be enhanced by allowing a more natural conversational style and freed the interviewer o be an attentive and thoughtful listener. All taped interviews, along with the focus group tapes, were fully transcribed, engaging the researcher in early analysis. As the credibility of a qualitative research study relies on accurate evidence being presented for data analysis, the transcripts were given back to participants to confirm the accuracy of the record with the opportunity to delete, amend, or make further comment at that time.

The tapes were supplemented with a researcher's field log. This was an annotated chronological record of the researcher's reflections of the circumstance in which the data was collected giving descriptions of settings, detail of actions and impressions of situations and issues. Methodological notes contained a first hand account of the processes involved in doing the research and the log was also an instrument for recording and organising ideas relating to the methodology. The log also included analytical notes on the course of the research, ideas emerging from the data and how they related to larger, theoretical issues.

3.6 Results and analysis

The stories were written based upon the transcriptions of focus group and interview tapes as they related to each family. They were then sent to families for editing and confirmation. Amendments were made where indicated by families and approval for inclusion of each family's story given by means of a consent form.

The stories are used as the main results in this study and form the central focus of the work. Presented in Chapter Four, they are arranged according to the chronological age of the child with vision impairment, commencing with the youngest. A profile of each family is placed with its story. The stories represent the lived experiences and truth of each family as they perceived them to be at the point in time of this study. While others may identify with various aspects of the stories, the accounts in no way claim to be representative of any other families of children with disabilities.

Analysis was based primarily on the content of the stories, with some additional material from the transcripts of the focus groups and family interviews, and observations from the researcher's log, also being drawn upon. Where data analysis has included material outside the stories it source is acknowledged (e.g. Tr.10; Focus Group 2).

Bronfenbrenner's (1979) ecological model which has been adapted by Hornby (1994) for use with families of children with disabilities (ref. Appendix 4) was used as the framework for th discussion. Analysis was made of the transcripts and issues discussed in relation to their location within the four systems of this model: microsystem, mesosystem, exosystem, and macrosystem. Coping strategies were also identified and applied across all bands of the model.

This chapter has provided a rational for the methodology employed in this study and described the process used in its implementation. The stories, generated from families' contributions through the focus groups, in-depth interviews, data sheets and other provided information, and amended and approved by families, form the core of the study and follow next. The final part, Chapter Five, might perhaps be viewed as an eleventh story, the interpretative perspective of the researcher. Some analysis was carried out somewhat hesitantly as the stories presented a viewpoint in their own right. However, it provides a means by which common strands from the web of experiences might be drawn together and located within the wider sphere of encounter and knowledge.

CHAPTER FOUR

THE STORIES

DYLAN'S FAMILY

Narrated by Cushla and Kevin

Dylan will be treated differently because of his blindness. People tend to see the blindness first, rather than 'Dylan' as a whole person. We try to turn it around. When I rang Playcentre to see if Dylan could start I said, "I've got a two and a half year old. Can I start him at Playcentre?" And then, "Oh, he's blind", way down at the end. It is just one of those things, like he's got brown hair. It's Dylan first.

In our family there are ourselves, Cushla and Kevin, Dylan who is now three and Jocasta who is eleven months. Dylan was born at twenty five weeks gestation weighing just seven hundred and eighty grams. Jarrod, who was our first child, died at birth.

(Kevin) Our backgrounds are very different. Cushla has got a big extended family in Nelson with grandparents, great grandparents and cousins. They are closeknit and very supportive. For me, it is different. I've had an insecure upbringing with broken families, no family at all really. But at the moment I'm searching back my family - not my immediate family because my father's dead, and I don't get on with my mother who I didn't meet until I was twenty one - but further generations back. My mother's side of the family is Maori and that's the side I'm interested in. When I was younger I actually got kicked out of a home because they found I had Maori blood in me. I've been brought up in an era when Maori language wasn't spoken and if you knew a Maori boy at school you didn't play with him. I was surprised when I found out I had Maori blood in me because it was so repressed. But I've spoken to some of the older members of the family and they are all really keen to see me and find out what's happening. I think it's good for the children to have two sides of the family because it's part of their heritage as well, they've got a right to know.

(Cushla) Dylan was born at twenty five weeks (gestation). He was in the neonatal care unit for four months and only had a twenty percent chance of life. We knew about the medical risks because I was working in a Day Care Centre with a woman who is now a very close friend, and her daughter was born at twenty seven weeks, six years ago. She has the same problem as Dylan, retinopathy of prematurity, but isn't blind. So we were aware that the eyes were vulnerable to the oxygen but we always thought, well, maybe glasses. When Dylan's eyes were first checked he had grade one retinopathy. The doctors wanted us to do follow up things. At first things got worse but then started to get better. Then Dylan had a bad bout of bronchiolitis at five months of age and nearly died again. Because of this illness he missed an eye appointment and while he was in hospital he had to go back on oxygen.

It happened like this. Dylan had been sick but our own paediatrician was away and the local hospital would not admit us straight away. The doctor didn't know me and wouldn't accept my judgement. We finally got in to the hospital at four o'clock in the afternoon and things were still uncertain. Then his hernias blew up. I had seen this during the day and by the time the doctors got there they were down again and they didn't believe me. Then a nurse saw and he was sent to another hospital - that was eight hours later. He died so many times going to the hospital, it was the worst ambulance trip. Kevin, at the time, was in a plaster cast and was taken to the hospital by a friend. When we arrived, the doctor, who was expecting to deal with hernias, all of a sudden had to put a drip into the poor baby's head because he was going to die. He said, "I never want to see another baby like that again." I hate it when they don't believe you. I always say that we are the child's professional. We know when there is something wrong. Our GP (General Practitioner) and other doctors that we know are just brilliant. But when you have a premature baby that's been sick anyway you'd think that they'd do a bit more than what they did. Dylan finally came home from hospital on June 23rd.

We don't know when the blindness happened but he was given 100% oxygen, it wasn't regulated oxygen like in the neonatal unit. Dylan was in the children's ward and they weren't used to dealing with 4lb babies. It's hard to identify what happened - whether it was medical misadventure or whether he may have had a predisposition to having eye problems *anyway. And medical opinion changes. Now they're even saying that maybe it is better to give babies more oxygen to get them off it quicker, and that in Dylan's case, maybe cryotherapy should have been given as soon as the grade one retinopathy was diagnosed.*

(Cushla) The first Wednesday after Dylan was discharged from hospital we had an appointment at the hospital. I went with a friend, a nurse I had got to know in hospital when Dylan was admitted, because Kevin was still in the plaster cast. The stress was just unbelievable. We were told that Dylan needed to go straight back to hospital the following week for emergency cryotherapy. There was only residual vision in his left eye and half the sight in his right. When I got home I left him in the car because he was asleep and came inside. I was bawling my eyes out and Kevin thought he had died, because I couldn't talk. My friend hadn't been able to drive me home because she was on duty.

We went and had the operation and it wasn't as bad as they thought. He had half vision in his left eye and a quarter in the right. But then on December 9th, 1992, Kevin was working away from here and we went to the doctor. My friend Christine and I had been at a party the day before and she had wanted to come with me because for some reason we were both worried. But she couldn't come and it was like we must have known really. I went to the appointment and was told he was blind - that he had lost everything. So I walked. I don't know how far. One day I'll have to go and find out. I didn't have the car so I walked to a friend's place and she wasn't home. Then I walked all the way back to my Day Care Centre. It was the only place because I had nobody, no one to go to. It was the longest walk. Later Christine came round. We couldn't get hold of Kevin till about midnight. Christine and I were reminiscing on it just last week. It was hard hearing it like that and you could tell the doctor didn't want to say. You could just tell, you knew without him saying. The nurse doesn't usually stay in but I'm sure she did on that occasion. The doctor was helpful. He put us in touch with the RNZFB (Royal New Zealand Foundation for the Blind) Child and Family Social Worker. He'd previously done that, but he sent another note off, I remember that. I'd been crying and then I stopped, and you could tell that he was upset because he'd seen Dylan for quite a while as well, and his eyes were getting better. And I remember the next thing I saw when I was out making another appointment was a guy with a white cane, a blind guy, and then I walked past the railway station and there was another blind guy, and it just seemed like, my God, everywhere there are these blind people now. It was good in the fact that I saw people out being blind, but it was in the fact that, oh my God, that's what he's going to be like.

(Kevin) When I found out I wanted to take legal action. I wanted to get stuck in because I thought that would help me to come to terms with it. But Cushla didn't want to do it so I backed off and left it and then when Cushla wanted to do it, it was too late. I really wanted to find out why it had happened and I had to repress that. We handled it differently. For Cushla, there was no way she could have dealt with that because she had a baby, she was the prime caregiver. Cushla feels that it's happened and now we have to get on with tomorrow. There's nothing that can be done about it. She can't put herself through all that stress of trying to find out what went wrong when we've got this kid that needs us now. The repression for me was difficult to handle. If I can't release something straight away I bottle it up, and bottle it up, until something will set me off and it will all come out in one massive lot. And it's not nice when it comes out. I'm finding better ways to deal with it now. It was just so much of a shock. It was like just turning around and saying he's completely blind,

and then he can see. And you build your hopes up on it and then all of a sudden it's gone. Like pulling the rug out from under your feet.

(Cushla) For both our children we would like them to be independent, respectful and to reach their full potential. And to be who they want to be, not what people might perceive them to be, especially in the case of Dylan. We want to teach them to be assertive because Dylan will be treated differently because of his blindness. People tend to see the blindness first, rather than 'Dylan' as a whole person. We try to turn it around. For example when I rang Play Centre to see if Dylan could start I said, "I've got a two and a half year old. Can I start him at Playcentre?" And then, "Oh, he's blind", way down at the end. It is just one of those things, like he's got brown hair. It's Dylan first.

For Jocasta it's going to be more of a struggle too. It's like there's a sort of a gap between them and she's going to have to bridge that gap because of Dylan's disability. She'll need to develop some extra skills, especially to do with communication. But at the same time she doesn't have to be forced. Like all children there will be stages when they are not going to want to know each other. They need to both meet in the middle and that will happen when they want it. Jocasta was only six months old when she first realised that Dylan was different. I'll never forget the look on her face. She had smiled at Dylan and got no response, and her face just crumpled. It was simply amazing that a six month old knew that.

I think there are advantages in Dylan being older than Jocasta. If she'd been born first with no problems then having Dylan would have been harder for her because he would have had all these specialists and she wouldn't have had them. But this way, that's Dylan. So she's probably quite lucky she's second. The situation's just normal for her. We wonder what will happen at school. We are looking at the children going to a small school where there's only one classroom and that goes right up to Form 2. If Dylan gets all the attention then I wonder how the sibling will feel. That's just looking at the future - you don't really know. What is of most importance for our family are the people in it, and that feeling of being wanted and belonging.

(Cushla) Friends are important to us. For me, I've got a few very close friends, and that's what I've always been like, having really close relationships. Sometimes I find it a bit hard with more casual acquaintances, like the other mothers at the early childhood centre that Dylan goes to, because of my problems with pregnancies. You are with all these women and they talk about popping babies out left, right and centre. Things like that make it hard. When I was pregnant last year and it happened to be right on the time I had Dylan (twenty five weeks gestation), I turned round and snapped at somebody because they said, "Oh, you know, you'll be all right this time." But I knew damned well it wasn't. They didn't know that I'd been in and out of hospital and had lots of medical intervention to keep this baby. And you can't just go and join in the talk at a mother's support group because it's like, "My baby does this and my baby does that, and my pregnancy was this," and it's all peaches and cream. Some might have had a baby a week or two early, but that's nothing. Women use the topic of their children when they are at a function to get in to talk to people. And sometimes you can just see them. If I say, "Oh, well, I lost one at seventeen weeks", you can just see them shut off. They don't know how to respond. They don't think until they go away and they might come back later and they've changed, because they have thought about how lucky they are. But it's getting better. There's one woman at Playcentre that I couldn't stand when I first met her. I hated it when she would be there. But now three years down the

track it's not so bad. Times change and I'm taking different challenges. I'm learning to not let people put me down.

(Kevin) My friendships are different. I like to go out socialising and I have a lot more friends. Often the friendships last for just a short period, but I do have a special friend. That is an important friendship for me. I don't want to blame my past for it but when you sort of get passed from family to family you get to put up walls. It takes a lot to knock those walls down. But I do like meeting people.

(Cushla) Our children's education is important to us. I am early childhood trained. Dylan first attended the local CCS (previously Crippled Children's Society) Family Centre. It is an early intervention centre and it's got an occupational therapist, speech therapist, early childhood teachers and there used to be a psychologist. It's a good support for parents and children. There are children with a wide range of disabilities and quite a number of children with Downs Syndrome. I really liked the Centre because it had many things that are good for Dylan. It had routine which I thought would be important, music, free time with the kids, and computers, which were good for his light perception. The RNZFB social worker had taken us there to see it. We were disappointed because we did not feel that the specialist educational support service supported us in the choice of this centre. They would have preferred monthly input from themselves along with input from the neurodevelopmental therapist. There seemed, to us, to be an element of ownership somehow. I felt that with early intervention much more frequent input was needed than that. It is hard to stand up for what you think your child needs because professionals have the professional edge. I could see that if I hadn't been strong I could have easily been swayed. We found the Centre great. They hadn't dealt with a blind child so young before and they didn't really know what to do initially. But they've read books and they were willing to find out.

From the CCS Centre Dylan went to Playcentre. That's been good too. He is used to other kids now and will be well prepared for going to school at five. And we've done things at home. We've got braille on the doors, cabinets, on the fireguard and on the coffee table. When Jocasta walks around she sees books, she sees words, so what's wrong with Dylan going around and feeling braille? My mum makes Dylan tactile books. We can get some from the Homai library but the problem is he gets a favourite and you have to send them back. Mum's made 'Hairy Maclary' and another one called 'It's Mine'. He loves that book. He plays with the grass that's in it and he says it's the grass and feels. The other book he looks at and reads in the mornings. I've also got this book called 'Pre-Braille Skills' from America. Mum's going to make him the tactile books for that and I'm starting to go through the programme, but it's hard to make the time. It will be easier when Jocasta's a bit older.

I have learnt braille and just passed the Braille Proficiency Course. I've let Dylan play with the brailler ever since I started learning. I just teach him - things like counting, teaching the keys, and feeling up over the brailler to what he has made. It's just like Jocasta who's eleven months. If she sees a pencil she picks it up and draws and now Dylan's drawing as well. These approaches have not always been approved of by our local support service who think he is too young. It would be nice to feel more supported in our efforts.

When Dylan turns four I'll be teaching him the alphabet and his name. He's so bright, he's going to need it. He drives me nuts now. He has O&M (Orientation and Mobility) and TDL (Techniques of Daily Living) from Sandra and Debbie from the Foundation for the Blind.

Debbie usually comes once a week and takes him one on one, or takes him out. We are making the decisions and choices to ensure that Dylan gets what he needs in education. We're taking over the role as professionals. It has been suggested that Dylan start Kindergarten. I'm not anxious for him to be going yet. Perhaps in about six months time, but we'll see how he is. Once he hits five he's going to have a teacher aide with him the whole time - why can't he have a childhood without it? The Playcentre's happy with him. He's going to develop in his own time.

Dylan has lots of friends. He doesn't have many kids come here because we're always busy but I find that when they do come the kids will play with his toys more than they will with Dylan because his toys are all noisy. But also it's probably that Dylan's used to playing with things differently. Not all kids go and bang two cups together to music. At Playcentre he tends to ride bikes and play with the musical instruments. Kevin thinks that he's got too much wind in his sails and he needs someone to 'beat him up' occasionally. It's because he'll push around the older kids that he plays with and they don't want to push him back because they know. And we say that some of the time they'd better just push him back - or because he can't see, sometimes we'll push on their behalf.

The local church made Dylan a tactile book too. Even total strangers from down there ask how he's going. We're not actually religious although we did get married in a church and have had the children blessed. My Nana goes to church and so they have lots of prayer for him. When we bought this house here the land agent said that he'd take a bit of material - one of Dylan's shirts or something - and pray for him. He was telling us how he'd seen people being healed and he'd do it for Dylan. And we just said, no. We know that it can't happen. It just can't. For some people it might. Like the land agent had someone that was deaf and then he got his hearing back. But it was one of those things that you get that are temporary and it is just totally different. We ignore it now. We just let people do what they think. My Nana had a nervous breakdown over it really because she believed that God would bring back his sight. Then when that didn't happen it sort of took away part of her feeling for God. Then she said about prayer and we said, "Look Nana, that's fine. You do what you want to do." Everyone's got their own beliefs. I mean, there's something there, but you know.

(Kevin) I'll always remember one thing Cushla said was that she doesn't smoke, she doesn't drink, she doesn't do drugs and she got a blind child, and you see these people that do all these things and they have healthy, normal kids. And losing the first one. She was the right age, perfect timing for pregnancy and there was nothing wrong with her. Perfect, you know. So you think, what have we done? We haven't done anything. You know, it's just one of those things. We're just lucky we've got him.

(Cushla) Sometimes we need to joke as a way of handling things. Another friend had a premature baby who is deaf and has cerebral palsy. We went to the 111 Day they had here in town and they had hearing and eye testing. And we thought, we'll take Sarah's hearing aids out and we'll go in with Dylan and not say we know they are deaf and blind and just see what they come up with. And we told people this and they were mortified. We didn't do it but we just thought it would be funny. What do you think they'd do? What do you think the look on their faces would be? We just thought it would be a hell of a joke.

The family and the community are both really supportive of Dylan. We don't make an issue, we just walk him down the street. Our friends with children take him out in public, to concerts and things like that. They ignore people's comments about him. It shows us that they've accepted his blindness as well.

We just treat him like a normal kid. You get people look at you. I got it yesterday and thought, oh tough. It's like we are hard on him. You know, if he's going to walk screaming, he's going to walk screaming. Just like we would with Jocasta. We're doing this, whether you like it or not, we're doing it. And you always get people that think you're such a cruel mother and a couple of times I've said, "Well you take him for 24 hours and see how you like it." They don't know the implications of that.

We don't care what people think. We used to get really narky with people because we'd go round visiting them and as soon as Dylan started walking towards something they'd put their hands out on the corner. We had to tell a couple of them to just leave it. They were worrying about him, not their furniture. Being over-protective. You just have to look at our house and there's no way it's child proof. But they learn pretty quickly. Dylan sometimes bashes into the door and it's wide open and we'll say, well you knew it was there. We tell him he should have his hands out, not in his eyes. And if he crashes now, he'll say, "I should have had my hands out, eh, Mum." But you know, we've got thick skinned. When you have to go through the sorts of systems we did and have to put up with lots you get thick skinned. Some things were hard to deal with. People shut us off. Kevin got called a difficult father in the hospital because he wanted to know what was happening to his son. And things like not having access to read the hospital notes and asking questions like "What does this word mean?" Why shouldn't we know? It's our kid. Some of the nurses were really good and others were really short on occasions. But they have a hard job and they remember the children when we go back on Dylan's birthday. It's just that some think that you shouldn't let parents know too much.

We have some problems with Nana sometimes. She comes from that generation when disabled people were put away into institutes. I'll never forget the time when she turned around and said, "What would happen if you died? Would he go to the Blind Foundation?" And I said, "No Nana." But she's a good advocate for him too. One day she took Dylan to the park and he had difficulty with the steps. And when she got back home she was going to write letters to the council complaining that the steps were too wide apart for her great grandchild. She was most upset about the park not facilitating a blind child.

The other problem, I suppose, was with Dad in the way he wanted to make exceptions for Dylan. Dad's really proud of Dylan and doesn't mind saying, "My grandson Dylan, he's blind and he does this, this, and this." But we don't make an issue out of that and I remember an occasion when I went down for a school reunion and there were hundreds and hundreds of people. At the church service Dylan was playing with a six month old and he started to get rough. So I just picked him up like I would any child and said, "Come on Dylan, let's go now." And Dad turned round and said to me, "Why didn't you tell her (the mother) that he's blind?" And I said, "Look Dad you don't have to live with it twenty four hours a day." You get over that. But Dad was meaning that he was proud of him. Then later I found out that the woman of the baby thought I had taken Dylan away because the little girl had leprosy. I just took him away like I would have any child. The mother was the *one that felt that way. Dad sees Dylan more often now and is more able to see that he's just like a normal kid.*

It's the same with discipline. We set boundaries that he knows. We want the best for him but we also don't want him to be mollycoddled. I cannot stand spoilt kids as it is. I could not stand having a spoilt special needs kid.

(Kevin) We both share the decision-making about Dylan. Sometimes Cushla has suggested things like Playcentre but I've always backed her up. If there's been anything major we always talk about it. I've got a lot of faith in Cushla with Dylan's upbringing. It's got nothing to do with her qualifications or anything. It's that Cushla won't put up with any shit, she won't see Dylan go through any shit. I respect her judgement.

I'd have to say that Cushla is the one who's most concerned with people's feelings in the family because she's got more contact with the family. But there's not any real decision made if it's not made by the two of us. There's got to be an agreement otherwise it's not really a decision. We are both involved in problem solving. We do it in our own different ways. We go down different avenues. I go to PVI (Parents of the Vision Impaired organisation) and Cushla does it through committee members with the Visual Resource Centre. Another way I am doing it is through CAD which is Coaching Athletes with Disabilities. I think we've got the same goals and just taking different paths to get there. We feed off each other's strengths to achieve it.

(Cushla) There are the major decisions, but you still have things like, what is the most important thing? Even tonight, for example. Is it more important that Dylan learns to eat by himself or is it more important that we make him sleep longer in the morning? Because he's waking up really early and by six in the evening he's absolutely exhausted. So it's things like that, that sometimes there might be more discussion, more back to basics to prioritise what's important. I think it would be great to have teacher aides that come into your home when you've got a pre-schooler with special needs. A couple of hours a day would be wonderful. It's really just small things. Like with Dylan's eating - how do you get him to chew with his mouth closed? I didn't find out until last weekend how to get him to stand up to go to the toilet. To people who have been through it, it's basic, but for parents coming up to these stages it's pretty hard. How do you go up to someone and say, "How did you teach your son to pee?" Or phone, like I did, and talk to a blind adult. How embarrassing. And he couldn't remember. It's the little things. With Jocasta, she is watching us all the time. If I say to Dylan, "I am hanging the washing out", he has no idea what I am doing. He might feel it sometimes, but she can see it.

I always thought it would be nice to have someone to come in and either help feed Dylan, or because that takes so much time, do something with Jocasta so I can feed him. Meal times have been a problem. We were giving Dylan different meals and when you think, Jocasta is already starting to eat what we eat, and he's only just started in the last six to eight months. He would try what we eat and some things he would like. Sitting all together is a lot easier but we would end up having cold meals because otherwise we would have to make Dylan sit there longer for us to finish or he'll get down and then he'd harass us and we will miss out anyway. And now we've got Jocasta as well. It's things like that, that people don't think about. So just to have a teacher aide come into your home for a couple of hours a day with a special needs child so that <u>you</u> can do things with them, instead of thinking, oh God, I've *got to do this, and I've got to do that, and they miss out. Or other things miss out. That would just be so nice. It would be like having a home help. They talk about teacher aides at school but then this is the most important time as well. But imagine the government going for that. I suppose it could happen because they've changed their ideas on early childhood, but it could be a few years down the track.*

It took us ages to find out what assistance we could get from Social Welfare. They were all cagey. We only had it from word of mouth. The government departments desperately need packages for it. Things like transport and Alternative Care. And finding out what things cover. We approached Social Welfare to see if we could purchase braille books with the Disability Allowance. They said, yes, and I ordered them from the American Printing House for the Blind and then they turned around and said no. Although they were special materials for Dylan they would not agree. Even the Blind Foundation don't let you know everything. You find out through word of mouth. The problems are to do with the services really. With the medical services they have to time it because you get the news and the doctors have got to wait until they see your reaction on how you take the news before they can suggest an alternative. But other places, like educational services, once you're on the books they should be in there. They should have all the information that you need for the Social Welfare and all the others. Or perhaps from the Foundation for the Blind. A pamphlet, or a guide of what is available and who you can get it from, is needed.

We've been lucky with the Foundation because they've listened to us. And they've acted on it. The Child and Family Social Worker has been good and O&M and TDL. With doctors and medical professionals we've been really lucky. Our doctor's perfect. She's a brilliant GP. There's been a few nurses we've had run-ins with and that unfortunate time with admittance to the hospital, but otherwise, it's been good.

We find that we are Dylan's advocates. Someone had to do it and do it from the day he was born. I think my early childhood training and Kevin wanting the best for his family has helped. I think we would have done it even if we didn't have a special needs child. Once they got to school, or even pre-school, we would have done the same. It might have taken longer. We've been forced to do it a hell of a lot quicker and I've changed a hell of a lot in the last three years, I reckon. From being meek and mild and going with the flow and being kind, to now being willing to say, "Well, I don't agree with this."

There's going to be hope for us when Dylan turns round and says he can do it for himself. That's when we've got to step back and let him go for it. I think that begins right at an early age. Like I can now go to Playcentre and leave him. You see other parents that can't do that and have a real problem with leaving. I couldn't do it when he was young but now I can quite easily. We will help him and will hopefully be in a relationship where he will come back and we'll be friends. I think that as he grows we'll grow.

(Kevin) The RNZFB Child and Family Social Worker and another parent of a blind child got me involved in PVI. It was the first support group I'd heard about for the vision impaired. I want the best for Dylan and maybe being with PVI is going to help us achieve it. And also to learn more - to learn from other people and see what they have gone through. In the beginning I could have just turned round and said I don't need this. Because the first time I was there everything was talked about in abbreviations and here were these people going on about people in high places and politics. Everything just went right over the top of my

head. I think the second time I went back was just to get a level on it and find out what was actually going on. I think the main focus of PVI should be the children and their reaching their full potential. It has to be. It's about being strong advocates on behalf of children. If our children go with what the government gives them now, they are just going to be forgotten about. There's got to be an improvement. There needs to be action as well as talk. In fifteen years time I don't want to be doing the same thing. So, the main reason I am involved is for Dylan, but also for the other children that they might benefit. And I would like to be able to encourage other parents, invite them to the meetings and ask if they know about this and that and let them know the options.

(Kevin) How have we coped? Stubbornness on both parts. We're not going to throw a marriage away, we're used to sticking together, used to working things out. Everything's not perfect and you work through what comes up. We have learnt assertion skills. I went to a course to learn assertion skills and now I'm more able to listen and work things through without becoming aggressive, it's taken me seven years to do that.

(Cushla) We have drawn on our inner strengths. I think our inner strengths complement each other. And that's been quite a stronghold on our relationship. I use coping strategies by talking to people and finding out more. I sometimes give Kevin a list of queries to ask people about when he goes up to a PVI meeting. So I find out things instead of just sitting there - like sending away to the Hadley School for the Blind in the US for information. It might turn back nothing but you don't gain anything if you don't do it. Cigarettes are Kevin's way of managing. The odd tears are mine, but not for a long time. The tears can be things like dates that come up. I don't believe that time heals. I believe that the pain is lighter but I don't think that it ever goes away. And you know, people have said, referring to the loss of Jarrod at 17 weeks, "You'll have another one." We're always told that, but it doesn't go away. The 22nd of April's still an important date to me. As far as we're concerned the kids have had a brother. And someone else said to me, "If Jocasta had a child in neonates you would have forgotten what it was like." No. I will never, never, forget. And that's me. Kevin reckons he could walk in there tomorrow and if the alarm was going he'd know which button to push. But we're coping with things like that and not hiding it. We talk about it and remember. Some days some people will say something and it just all comes out. And other days you won't feel like saying anything. It just depends on things. Dealing with the emotions - you just do it.

Our communication skills have all improved. Overall, our main way of coping is that we just jump in and do it. We have drawn on each other, along with the knowledge of support available, if we want it, from PVI and the Foundation. Most of all our support has been through friends and family.

(Kevin) For the future I need the Williams Family. We need equal opportunity and for Dylan's education, it will be having people you feel you can trust. I think we will get adequate support from the Foundation no matter where we are. Ongoing professional development and training is important as are teacher trained O&M's (Orientation and Mobility Instructors) with child development knowledge. Listen to the parent. Professionals that work together with parents, with some of the professionals coming and seeing Dylan at home, is our vision. Professionals not thinking that they own the child, but rather having empathy and working together as a team is important to us. Also a National Body needs to be set up for vision education.

You usually find that no matter where you are, you are always going to get the same parent turn up and they're the ones that really care. Not just for their kid, but for the others. Sure, you will occasionally get the ones that are just there for themselves but they are far and few between. We're not just there for our own kids. It has been difficult, but it's made us stronger, has helped us grow. It's been a full-time learning experience really. And the way we've learnt is by just doing it.

FAMILY PROFILE

Child:	**Dylan**
Age:	3 years 2 months
Sex:	Male
Visual condition:	Retinopathy of prematurity, light perception, Onset at 6 weeks old Condition diagnosed by doctor at this age Level of vision is stable Braille/tactual mode of communication
Educational placement:	Dual placement - Early Childhood Family Centre (1 day per week), Playcentre (3 days per week)

Parents:	**Cushla & Kevin**
Ages:	25 & 33
Marital/Parental situation:	Married
Vocation:	Mother; Student in Community Recreation Course

Sibling:	**Jocasta**
Age:	11 months
Sex:	Female

Family:

Time in present community:	3 years
Most important to family:	Family itself, secure future for children
Effective support systems:	Family, friends, RNZFB
'Gift' to other families:	"Follow your own instinct. You are your own child's professional. Don't be swayed (all the time) by the professionals."

ANNIE'S FAMILY

Narrated by Sue & Richard

Education is probably our biggest issue. Ever since she was little, activities to do with Annie to enhance her progress, like eating and probably even playing skills and walking, we didn't really know about. I think we assumed that people have been blind forever, it's not a big deal and they cope. ... I think we just assumed that she would catch up. We didn't realise that we had to put so much effort into her achieving the normal milestones.

There are five of us in our family. Richard and myself, Sue, and our children Annie, 6, Michael, 5 and Josh, 2. Annie is totally blind, she's got no light perception. She is a very happy and contented little girl, always laughing and smiling, and has the ability to make other people around her happy. Annie loves music. She sings, likes playing musical instruments and seems to have an amazing sense of beat. Annie has a great sense of humour and loves her own jokes.

I guessed when Annie was about two weeks old that she was blind. At first we had trouble trying to convince the specialist. Part of the reason that we didn't go through that grieving process initially was because we were busy trying to convince other people that she was blind. We were told it was lazy eye muscles, and all sorts of different things. Richard's mum actually rang the RNZFB social worker up and he came out and visited us.

We've never had a problem with Annie's blindness. Annie was Annie, we loved her just as much and she was such a cute little baby. She was a little bundle of joy and very placid. One thing that always sticks in my mind was the first thing the social worker said about never having seen a blind kid smile so much. Usually because blind babies don't see you smile they don't have any incentive to smile themselves. But we've always got so excited about Annie smiling that she knows that we're happy and she keeps doing it.

(Richard) I can remember when Annie was born, I noticed her sunken eyes. I asked the doctor why her eyes were so red. I reckon she must have been poking her eyes even in the womb. You could see the eyelids had a darkish tinge, even when she came out. In all her early photos she had red eyes. I think that it would be helpful if parents could be told about the mannerisms of blindness and how to try to eliminate them. Our social worker didn't tell us until she was a couple of years old. When we asked why he hadn't said anything he replied that he hadn't wanted to offend us. I can see partly why he didn't because you don't want to become too paranoid about it. I've seen other parents whose kids poke their eyes constantly and they actually get quite aggro with them at times, whereas we just have to say to Annie when she gets tired sometimes, "Fingers", and that is enough to remind her. I think we're all reasonably positive about Annie and it means a lot to me that the boys include her as much as possible.

(Sue) Annie's language is quite good now and it has always been reasonable. She started off saying nursery rhymes and she had perfect pronunciation. People used to say to me, "Oh, she talks so well", but she didn't understand what she was talking about. The first sentence she ever said was when she was sitting on Richard's knee, and she just slipped and Richard said, "Oops, you fell" and she said, "Jack and Jill went up the hill, to fetch a pail of water, Jack fell down... ", and she stopped, and she was relating it to 'Jack fell down'.

Annie's got a very good memory and can repeat stories and songs but if you ask her a question about the meaning of the story it has no significance for her because she has no experience of it. We think about these things a lot being round her all the time. I try to put myself in her position much of the time and actually think what it would be like to never see anything. It takes a while to realise it. For example, it only dawned on me a couple of weeks ago, when I was thinking about her feeding why it was taking so long for her to scoop her food. She's always been really good at getting the fork and putting it into her mouth, but certainly when I thought about it and I saw her sitting at the table, her mouth was about level where the table is, and her arm actually had to reach up above her head for her to be able *to scoop. It's just not efficient, and it probably doesn't feel very good to her either. It had just never occurred to me that that might be a reason for the difficulty and that she was not in a very comfortable position. Hopefully with an appropriate chair she might learn to eat properly.*

What we need in helping Annie is appropriate advice which relates to what's happening now. It's getting that advice to reinforce that what you're doing is right and to get new ideas. A lot of the time it's just talking to people who really know. It's important to explain what the ideas are going to lead to and why they are so important. Otherwise some exercises may seem pointless to us, whereas the professionals know what they're doing. What sometimes seemed stupid to us at the time without adequate explanation, in hindsight was obviously very critical to Annie's development. It also gives an idea of what the next step is so that once she's achieved the step we're teaching, we can move on to the next one. So, there's education needed for the child, and education for the parents as well, especially in the first few years. A lot of the things that need teaching are so crucial, like her walking, for example. She didn't walk until she was four, and I suppose, once again, we just assumed that she'd do it when she was ready. It would have been helpful to know that we had to teach her, and what to do next after she had learnt to stand. I'm not trying to blame the professionals. It's all a learning curve for everybody.

(Richard) For me, I found the most difficult stage of Annie's development was when she went through a phase where she was very clingy to Sue, and if Sue went out, she'd just scream. You couldn't do anything, and in the end you'd have to just walk away from her, or you'd lose your cool. When that sort of thing's happening you think it's never going to end. It does eventually. Once the communication started coming along she was able to start to tell us what she wanted. That made it easier.

(Sue) Annie's beginning to learn now to express her needs. One day recently when we got back from Auckland Annie's crying was really irritating us, and I said, "For God's sakes Annie, what do you want?", and she says, "I want to go to Upper Hutt." "What for?" "Go to the shop", "What for?", "Want some chips." "Oh Annie, hurray." You know, if she had said that in the first place... She had just been in the car for six hours and she was hungry.

Annie's so willing to learn. She's such an appreciative little girl that she's just a delight to look after most of the time. She has her moments as well. She's got all different sorts of emotions and to me that shows a good sign. You know when she's sad, you know when she's happy, you know when she's stroppy. And I think that's good, I think that's healthy. If she was being passive all the time, showing no expressions, I'd be a bit worried.

There have been implications for the boys. For Michael in particular, now that he's starting to do sports and things, we find that we're limited with what we do with him unless we can include Annie. We have started to go up in the bush and things like that now because she enjoys it, but we're very aware of the risk of limiting their experiences. I think that is because we don't like to dump Annie on anyone else. We like to include her in all the activities as a family member. Annie went through a phase where she'd scream her head off if we went anywhere strange. When we were up at the beach, we'd tend to sit round the bach more because if we went down to the beach and we had a bad day with Annie it just wasn't worth the hassle.

We treat Annie as though she's a normal kid. She can't get away with behaviour any different to any of the other kids. I think we were a bit soft on her especially in the early days. She'd cry and we'd think, oh, she doesn't want to do that because she's blind. It doesn't interest her, it doesn't appeal to her, and really she'd just been manipulating us. The more kids you have, you realise. Because she's our first child you don't sort of realise the tricks kids play on you. The boys do exactly the same thing. It's quite interesting looking back now, because Michael's getting to the age where he's doing a lot of those things. You think, oh you little shit you've been having me on this time.

I think, more and more, we're finding the blindness doesn't preclude Annie from a heck of a lot anyway. It's just our perception of how we think she's going to react that dictates what we actually do with her. Going for walks in the bush is an example of that. We thought, there's no way Annie would want to do that, and she enjoyed it more than the boys. She was tripping over twigs and she was listening to the birds and the bees - she just loved it, it was really neat. It's the real natural sort of surroundings and things like that, I think she enjoys. In the early days when she used to cry when she went anywhere, we just didn't go, and now we take her anywhere. She enjoys herself as much as the others, and it's really gratifying. We took her to see the 'Lion King' and she totally enjoyed that. It's so neat to think that she can be a part of those things, whereas before we avoided having her screaming in front of hundreds of people. In the end we just had to be persistent. There have been a couple of times we took her out and she cried blue murder, we just put up with it, and I think she probably started to realise that she's not going to manipulate us too much. And we learnt from others as well as from our own experiences. We saw that she would let staff at the early childhood centre do things with her that she wouldn't let us do and we modelled on the way in which the hostel staff responded when children behaved in that way. Sometimes it's just introducing things to her the right way too. You don't throw her into things. She's got to know that she's secure. She's getting more and more accepting and probably a bit less apprehensive about things now.

Annie and Michael are now in the same class. It's worked really well. He hasn't had much to do with her actually, he's been keeping his distance. He does his own thing. But then again he explains to the other kids. He's been really good in that way. They'll ask him questions about Annie instead of asking the teacher, and he feels quite confident and important. They ask things like how Annie does pictures, where she sleeps, if she rides a bike, or goes shopping. And Michael will turn around and say, "Of course she does, don't be silly, she's only blind", which is really quite good I suppose. But he's helpful, and it's interesting looking at it from his perspective. He's got quite a mature outlook, for a five year old. It's really positive.

Joshie as a two year old is quite amazing. Annie and Joshie have always had a real special relationship, because he's always been her little baby. Even from day one, if she'd hear him crying by the cot she'd go down and be putting her hand through and patting his back to quiet him down. Now if you say to Annie to go to the toilet and she gets a bit lost, it's Josh that will grab her hand and take her. Josh will often come to the rescue. I've never seen a kid like him.

I think the boys were both quite young when they realised that Annie was different. At probably about a year old Michael and Josh became aware that if they wanted to give Annie something they'd have to put it into her hand. Probably that came about through watching *us, but even now, Josh, who is two years and three months, when he takes Annie to the toilet, will sit there and pull her pants down for her, which is good in some ways but not helpful in others. But she's independent in most things anyway. No, they're really good. I think the biggest issues are the limitations we have as a family. I'd really enjoy going up to the mountain or down south skiing, but we can't just do that. We can't leave Annie in the motel, or whatever, and I think she's too little to actually learn to ski - she'd require too much attention. It's things like that, that if Annie was sighted we probably wouldn't think twice about it, we'd just do it. It's a bit of a tricky situation. Annie's part of the family too, and I want her to be as much a part of it as everybody else. We can't do everything. You've just got to learn these things.*

In all, we've got a good relationship. I think, if anything, there's a lot of love in the family. The kids come up and give you cuddles or kisses all the time. A lot of boys probably wouldn't be interested in that, but they're really neat. There's lots of security, and I think that probably helps.

Our extended family have responded in different ways. Some members are apprehensive, while others get a bit overzealous with Annie and really go to town with her. But then if you ask them to babysit her it's "Umm, umm." They're reluctant. I thought at first it was because she used to cry. But one lot of our parents that live further away often have the nieces and nephews at their place for a weekend and they've never invited our kids up there. (Richard) I think part of that is because they're not sure. I noticed with Sue's parents too you sometimes get the feeling that the favourite granddaughter gets invited out. I don't know if it's us just being super sensitive.

(Sue) My mother will ask Mike to go out shopping, but she wouldn't take Annie because it's too much hassle. She used to come down to our house when we would be somewhere else, and she'd be in the kitchen. She'd have a packet of biscuits, and say "Here Mike, do you want a biscuit?" - just whispering to him - and he'd say "Yeah, okay." And he'd grab one. He was only about one at the time and he used to always grab one for Annie. But mum would give him one and then she'd put the packet on the bench, and Annie would be sitting there crying. She'd pick up on all that. Most kids wouldn't have known. They wouldn't have heard the rustle of paper, but she knew what was going on, and mum quite often forgot to include Annie just because she couldn't see. I think she was assuming that Annie didn't know what went on. She also talked in a louder voice to Annie but part of that was trying to make her voice sound as exciting as possible.

Some of our brothers and sisters are really good. We've never forced Annie on anybody, we wouldn't do that. I think they probably perceive her as having an intellectual problem because she's getting older and can't communicate as well as the other kids. I don't think they probably understand.

Our friends' children Annie relates to quite well. Generally though kids are really good with her. Just excellent. Kids just don't have any sort of hangups like adults. They don't push her, and if parents leave them be and don't intervene, things usually work out really well.

The community at large are pretty good and blindness is perceived quite well. Shopkeepers in particular always ask how Annie is doing and people ask if she is going to get a guide dog. They're really interested.

We found it helpful to have contact with a blind adult who could act as a role model. In this respect Vaughan was somebody who was quite useful to us because he was teaching braille to a group of us who were parents of blind kids. People have different experiences, but it was quite handy to know what he thought about different things, especially education.

Education is probably our biggest issue. Ever since she was little, activities to do with Annie to enhance her progress, like eating and probably even playing skills and walking, we didn't really know about. I think we assumed that people have been blind forever, it's not a big deal and they cope. We probably were a bit too laid back and we shouldn't have been, but I think we just assumed that she would catch up. We didn't realise that we had to put so much effort into her achieving the normal milestones. On the other hand we didn't want to be too pushy. I've seen other parents with blind kids who have the attitude that they want their kids to be achievers. I believe that you've got to let your kid find the way too. I've had nephews and nieces who've learned to talk at different rates. We all do things at different rates, so we can't get too hung up because our kid isn't as good as the blind kid down the road.

We're really happy with Annie's development at the moment. She's making big steps now. Communication has been a real issue. It just wasn't there initially. It's really hard as a parent not to be able to communicate with your kids. You don't know where you are and you never knew how much she was understanding. We probably underestimated what Annie understood and I think there's a certain element of anxiety there. You wonder whether she's ever going to communicate, but we've got a lot more confidence in her now. She's certainly got ability to do some things so we can work on that.

The pressures really mounted up when it came time for school. Before school everything's sort of easy. You have this baby and just put them through. But beginning school there's the choice of school to make, there's the prejudices that you face, and the teachers not wanting to teach them. Trying to make the decision on what we thought was best for Annie and not really knowing was hard. There are also pressures to make decisions which don't impact too harshly on the rest of the family and finding the time to spend with the other children to prevent the family from becoming dysfunctional. In that respect we've expected a lot of Michael. We've treated him like a ten year old instead of a five year old and he's responded well to that. We've been lucky but it does have an effect on the other kids.

Annie began at an early childhood centre when she was one. It was run by the IHC (New Zealand Society for the Intellectually Handicapped) and provided good stimulation and early intervention programmes. We used to leave her there and the staff of the centre said that Annie was absolutely perfect and had a great time. We spent a year there and then Annie went to a Family Centre which was operated by CCS. A staff member from the first centre saw me a few months after Annie had left and asked how she was getting on at the new centre. I said that she was doing really well and then the lady said that she was pleased about that because Annie used to cry all the time when she with them. We felt then we had wasted a year of Annie's life with people who had said she was happy just to make me feel happy, which I really resented. She'd have been better off at home with us. I could kill myself for not knowing she was so unhappy. I was angry. It leaves guilt and the feeling that we wasted time for Annie. Nobody wants their kid to be unhappy. I think the centre thought they were giving me a break, but that's dangerous. I realise that some families need those preschools more as a relief for parents but I didn't need to leave her there. I was coping quite *well then. In some ways it was naive of us. We trusted people, and that experience contributed to our not having the same degree of trust.*

At the CCS Centre there was a real family focus. Here Annie had access to a speech therapist, occupational therapist, and psychologist. There were different role models as well in that there were other kids with different disabilities and I think kids do learn from each other to some extent.

I'm a big believer in a range of educational options. In some situations I really don't think the mainstream is appropriate. I think special schools are a definite necessity for some parts of a child's education. Not necessarily all of it. I don't believe you can mainstream a blind kid unless they've got to a certain level and that was reinforced by our own experience.

When Annie was five she started at her local school. Annie's been accepted really well into the school, probably over-accepted. They almost want to do too much for you. The school's fantastic. I think kids can understand blindness. One thing I found amazing is that she's in the new entrant class and every kid, from the new entrants up to standard four, has something to do with Annie. They greet her when she comes in the gate, they haven't lost interest, and the boys in standard four all want to work with her. It's just really amazing. These are predominantly kids from lower socio-economic families too, which is quite surprising. It's been really beneficial for one of the toughest little nuts in the whole school. He's been buddied up with Annie. He's spent a lot of time with her and they're good for each other. He doesn't take any nonsense from Annie, and Annie won't take any from him either.

The school's been great right from the beginning. I think part of the success is they had a really good principal. There are quite a few children with special needs at the school and it has quite a good reputation. I think the school might have done a bit of PR before Annie arrived, saying there's a blind child coming. The kids ask questions. If they don't know they ask, and Annie does the same which is really good. It's a lovely school, and it's a shame to leave it. We don't want the school to think that we're in any way unhappy with what they were doing because I don't think they could have done anything too much different. We always had a good experience with school, there's never, ever been any question about Annie's teacher aide hours or anything like that, she's always had full-time hours.

Although the local school did their best for Annie, the major issues came when she got into the mainstream with insufficient specialist support. We found difficulty in trying to talk people into doing things the right way because there didn't seem to be a lot of knowledge out there. Overall, we've had a lot of support from all sorts of different people and a lot of family support, but in education there does not seem to be the specialist expertise.

One of the biggest problems that we've had in our personal lives is the fact that we had to split the family up to sent Annie to Homai when she went there last year for six months. It was to give her the best that was available. I can't describe how hard that was for us. It's lucky we're still together. The thing I resent most of all is that we had to make that decision at all. It shouldn't be. It was a really tough decision to make.

We knew that Homai was going to be the best option as far as Annie's schooling was concerned but it was coming to terms with her being away from us and somebody else looking after her because she's such an integral part of our family. Being put in a position of having *to make decisions regarding best options for a child was really tough. If it was our boys we wouldn't have had to make that decision. It's a combination of where we live and the system. Then there are other pressures from friends and family, opinions expressed on subsequent pregnancies and value judgements projected. As a result the family became dysfunctional without her. Dysfunctional in that it's been really hard on our relationship. Richard and I were forever wondering how Annie was feeling and we forgot about spending time with ourselves. It was hard not to feel that you had abandoned her and let her down especially when it was someone's birthday and you'd ring her up and visualise her on the end of a phone flapping with excitement ready to take off.*

I think the mainstream initially didn't work for Annie because much of what she did in the class was irrelevant to her. When she went to Homai she progressed really well. After six months when she came back home I was teacher aide for her in her local school on Mondays. So much was totally irrelevant - "Annie apple is 'a'. It goes round, up and down." It doesn't go round, up and down for Annie, it's a dot. I don't want to generalise, but some kids with special needs you can put in a classroom and what 'a' is will eventually be understood. But for certain kids it's not what it is for them. There needs to be mainstreaming but the kids need to be taken out for specialist curriculum teaching. There can be a balance but you can't just expect kids to cope automatically. The other aspect that has been difficult for Annie in a regular classroom is the noise level in the background. There might be one to one teaching for her special needs but the noise level creeps up and suddenly she's lost concentration. There are some elements which are debilitating to teaching a child like Annie in that environment.

At the moment if Annie's to survive in the mainstream she's going to have to be withdrawn for disabilities specific instruction like braille and TDL and O&M. I think that's really important, and I don't think a teacher aide can teach that, unless they've got the necessary skills. In some ways Annie's teacher aide has got a lot of initiative, but in other ways it's just no better than a baby sitting service really. Teacher aides are really a godsend and I don't envy the work that they do, but more is needed.

Auckland just dawned on us very, very slowly. It's funny, we got out of the car and we just said, "It's not working." We both sort of thought exactly the same at the same time. We hadn't actually talked about it at all. About a year ago we decided that we were going to move up there and then people said "No, no, no, you don't change your life and the life of your family for one child", so we changed our minds again. Now we've got back to thinking that way again which is obviously the right decision. It's not that we're changing our life for one child, it's more that, Annie won't fit in everywhere. We will, it's not a big deal for us. So, we'd rather give Annie the chance. We're fortunate that we're in a position where we can do that.

We are now looking at selling up here and moving north to get that education. I don't resent it and I'm quite looking forward to it in a lot of ways but, with Michael, we enrolled him at the school and that was it. Already in a term he's going up a class and there are just no problems, it's just a breeze. Other people just don't realise what you go through. They have no idea.

(Richard) I probably find going up to Auckland harder than Sue. But that's just my nature, I'm sort of set in my ways. Building this place, you put a lot of your heart into it. But it's

not like it's something you can't do again. It must be a bit hard for Mike We've told him he's going to Auckland again, but he doesn't seem to be worrying. You never know if he does though. But I think he's at an age where it doesn't make a big difference, he hasn't formed any really close friendships yet. I think that's another reason why it's important to shift as soon as possible - so it doesn't impact on their lives as much. It will be hard, especially for little Josh who has a pretty close relationship with Granddad next door. I think it may be more difficult for them than for us in some ways. It's not just yourself, it's even the lady next door. She's a spinster of sixty seven and she looks upon these kids as grandkids really. She even wanted to learn braille to teach Annie.

(Sue) Even at this stage it's quite hard for Annie to make friends with other children. It's quite a difficult function. It's communication. I was watching her in the school playground today, and playing with a sighted child is quite hard. She's become aware of what play is but she doesn't quite know how to pull it off. I think she's aware that she wants to play and that's why I think the mainstream's really good, but she needs basic skills before she can survive - before she can participate in the mainstream. It's a real dilemma at the moment. If she does go back into the class at Homai there are some reasonably normal kids, that she can form relationships with. (Richard) It's so easy to look at kids and be superficial. Even as a parent of a handicapped child you do the same thing. But when you actually spend time with the kids you realise they all have something to offer. Like the big girl in the wheelchair, she's a lovely kid. She's giving you big cuddles and kisses, but if you just walked into that class and looked around you'd have thought she was away with the fairies. It's probably stuff we've all been brought up with. This generation that's coming through is better than we were.

Another reason that makes me so adamant that going to Auckland is the right decision is that we need to look ahead. Because if Annie's going to get a good basis anywhere, it's going to be there. At least you know you've done the best of what's available. Then if she grows up to not be quite so independent, then at least you've tried, and you can just take it from there. But you've got to give them a good grounding. You can't just throw them into the mainstream and see if they sink or swim.

(Sue) I think going to Homai is definitely the right choice, but I'm not prepared to put Annie in a hostel. I don't want to take her away from home, I think that's a real emotional thing. We couldn't do it a second time. It was hard enough the first time. When she was there I was visiting regularly and every time I said goodbye it just got harder. She'd be laughing and carrying on, and she'd had a really good weekend and we'd get to the airport and you'd say, "Bye Annie, I'm going now." She'd say, "Bye-bye mummy." And she'd go all quiet and silent, and I'd just be in tears with a lump in my throat getting onto the plane. I hated it, I wouldn't wish it on anyone. I felt really cruel, I really did. I wouldn't do it to my boys. It's too hard. But, by the same token New Zealand obviously can't have Homais everywhere. I'd like to see the kids go in together in clusters in schools and I have suggested that but it didn't find favour. It would have the advantage of concentrating the resources but it was felt that all the kids had their own IEPs and that gave them more identity. I don't want to push the issue, I was just trying to make the situation better, not worse.

It might not be for ever that kids need a special placement, but they need to get established, to learn the skills to access the regular curriculum. I think that we ought to take notice of the literature from America where mainstreaming has been going on for a long time. There *are people there that want total inclusion but educators who are teaching blind persons are saying no, it's not right. There are times when they need time out. Mainstreaming can work but there needs to be flexibility to meet the child's needs.*

Annie's had a lot of people in her life. It's amazing how many people come and go. They seem very important at the time. I think generally people do their best, and they want to help Annie, which is really good, but it just makes it all the harder when you have to move on and say goodbye. You feel guilty. When Annie went up to Homai, I felt so guilty about taking her because I was putting this teacher aide at her local school out of a job, and stopping her from working with Annie. It sounds silly, but it was really awful. The people have been so special, and so supportive of the family. It's different to just a normal teacher-pupil thing. There's a close relationship. Annie's just one of those kids that seems to melt into people's hearts. A lot of people say that they really enjoy working with her, they really love being with her, and looking after her. She's got a very bubbly personality and she seems to have that effect on people that they enjoy working with her.

Concept development has been a real issue for us. There is a lack of understanding about concept development. Linked to this is the fact that people keep labelling Annie intellectually handicapped, whereas we're saying that we don't know if she's intellectually handicapped, to us it doesn't matter. Obviously her blindness is a major handicap and we're tending to say that the problem is concept development because how can she know about something if she's never seen anything? How can she know about something unless she physically experiences it? I don't think there is a good understanding about blindness because few people come in contact with it often enough.

We've had our ups and downs with professionals at different times. We don't trust professionals in that we never take a professional's word without thinking it over for ourselves. Never, ever now. There are some you trust that you've known for a long time.

I think one of the things that I've found difficult is the fact that, with the paediatrician and the ophthalmologist in particular, they've never really dealt with a congenitally, totally blind child. I think that's a real problem in that once again the paediatrician jumps to the conclusion that Annie's intellectually handicapped because she's not communicating the same as other children and not doing certain things. I think the saddest thing about it is that some parents might just take that advice and be done with it.

I don't trust professionals because I have found they say things when they don't really know the answers - especially the medical profession. Instead of going away and finding out what they're on about, or saying they don't know, sometimes a diagnosis or explanation is given that is wrong. At first you do think that they know, and that they are always right, and have got all the answers. I think, if anything, I'd like a professional to say to me "I don't know." Blindness is a low incidence thing, so why not just be open and honest about it.

With the paediatrician I have no doubt whatsoever that he's a very competent doctor as far as some things go, but he doesn't know a lot about blindness. I don't blame him for that. He's been really helpful trying to get information for us. One thing we don't like is professionals writing letters to other professionals about Annie without our knowledge. One doctor would send letters about Annie which we would never get to see and I just didn't think that was on. And I can remember too, the last assessment we had when we went to see the *paediatrician, people had written letters to him, which they'd never shown us. I think that if any correspondence goes between professionals we should know about it. We didn't agree with what was in the letter either.*

The diagnoses about Annie have been different too. When we went to the initial eye specialist he told us that the optic nerve was all wasted, and then we go up to the second eye specialist who tells us that it's something else to do with the retina and that there's nothing wrong with the optic nerve, it's completely healthy. We have especially experienced frustrations with attending the Low Vision Clinic. We wondered why we bothered going when we sat around with a one and a half year old kid for three hours in a waiting room. Then they showed her a piece of cellophane saying, "Oh, she can see that, she responded to it." There's nothing wrong with her ears. What a waste of time, why did we bother? We used to trek in there every year to the Low Vision Clinic. She used to scream a lot, she hated hospitals.

Experience is really important. Some people train but have had no experience and others are experts in their field, like the occupational therapist, but have no knowledge of blindness. Working as part of a team alongside those with a knowledge of blindness is one way of better meeting the needs of the kids.

One of the benefits of someone that does see a lot of children is that they build up knowledge and experience. That's why I think that a special school is really critical, especially in blindness and probably deafness too. Now we've come up against this perception that Annie's intellectually handicapped rather than concept delayed because of her blindness. We're open minded on it but you do always look for other possibilities. I've always believed to some extent that when she picks up on things, the concepts she understands, she understands well. This labelling we feel is beginning to impact upon the types of services available to Annie. The level of services around the country are so different. In another area there's a kid exactly the same as Annie getting two or three hours educational support a day. I've recently been reading a lot of research about kids who are just like Annie and with the same mannerisms, and the concept development comes out loud and clear. But we have difficulty convincing others.

As a parent with a child twenty four hours a day you do pick up a lot of things. You understand because you put yourself in that position and you cope with it. You don't try to make your child out to be better than they are. There's no point to that. I'm not saying that parents are professionals, I'm saying that parents are professionals in where their child is at. They have a lot of knowledge of history and background but not of where the child is going. That's where the missing link is all the time. I think what I'm saying essentially is that you go to a professional and they may think, "Oh, no, another bloody parent", but parents have got a lot to offer. They know what the child can and can't take. It's a combined lot. Professionals approach Annie in different ways. One thinks, "Here's a challenge, I'm going to get through to this kid" and she has, whereas another goes about getting through to Annie in a different way and is not having the same effect. I take a lot of the blame for Annie because we haven't been hard enough on her but then we've done everything based on the information that we've been given and it hasn't necessarily been the right information. I haven't neglected my child. We love Annie as much as we love our boys and our boys are well adjusted so we can't be doing everything wrong. There's got to be a balance.

Sometimes professionals can go too much the other way. At our last IEP (Individual Education Plan meeting) the principal said to us that we were the parents and we had all the experience and knew everything. I disagreed and said that I was the expert on knowing where my child was at now but that I relied on the professionals to help me make the next step. While there is an element of initiative, I rely on professional advice so that I can analyse and work out what's best for Annie. I don't claim to be an expert on blindness or people in general. Professionals are really important but they just need to acknowledge the value of the contribution parents can make.

I haven't had a lot to do with the policy makers but I do think these people understand what the problems are. However, I don't think they have the ability to do anything much about it because a lot comes down to financial considerations. It's such a huge and diverse area, special education. It's the minister who makes the decisions so if the Minister doesn't understand, or doesn't want to understand, or can't afford to understand, it becomes a problem. I think people out there generally do want the best for their kids. Nobody can say that they want to deny kids an education, but it's how to go about it, that's the real issue. I don't think anybody's out there to deliberately harm the children. Everybody's needs are so different. I think there's a lot of merit in the proposal that PVI put forward in having a national body specifically for vision education to get a consistent policy. Everybody wants policy but as far as I'm concerned you can only have over-arching policy, and then I think that each different area has got to develop their own strategies within it. Policy makers can't possibly understand every different disability. People within the different sectors might be able to have a bit more idea, like the deaf community, or the blind community, but I don't think six people from different backgrounds can get together and make intricate policy on specific disability areas. That's impossible.

(Richard) The RNZFB Child and Family social worker has been a big help. He was our first interaction with the RNZFB and he introduced us to a pre-school for Annie. We have got to know him very well and regard him as a very close family friend as well as our adviser and counsellor. He has done a lot for Annie and the family as a whole. He used to run fathers' nights down here. I found that really helpful. He would do several at once for the mothers and fathers, mainly I think because he thought that males amongst themselves would tend to open up and that is true. A lot of fathers probably react to problems totally differently to mothers. Once we had a night on IEP's and I think there was one father who had been to an IEP of all those there. I just couldn't believe it. I've been to all of Annie's IEPs since day one. I like to know what's going on at school as well. I know the feeling when you get information second hand because Sue goes to a lot of these meetings with her PVI. And quite often the assumption is made that I know things whereas I get quite frustrated. I go to everything. There's been the odd specialist appointment where I haven't attended, like the low vision clinic, because I've got so disillusioned trekking in there every year - I mean, she's blind, what's the point of going and seeing the eye specialist every year? I've always gone up to Homai for the assessment there. I feel really strongly about not getting the fathers going to that. It is one really good opportunity for fathers to catch up on where their kids are. And that is the reality of what they did when the funding was reduced. They cut the fathers out.

Social Welfare with Alternative Care and Handicapped Child's Allowance, and those sorts of things have been really good. At one stage we went for a suspensory loan. We turned it *down in the end because we thought we were shifting, but we have had absolutely no problems whatsoever. They were very helpful.*

Of all the doctors we've come across our local GPs have been brilliant. They've all been good. They've always been interested in Annie and in learning what we had to say about it as well, which is quite interesting and surprised me. They were obviously keen to extend their knowledge.

(Sue) One of the reasons that I've probably found it easy to deal with some things is the fact that I've been involved with PVI so I know what's going on. I know that you can ask questions, and you are allowed to challenge things. You don't have to sit there being weak.

I've found being part of PVI has opened up a lot. I've seen what you are entitled to do as parents. However, I don't believe that because parents are entitled to certain things that they should automatically go out and get it. I don't believe in taking the system for everything it's got. I feel it's my responsibility to bring up Annie, it's my choice to have a child, it's my responsibility to look after her. I resent a little bit, that people think society owes them a favour because they're blind. That's a terrible attitude as far as I'm concerned. It's just knowing and being aware of what's there, even though you might not use it. There's a great relief to some extent in knowing that if you do get into trouble that you can revert to these things.

(Richard) It was the RNZFB Child & Family Social Worker who motivated us to become members of PVI. We went along to a meeting one night and all the old guard wanted to get out in a hurry. It was a setup really. So Sue trekked off up to this conference, and came back on the national committee. It happened all very fast.

(Sue) I was interested, but I didn't exactly know what I was getting into at that stage. I knew it was a parent support type thing, but that was all. Even when I came home after being voted onto the national committee I still didn't know entirely. I suppose there's only so much you can take in when you're first learning. But I got onto that, and five years later I'm still there. I've really enjoyed it though, it's been great. I find that sort of support from parents and going round the country and talking to different people has been invaluable to me. I think the committee have a lot to offer. I just thrive on the good that they try to do for the kids. The main purpose of PVI is ensuring that the kids get a fair go, ensuring that some sort of consistency is achieved, and carrying out its role of advocacy and supporting parents. The real issue is that the kids get a fair deal. That's the thing that drives everybody to be there.

We're the sort of people that the social worker used to sit there and wait for us to crack. We never did. How have we coped? I think the ability to actually talk about things has helped, and I think we're both reasonably rational people. We actually put a problem there and then we look at ourselves to see if it's something that we're doing wrong and how we can contribute to making things better. We certainly haven't neglected Annie. We love her as much as our other kids. We love her to bits and we'd never do anything to harm her. We do what we think is in her best interests and it's not always right, but then you learn from your mistakes. We've always been supportive of one another. There are times when you can see that the other one's going to lose their cool. We've probably got more support from each other than anybody else. I think we've been quite fortunate in that we talk to each other and we both accept Annie's blindness. So many marriages break up. It's quite scary.

We have gone through phases where certain friends have been quite good and we've got quite a good neighbour here. Although she doesn't have a really close relationship with Annie, she is very supportive, probably more supportive than the family in a lot of ways. And one of the reasons that I was quite keen to move to Auckland, was because the people who worked with Annie in the hostel, even though they're not part of the family, they understand her and they have been a great support to us.

As far as we're concerned Annie's got heaps of potential, she's got a really great personality, and she seems to thrive on doing certain things, so why write her off? We've got certain minimum targets we want her to meet. Our expectations aren't great but we do have some. Mainly they are to do with Annie learning to be reasonably self-sufficient. I think our vision is that in fifteen or twenty years time we'll grow to be a two person family, instead of a five person family. I don't expect any less than I would if Annie was sighted. Even then we're saying if she doesn't reach that sort of independence, then we're quite happy to maybe put a granny flat on a section, get somewhere, and semi-look after her. We're not saying we want her out in the community and out of our hands either. If she does that, then great.

I think one thing that I've always maintained is that as long as Annie's happy then I'll be happy. If she grows up to be a happy adult, that's all I can expect of her. I'd hate her to grow up miserable and resentful, and I'm certainly not going to help contribute to that. To grow up to accept the way she is. It always helps me to see older blind kids. I know that they're all different but it extends our horizons. I think one thing that we'd both really like to see is for her to have a relationship when she's older. Once again, if she's not able to handle a relationship, then I'd rather see that she didn't have one.

We don't have big academic expectations of Annie, but by the same token we've still got education insurance taken out for it in case she does go to university. We didn't do anything different for her than the boys. We actually said one day when we were feeling depressed, we're wasting our money. But we're not. It would be bloody terrible if we hadn't done it for her.

A lot of parents don't actually realise some of the problems that their kids can go through, and don't know how to help them. For example, homosexual relationships are meant to be very easy to get into because they don't understand that. And I suppose one of my biggest fears for Annie is her vulnerability. It's bad enough having kids and teaching them about AIDS and things like that. Annie's so much more vulnerable, I get really frightened. But I think that's a natural fear for all parents anyway. The other thing is about periods. When she gets to that age how is she going to know? I was thinking about these things when she was two weeks old. Things like stranger-danger and periods. That's why I think there are certain things where kids and families should be getting specialist input because parents can't be expected to do all those things.

It's the little things. I can remember going up to the hostel at Homai and Annie was being taken to the toilet by a staff member when I was there. And they closed the toilet door. That's not a thing we'd ever do, but it's quite important. It was the same when the kids were having showers, they were most insistent that they got used to doing that. Developing a sense of privacy. And when you think about it, it makes a lot of sense. We don't do things like that so maybe that's something that I should be focusing on. Then, there's quite a lot of effort in actually making Annie do things herself at times. It just becomes a routine, I think, *a lot of the time. Especially when you've got three kids and want to get them into bed as quick as you can because you just want them to go to sleep. Some of those techniques of dressing have to be taught to the parents too. As parents, nobody ever tells you those things.*

I think we understand Annie's blindness pretty well. We don't know all the answers, that's for sure, but I think we know basically where we're heading with Annie. That's half the thing that keeps me going within PVI and on the Foundation for the Blind because I don't need to worry about Annie, or I don't think I need to worry about Annie. I've learnt Braille so I can teach her if I have to. Obviously we need support but we'll do everything we can to meet her needs. I think awareness is a big thing. While Annie's got us, she's not going to miss out on anything.

FAMILY PROFILE

Child:	**Annie**
Age:	6 years 6 months
Sex:	Female
Visual condition:	Lebers amaurosis Congenital Visual impairment first recognised by parents Totally blind Tactual mode of communication
Other conditions:	Some degree of developmental delay
Educational placement:	Three placements during research study 1) Homai Vision Education Centre (6 months, short term) 2) Local primary school 3) Homai Vision Education Centre (longer term)
Parents:	**Sue & Richard**
Ages:	29 & 34
Marital/Parental situation:	Married
Vocations:	Accounting, computer background; civil engineer

Siblings:	**Michael & Joshua**	
Ages:	5 years;	2 years
Sex:	Male;	Male

Family:

Time in present community:	At the commencement of the study the family had lived for 20 years in their present community and 2 and a half years in their current home. Towards the end of the study the family moved to Auckland in order for Annie to attend Homai Vision Education Centre on a full-time longer term basis.
Most important to family:	Happiness, stability & health
Effective support systems:	RNZFB, PVI, NZISS
'Gift' to other families:	"Get yourself informed and possibly involved in support systems like PVI that can help in so many other ways. Relax and get on with life."

SARAH'S FAMILY

Narrated by Sarah, Kayla, Amy, Jarin, Daniel, Georgia & Lance

Sarah's just had to be part of the family. For us it's been realising ourselves as normal. I mean, no doubt we had abnormal situations happening in our family that other families don't have, but it's accepting ourselves and having our friends accept us. "Oh, yes, that's the R.......'s." That to us has been a real support then, not having to explain. It's just really accepting that this is how this family works.

Sarah

My name is Sarah. I am blind and I have two sisters and one brother and I have friends that play with me. I'm nine years old, I turned nine in May. I like school and my interests are music, story tapes, writing letters, and art.

When I get up in the morning to get ready for school I usually put my eyes in front of the TV then I go and get dressed for school. I like school. I am in standard three and I like my teacher. She is nice and kind. I am in room eleven and my favourite things are maths and art.

My favourite songs from school are 'Colour my world', 'Ho, ho ho', and 'You put me at the top of the world'. Other things I enjoy are reading and dancing. My favourite numbers are 2, 3, and 4, and my favourite colours are white, blue, yellow, purple and pink.

I love my family. I like it when we pull together and that we all help out. It is good that we all live under the same roof. I'm lucky to have two sisters and a brother. I like it when my family's here because that shows that they love me and care, and I love them and care about them too.

When we want to go somewhere we have family meetings to see what we are doing - like when we are going and what time we are going to leave. We have to have the meetings straight after tea. I'd like to spend a bit more time with them (the family together) - where we'd go places like out to tea, or to the park with a home-made lunch, or just a picnic lunch made by someone. We should actually go on more trips to spend time away, because we often get phone calls from people that we're not expecting.

I like it when Mum or Dad helps you with your project work or whatever you need to get done from school, like homework and reading. And some problems that you have at home, like you have problems with your brothers and sisters, they're always there for you to talk things through and help you.

We like to surprise my Mum and Dad. Especially when they're not expecting us to tidy up the house like me and Kayla and Amy did yesterday. And Mum came home and gave us all a treat. It was a Trio.

Kayla, Amy, Jarin, & Daniel: Siblings & Cousin

Kayla

My name is Kayla. I am seven. I like going to school and colouring in and drawing. I like going up town with Mum and playing games with my sisters. I like going to my friend's house and my friends coming here. I go to school and I like my teacher. I like to read and ride my bike. I love my family. I like it when Daddy does the wallpaper and I help him. I like going out on picnics and I like it when Mum and Dad come out. I like giving them a big surprise and a big hug and a big kiss. And I like it when people come for tea, like you. I just like my family.

Amy

Hi, my name's Amy. I've got two sisters and a brother. My cousin's Daniel. I'm 12 and my favourite music is 'Boys to Men', and 'Salt and Pepper'. My interests are going out with my Mum, going to the pictures with my friends, and staying at my friend's house. I love my family.

I go to Intermediate. School's okay, although I don't like it all that much. One of the best teachers I liked left. I don't like my teacher at all but my Mum thinks he's gorgeous. I'm sort of looking forward to College next year but I'm a bit worried. I've had a few ideas about what I want to be in the future. I'd like to be a photographer or something to do with the water, like work with dolphins and whales. That's really all. I haven't really thought a lot about what I want to do.

The good thing about my family is when we do try, we work together really well. When we are working towards something we can all achieve it. We can all try at things. We may not get it, but we may get it next time. We're hoping to go to Auckland next January. And we're sure we'll get there. At the moment in our planning we're having family conferences to decide if we really do want to go because we've got friends up there that we could stay with. And we're thinking of the things that we want to do there. When we decide what we want to do, we can start saving. And we might get the money by the end of the year.

Most of the time we can work together and that helps Mum and Dad out quite a bit. They can get under a lot of pressure. And I owe it to them, I reckon. I really like it when my two sisters don't fight and when Mum tells them to do something they usually do it, not with arguing. That really makes me feel like they can do something without fighting every time, which is amazing.

I've really liked it when my family's been there for me because I have done pretty stupid things in my life once or twice. I've just liked it when my Mum and Dad, brothers and sisters have been there for me. I've really appreciated that. I feel that in our family you can make your own decisions without anyone getting in your way, and if they do, they step back. Like, they know if you're going to do something wrong and they might warn you, but you might still go ahead and they will support you after that still. We've got the opportunity to learn by our own experiences and make our own decisions. That's what I've been really thankful for. It really doesn't pay to lie with my Mum and Dad because they are going to find out anyway.

A couple of Christmases ago we went down south to see my Uncle Bruce and Aunty Carol and it was in Christchurch. It was really good because we spent time together by ourselves. We didn't really need anyone to butt in. In the second part of our journey we went to Hamner and we could just sit down and discuss what we were going to do next and stuff and just really listen. I'd like to go out for more trips with just our family and go away for a couple of days to get away from here. It can get a bit frustrating never being on your own as a family, never getting a chance to be by yourself. There are other people always coming in and out all the time. It would be just nice to get away - just the seven of us.

Jarin (Jay)
My name's Jarin. I've got three sisters and a cousin and my interests are riding my bike and modelling. I'm fourteen. I find school hard because I can't read properly. But I'm learning. I'm in the fourth form. I've mainly learnt by listening because writing doesn't work for me. In the future I'd like to be a truckie, I'm going for my licence soon.

The good thing about this family is that we work together - we're good under pressure. It's stable. I like my Mum and Dad because they can sit there and listen to you. They won't get angry and that. They're good listeners. Or if you've done something wrong and you tell the truth, then that's it.

Daniel
My name's Daniel and I'm 17 years old. My interests are sports, art and music. I'm an only child, no brothers and sisters. I don't go to school. I want to get a job. Any job. I wouldn't mind being in the cooking profession, something like that. A cook or a chef preparing food. But I'm not really sure, I haven't really made up my mind. I still don't really know, but that would be one of the things that I'd like to do. That or art. Be a painter of something. At the moment I'm on the dole so I'm pretty sort of desperate for a job and to make some good money.

The thing I like about this family is that it's a stable environment. My parents have split. They split when I was two years old and I've lived with my mother most of my life. It's a stable environment here - two parents, sort of one big family. You know, everyone's got their bad points but then everyone works together, tries to help each other out. It's good to learn by your mistakes. If you learn by them something good comes out of it. So it's a bad thing, but it's also a good thing.

Georgia & Lance: Parents

(Georgia) We've been married eighteen years and together for twenty one. We have four children, plus one extra. Lance works as a painter and paperhanger. He's been in the trade twenty two years and in his present job for fourteen and a half.

Our lifestyle, as our children have told you, is really hectic. Very open and very hectic. I think, sometimes that's detrimental to your family unit, but sometimes it's out of our control as well. Hopefully it's good character building for the kids for later on. We believe that it is important that our children learn to think for themselves. I work off a logical base and I like my children to think for themselves, have a go at something, in a holistic form - like to think, if I'm going to do this, what are the consequences, and do I want to have to go through those consequences, or not? If I can teach my children to think for themselves and to really, genuinely like people, I think I'll be doing quite well. Especially with Jay and Sarah, because for those two, attitudes are what's going to get them through life.

(Lance) One thing that is important, and I think it's important to every family, is honesty. You know, sometimes that's not easy when you're a kid to be honest in certain situations, it's not easy for adults either. I probably don't think as logically as Georgia, and think things out quite the same, but one of the things I like to try, and which I think is important for the children is giving it a go. At least giving it a try, whether they fail or succeed at it, it doesn't matter.

We are a Christian family. I struggle a little bit in that area at times. Georgia and I aren't from Christian backgrounds and while I've certainly struggled a bit, we're certainly trying to bring the children up with Christian values.

(Georgia) For me, I don't have a hassle with that part of it. If the children know that they are loved by God and by us, and that this is God's lifestyle and what His expectations are, that is what matters. You treat someone like you'd want them to treat you. So, I guess I'm not so keen on them to have a head knowledge of the Christian attitude, but I certainly want them to be able to demonstrate it.

I think that because we've had such an open household all our lives that sometimes our family background becomes fragmented. It would be good to take time away when it's just us, just the family unit, and that's something that we take on board but we find really hard to do. It's something that, as they're getting older, we're realising we're going to have to be more diligent in doing, being more selfish for our family. It seems to be always easier to find time for people outside the family, but you never seem to be able to find time for the family itself. But the times we have done, it's been invaluable.

The last time we went away for a weekend we nearly decided not to go because we were all quite sick. A couple of the children had diarrhoea and when we got there they were absolutely horrified because there were no shops, and Jarin was absolutely devastated because there were no hills to ride the motorbike around in. But we actually ended up having a great time. It was really hard to come home. We've always talked to our kids, and never, ever, not told them what's happening with situations in the family. We've always made a point of sitting and talking things through with them and then finding out how they feel about it all. And on the Sunday of this weekend we decided to just actually talk about how each *other was feeling. We thought we'd do it over breakfast. Well we finally got up from breakfast at half past twelve - we'd been at it a few hours. So many things came up. One thing I'd really like to see, and I'll know that we've succeeded if they treat everyone with equality, is just to be accepting.*

I think the hardest time for me was in finding out about Sarah's condition - more so than any other areas that we've had to deal with. Sarah was born a couple of weeks early. We knew that we were going to have Sarah, and we had been calling her Sarah for a long time. Even our doctor had started calling my stomach Sarah. All my other babies have come really, really quickly, and Sarah hadn't. My waters broke and we hung around the hospital. I mean, they had the emergency room all ready for us, 'cause that's how we normally go - and we got there and we just didn't do anything, absolutely anything. It was so different for us to be hanging around. They had me walking, climbing up steps, and all types of things to get me going 'cause they wouldn't send me home because of my waters.

The months leading up to Sarah's birth had been difficult. My Mum, six months beforehand, had had a major stroke and was living with us, and my brother was going through the end of his cancer treatment. Mum was at this stage walking with a walking stick. She had been doing Massey University study when she had her stroke, learning Latin, learning Greek, you name it, she was an amazing lady, self taught. It was a typical family situation for us, everything came at once. That just seems to be the way things happen in this house. And that's one of those areas that you've got no control over.

When Sarah was finally born, she was born with four student nurses looking on. We knew the nurses really well. In this place here, you know, you made your own bed after you had a baby. So you got on really well. It's almost like having the birth at home. So we had these four student nurses and this beautiful little baby, and all we could think of was, at long last Lance has got his blue-eyed blonde. We didn't think there was anything wrong except that Sarah seemed extremely premature, she was covered in vernix and had no eyelashes, no eyebrows, and no fingernails. Thankfully though, her lungs were really good, and her heart and that sort of thing were good. She wasn't put in an incubator or anything else like that, but she was taken care of. So we didn't notice it at first. It was the doctor that first noticed.

The doctor was saying, "Oh, this is Sarah", and she'd already introduced her when she came out as Sarah, and she was going, "Oh, Sarah, she's blue eyed", 'cause, I mean, this kid just opened up her eyes and they were just so blue. They put her on my stomach. They had wrapped her up because she was so covered in vernix, and while she was still on my stomach and they were waiting for the placenta to come out, they had a bit of a look. It was then they picked up she had webbed fingers. One nurse started to take her away from me, and I just grabbed her and said, "No, get your hands off", and the doctor says, "No, no, she's alright." The nurse says, "Oh, her fingers are webbed", and we just sort of said, "Oh, yeah, that's really unusual, she'll be a good swimmer", because they were totally webbed. They felt that everything was really good at the time. When we left they said she would need to get her fingers separated and the doctor was straight up about it and said that by the look of it she could lose her little fingers.

We had to have an appointment with a paediatrician before Sarah could go to surgery and that was when she was ten weeks old. In that ten weeks my mother had another stroke which had debilitated her more. When we went to the doctor I strutted in with this gorgeous little *baby that everyone kept going nuts over. She was a neat baby, an absolutely really neat baby. I walked in and I hadn't even sat down, hadn't even shaken his hand, and I am sort of holding Sarah up in my arms so he could see the face, and he said to me "Is this your baby?" I'll never forget that, you know, "Does your husband look like..." I mean, he hadn't even introduced himself, "Does your husband look like this?" It got to the point where he asked me whether the baby had possibly been swapped in the hospital, or what my other children looked like. Was there anyone else in the family that looked like her, did my husband have such vibrant blue eyes and smallish facial features? And I'm going "No, no, no." In the end I said, "Look, I've just come here because we need a surgeon. He brushed that aside and I was in tears. I just walked out of that room in absolute tears. I mean, I had bought in a beautiful, normal, perfect baby to him, and he had totally just blown me off my sails, I just couldn't believe it. I went to a friend's place and bawled and bawled and bawled. Two days later our doctor rang up and said that he wanted to see both Lance and myself, so we went up. The paediatrician had actually written a letter stating that this child, as far as he was concerned, had ocular-dental-digital syndrome and that he had organised for her fingers to be done. He wanted to see us again, and he was quite prepared to tell us himself or it was up to our doctor. He had left pictures, and everything else. He had left as much information as he could. The next time we saw him I felt totally unconfident. The third time I went, when he wanted to see that I understood the information and that sort of thing, I felt a lot more confident. I said to him that he had blown me away, that he really had hurt me, and that we were quite devastated.*

You know, poor Lance. He had to go through a blithering wreck of a wife who's total mothering instincts had been just blown away. The doctor apologised. He said that as soon as I walked in - she had a little dimple in the middle of her bottom lip - and he said that immediately he recognised the syndrome. He had seen it only once before when he was doing his training. He's been marvellous ever since. But the problem was that, though we coped well with everything, although he explained things well, he never put us onto anybody. He never told us there could be hearing impairment, there could be a visual impairment, there could be this, there could be that. We just came home and had to deal with it.

There were interesting reactions that we had from family members. My Mum felt guilty because of the time I had spent with her and that's why we believe she had a major stroke. My brother felt really guilty because of his cancer. Lance's family was rather interesting, especially his grandmother, as much as I love her. She said, "Well it must be something wrong in your family, 'cause there's nothing like that in our family." And my other brother was, sort of, "Oh, well, you know, what do you expect?" There wasn't the support there from our families that we had hoped for and that really hurt. There's a lady in the Chapel called Auntie June, and she'd been coming and helping me with Mum. And, she was brilliant, she was our support. She and her husband and her daughters were the ones that just came in and really supported us. At the time I had to take Jarin to school, Amy was at Kindy & Care, and Mum was at home, and Auntie June would come in and she'd do the dishes and help me get Mum up and dressed, and washed, and everything. I used to come home and find Sarah tucked up in Auntie June's cardigan - all wrapped up and stuffed down the cardigan - and she'd be doing the dishes, singing away. So she was our main support. She just came in and nothing was a problem, and she and her family totally loved Sarah. Although Sarah was a happy chappy she didn't communicate much. But every time Auntie June would start singing Sarah's hand would go up to the throat, and she'd push Auntie June's throat more and more to get her to sing.

Sarah had the surgery done for her fingers when she was a year old and the second operation when she was five. When she was ten months old, she was pronounced profoundly deaf. We had an audiology test. Everyone centred around that, and getting her hands ready, but we never worried about her eyes. We knew that they didn't dilate like ours do, but there wasn't the emphasis, which I think was a bit of a shame for Sarah. Looking back on it I feel maybe we didn't pursue that area as we should have. But she had her first surgery at twelve months and came through it with flying colours. Then I fell pregnant with Kayla. Sarah was two when Kayla was born and up until then she had never spoken. While I was in the hospital Sarah went and stayed with Auntie June and Uncle Fred and the girls. When they brought her to see me the first thing she said was, "Mummy Baby", and it just blew me away, because we always talked to her, we always sang to her and that. And they got her talking. This development also coincided with Sarah having had grommets put in her ears three weeks previously.

Sarah was a really happy kid but things that everyone noticed straight off, was the eyes and no hair. We were really despondent with that. She's had trouble with her teeth too. One of the other things for us was that no one particular agency would pick up on her because her nervous system was not affected, or her brain as such. We had trouble seeking the right help, and the fact that the disability brings her into three different sorts of clinics complicated things. Sarah's actually now registered under five clinics at the hospital, including the paediatric clinic. Nobody would pick up on her until the Foundation for the Blind did and then we had some clear direction. We had at least someone that was supporting us and was taking on board some of the other issues with her too.

Sarah's visual impairment wasn't fully diagnosed until we attended the low vision clinic at Homai College when she was three. She had been going to Kindy & Care on a regular basis for a while and I found that she didn't seem to respond a lot to visual stimulus. It really concerned me, and at one of the paediatric clinics we mentioned something and the paediatrician said that he thought we automatically would have gone along to the Low Vision Clinic. I mean, he was a lovely man, but so erratic. So we went along to the Low Vision Clinic. The first ophthalmologist, who we had been attending for some time, was an arrogant sod. He was absolutely amazing at his job and he probably had diagnosed Sarah properly, but he was the most incommunicative person. And he wanted to get this little kid wearing glasses. The glasses were heavy, and Sarah's got no bridge to her nose. Well, she put them down the loo, and we had to get our friend the plumber to come and unblock it. She'd hide them, she'd lose them, she'd step on them, she hated them. Every time I went to the Low Vision Clinic I felt intimidated and what really finished it was one day the lady who fitted the eye patches turned around and she just growled at me and said, "Don't bring your daughter back 'till she wears glasses otherwise she's just going to go blind", and I mean, they were dilating her eyes every other week. Sarah would get up there and take one look at the place and just perform. I used to hate it. We used to sit there for two hours and wait, it was just the pits.

I just didn't know who to go to, so I went to Social Welfare. They said they couldn't help me unless she went blind. I went back to Kindy & Care because I couldn't think of anywhere else to go. I knew the supervisor really well and I just walked in and burst into tears and said, "My daughter's going to go blind, I don't know a thing to do." She mentioned the teacher at the Sensory Resource Centre. So we made contact and things just fell into place. The RNZFB Child and Family Social Worker came and it was superb. We tried to get a

Disability Allowance or Handicapped Allowance, and I was told that we were actually trying to defraud because this girl doesn't exist with this condition. I was sent a letter saying so. Those early years were just so difficult for us. We later changed ophthalmologists.

Some of our extended family don't understand Sarah's conditions and had difficulty in knowing how to react, but others have given the most amazing support and acceptance. We asked our friends why this was and they said, "Because you've never treated her anything different." We've always been open with the situation and we've never sheltered her. Sarah's just had to be part of the family. For us it's been realising ourselves as normal. I mean, no doubt we had abnormal situations happening in our family that other families don't have, but it's accepting ourselves and having our friends accept us. "Oh, yes, that's the R.......'s" - it's just, don't worry about it, you know. That to us has been a real support then, not having to explain. It's just really accepting that this is how this family works.

The interesting story is that when we knew all the information about Sarah's sight and her problems when she was a baby still, we decided to have no more children. After a lot of thought and prayer, and having to convince the doctor, we decided we wanted a vasectomy. We weren't going to have any more children. Well Lance had a vasectomy, I had a motorbike accident, we didn't wait for clearance, and we ended up having Kayla. And I think, for our family dynamics, that's been the best thing to ever happen for Sarah, because she's had to just get on with life because she's got a young sister. We're just really thankful for that now. Kayla's a great bonder. She can swim between the three other children and pull them together.

In a way we've had more difficulty dealing with Jarin's disability. That has made Sarah's disability seem like just another thing, it's not a major problem with our family. I think she's fortunate in the fact that we know so many families that have got a child with a disability. I think with Sarah, for us the main thing has been obtaining the correct information as to what were the extent of the disabilities, and trying to obtain some sort of commitment from the professionals as to whether they are likely to degenerate or improve. So it was finding out exactly what her disabilities were and where we went from there. And it was dealing with the emotional stuff that goes with it. In the beginning you are in shock. That is followed by sorting through feelings. The emotions that came through impacted on the feelings and relationships already in the family and did affect us. It has been a significant issue and on reflection I think the main thing was actually getting back as a unit again.

We were really lucky with pre-school for Sarah because Kindy & Care was here and they totally accepted the kids with disabilities, no matter what. They have a regular roll of them. And I think by that stage, we had got involved with PVI and had learned so many skills that we never knew we had. I think it's made us grow up a lot more wisely than maybe otherwise, and by that I'm not saying that people don't grow up wisely without disabilities in the family. It's made us grow with our family as well. I'm very selective in who I approach professionally and I greatly believe that if you're not happy with a person then you go to someone else. With schooling I had had such a devastating time with Jarin that when Sarah came along I wasn't prepared to go through that again. I was a lot more assertive, and I think I've learned those skills. If I haven't appreciated someone when I've gone to them professionally, then I've told them about it, and either worked through the situation with them or changed. I don't have any guilt problems with that. And the same came with school. I *put in the preparation and when it came time for Sarah to go to school it was the principal that rang me up said, "I've got some time tomorrow, come and have a cup of coffee."*

(Lance) For me, one of the areas I've struggled, is that it's Georgia that's taken the brunt of all these visits with professionals, as far as Sarah goes. I've only been on them occasionally because I'm just not there. So she's developed most of the skills. I've just tried to pick up on them along the way but she's using them because she's around these people all the time, I'm not. I think I met the paediatrician once, and I think I've been to an eye clinic once. I went to Homai for the week of Sarah's assessment, and I went to the hospital when she had surgery. The week at Homai was probably the longest time I've spent amongst any of the professionals. So poor Georgia, she's at the front line all the time and I try to be supportive in the back line but sometimes it doesn't seem to quite happen how you'd like it to be. My boss isn't too bad for taking time off for days like that, but I try to keep them down 'cause it's awkward jockeying between the two. But I know I have no problem getting the time if it's to do with Sarah, because though the boss probably is not completely understanding of where Sarah's at, he knows enough to appreciate that if I need a day off for Sarah, I get it.

(Georgia) I think that's the hard part for husbands, or for partners, because I look at so many who have broken up because the partner of the relationship has felt unused - that's not quite the word, but they feel left out of it. Lance has thought that I've gone far ahead of him in growing up, and in parenting. Lance is the balance. I mean, I come home, I rant and rave and I feel really shitty and he goes, "Yes dear, I understand dear", and then you start talking about it.

(Lance) Sometimes when Georgia's trying to pass on what happened it just gets worse, because sometimes you want to say, "Look, I don't really need this right now", but you know you'll get something thrown at you, and you know she's so excited or all wound up. And you've got to try to get enthusiastic too. She's had the day with Sarah and you've come home, and all you want to do is just crash sometimes. You think, oh no, here we go. And sometimes, for the husband, it's hard to get enthused, even with what you're hearing. I try to be an anchor but sometimes drift around in the tide a little bit. I think that we have good rapport with it, but sometimes I do feel Georgia's moved a lot further than what I have, and I tend to resent that a little bit, and so you withdraw. But we're still a good balance. That's why the whole family unit still functions - we're not as dysfunctional a family as 'The Simpsons'.

Sarah's school experiences have been really good, very positive. She hasn't had a negativeness or been placed down the back of the classroom with crayons like Jarin had. She's had a very positive time at school in fact. Sarah's totally mainstreamed. She had half an hour a day teacher aide time, which is, more often than not, used in the class situation or small group situation, and occasionally - like at the present moment we're working on keyboard skills - she's withdrawn out of the class for the half hour. The computer's in the library, so the teacher aide goes down there and she's getting skills there too.

(Georgia) Sarah's developmental level is not affected at all. The only time that she's been behind in her skills is because her hearing has been down, or the vision. I think, because of her bone structure, puberty's going to be a really interesting thing with her, because she has flat bones instead of round bones. She's quite hippy now and she's always had a bust.

And of course one of the things that they can't tell us about is the fact of menstruation. Not knowing about Sarah's conditions has been a major issue for me. I've found someone with the same vision, but I have not found anyone with the syndrome who is similar to Sarah. I asked the paediatrician to write away overseas and Parent to Parent found me a thirteen year old in America, but the child was severely mentally handicapped, and that's the extreme of the condition. Boys are usually not born alive. But, it's the frustration of not knowing. I know that Sarah's hit her milestones, and she's doing really well, but there are times I just really wish I could talk to someone who's got a daughter like her. We know that she would probably not have any children. Medical advances do occur, but if it did become possible, being genetic, her children would have the same syndrome.

Now that Sarah's starting to get to the end of primary school the other issues start coming in - like the social issues of when she's hitting puberty. There are times when I'm just not going to be able to have as much information for her and she's going to start wanting information herself. She's never really asked about her condition yet. I think she's always taken it as accepted that that's just life - that some of us are like this, and some of us are different, some of us are like Amy, some of us are like Jarin, and some of us are like Jenny who's got multiple disabilities. So she's not really enquired but she hates people calling her 'small eyes', and I think sometimes she gets a bit more reluctant to meet new people. Having gone through puberty before with the two older children, I would, for her sake, like to try to find someone else like her, even if they're older. So not knowing what the future holds for us in certain areas is a concern.

I've always been in control of the situation. I think it's to do with being afraid of letting her down. I've been able to walk in, and if I haven't agreed with something I've been able to negotiate or change it. There's a time I'm not going to be able to do that because she's gonna have to make choices herself. One aspect of that is actually letting go and allowing her her own freedom to do that, and the other aspect is, having to do it because I can't help her. So, I've learnt how to handle things and maybe I've learnt to handle them too well, because now I control it very well. I'm in a comfortable zone. I won't change schools, I won't move out of the district because I know what teacher's good, and I know what teacher's not. I know what doctor here I'd allow her to go to, or we wouldn't give the time of day for, so I've controlled the situation.

(Lance) In a town this size, you build up a good network of who's who - who's best to have, who's not best to have. That's a part of the stability of it all, and like Georgia says, you can be in control of it to a certain degree. Georgia's got involved in PVI, and with the special needs area within schools, and then the Board of Trustees. And, yes, there's going to come a time when Sarah will be wanting to make those decisions for herself.

(Georgia) An example of the level of support available here is what happened when Sarah and Kayla were walking home from school one day. Some girls from another school started saying, "Dumb and dumb, dumb, dumb", and name calling. Kayla was more upset and the next time the girls actually pushed Sarah. I mentioned it to the principal and he was up in arms, "You find me her and I'll go down to the school. I'll be there." I didn't know, but he went and spoke to Sarah about it, and she told me a couple of days later that the next time they walked home he followed them in the car.

The other issue, I think, is not making Sarah special. Her condition is special to her, the same as Amy's asthma is to her. If Sarah forgets her glasses going to school, I'll give her a rib about it just the same as I'd give Amy a rib for not having her medication. Because that should be just part of her lifestyle. By a lot of people we're considered really hard, but she needs them to be able to function as a person.

I'm not going to shelter Sarah. I mean, I won't let her ride a bike on the road, I'm really adamant about that and she may never get a driver's licence the way her eyesight is. I think that's really sad, but she's going to have to come to terms with it. And I think sometimes Sarah chooses to have selective hearing. If she's just not listening I'll be as hard on her as I am with the others. And sometimes we just forget. At this time of the year, winter time, Sarah's at Brownies, and I might drop her off and just walk her across the road and sometimes forget that she needs help to negotiate things. She'll say, "Oh, but I can't see", and I think, oh, that's right. And I don't know whether that's good or bad but it's not sort of singling her out from the rest of the family as being different.

The church we go to are really good. One day, after we had gone back to hospital for the second surgery they asked us to come and just talk about it. I thought, oh, you gotta be joking. For a lot of the families in the Chapel we're really different, because we don't come from that sort of church background, and I guess we're considered quite different in some of the ways that we approach things. So we decided that if they wanted to know we'd tell them and that we'd act out the first meeting with the paediatrician. So, very quickly, we did that. Lance acted as the paediatrician. I asked that it be done when the children weren't there for Sarah's sake and for all of her brother's and sisters' sake. And we just blew them away because they hadn't realised it. You could see the reaction. We came back on and said, "Well you now know as much as we do." It was just very, very short and we said that the surgery had gone really well and that we really thanked them for the support. But Sarah is Sarah, and she's just one of our family members and you shouldn't need to know anything else except that her vision is very low, so don't expect her to see something, don't expect her to hear - but that's the same as Mr. Jones, an elderly man, who's sitting over there and been in church for seventy five years. You just apply that same thing, but you don't go ahead and do anything different because that's not what we're asking. And they've always been really good.

Professionals are an interesting one. When you first come to professionals you have an expectation that they know and they understand, and you find that these guys can be real pains at times. You haven't got a lot of information and you desperately want to know information. You want good grounded, solid, information and you go to these people thinking, he's a doctor, he's a paediatrician, he's an ophthalmologist, surely he must have some insight into this. Then you find he may have head knowledge but he certainly doesn't have knowledge to make it work for the child.

Prior to realising that I had a voice, I was absolutely dumbfounded by professionals. I don't let too many people intimidate me now. But at first I felt intimidated, I felt worthless. I've now come to realise they put their pants on the same way as I do. I treat them with respect, but if I'm not getting the required response I let them know. It's not necessarily knowledge I'm looking for, but it's just the acceptance and the mutual understanding that we're here to work together - not him to work, not him to make all the decisions, not me to make just the decisions, you know, it's a mutual communication, and a mutual understanding of what needs *to be done. Then I'm okay. Unfortunately I think I've become intolerant of people who won't work in that way, very intolerant. And I think that's really probably something that I need to relearn - tolerance of those type of people.*

I guess having a child with a visual impairment, hearing impairment and a few other things, I've always believed in linking into whoever is relevant at the time in assisting with Sarah's needs. Sometimes it is actually important to keep these professionals in their little slots. We've got a vision for Sarah and our family, and there's a lot we've talked about, and sometimes these guys, these professionals, come in because they are trying to install a vision that they have. And I'm not interested in that, and so in some ways, for me, it's easier to keep them at bay and get at this one and feed them the information they need. To take one at a time. My experience is different to some other families because my daughter is mainstreamed and she does very well in the mainstream. I mean, I'd like more teacher aide hours, but I accept what she's got, I'm realistic. I have a very good support system, but on the whole, I like to keep my professionals away from each other.

I think it's quite significant with parents, and listening to people's stories, that you find your child has an abnormality (and you are in deep shock) and you go through the grieving process of not having a normal child and everything else, and then you come to accept the fact that your child does have a disability and you start seeking to find out maybe why, or maybe how to cope with her and what's the long term effects, and that kind of thing. And you start looking at professionals and all those kind of things, then you come to the next stage when you realise that really you are the best person to ascertain that. That you can't expect the professionals to know - to fully know - because they're not flexible and willing to have a look. Parents become quite flexible. You don't say that your child is much better than what it is. You're far more realistic. So being realistic you're more flexible to have a look at things, and to test things, and perhaps say, no. But professionals aren't because of that word 'professional' Parents come to a realisation that these guys know so much and you listen to them and take out what you feel is appropriate, and you discard the rest. You totally discard the rest.

Professionals don't have that process where they start listening to parents and saying, "Okay, let's look at Sarah, or Alice, in this light and they've both got the same problems, the same disability, exactly the same, but let's look at them individually and be flexible." I think you occasionally get professionals that can look at individuality and take in more of a holistic view, but unfortunately I believe that in most parents' cases it's very rare that you can find someone. There's a long way to go.

I think it's a real shame that a lot of policy makers have actually lost sight of what's important. Policy makers need to regain the vision of our children. I'm not saying I'm a total inclusionist. I believe there is room and there is need for protective living areas, and protected education areas as well. I still believe that units like those the IHC run are a good first step. I believe that there still needs to be something in place on a mini scale. But unless policy makers change the emphasis on success - success in whatever area, at whatever level, and making resources available at early intervention age, school age - they are going to have to develop a new form of institution. The reason is their community's not going to be able to support them. Policy makers have got no eyes. They aren't actually seeing what they're dealing with. Yet they hold the lives of those kids in their hands.

I think the only way to get things changed is by there being parent active groups like PVI, like CCS. It's about actually teaching the parents of kids with disabilities to be advocates for themselves and their children, and then if you can, to get them up and going. On the whole, parents with children with disabilities need to stand up and be counted. And there should be support for those parents so that their marriages don't break up, that they don't feel that they are failures.

For us, we cope by just getting on and doing it and we discuss things as they come up. We are conscious of involving the children. I'd like to think that our kids come back one day and talk to us about anything and know that they are not going to be judged by us - that we always have a listening ear - not necessarily advice, but a listening ear. When things get too much for me I just get into a book and get hooked out of the world. And if there's too many people I just disappear. To me, a day in town is far better than sitting at home knowing people are going to phone me. For Lance, he just goes to sleep and uses TV as a means of bugging out.

I've found it's really important to find out who does what and how they do it. And to use those people that you feel comfortable with for support. You need to prioritize. Sometimes you've got to go out there and say, what is important here? What really is important to us and Sarah at this time? And you may have half a dozen things on your plate that you'd like to see happen, but you've got to prioritize it down and not have so many expectations. It's amazing the number of parents that expect a lot without actually putting a bit of themselves into it. So that's what I say to my kids. They are responsible for meeting their needs too. The doctor doesn't know that maybe Amy's run out of medication for her asthma. You've got to tell the doctor. The optometrist doesn't know Jarin had broken his glasses again, but Jarin knows how to get to the shop to take them down for repair. And with Sarah, when someone doesn't know that she can't see something, she has to say, "I'm having difficulty here. I really do need your help here, I can't see very well." Make your disability work for you, not against you.

I think the service that we've really found useful has been the Foundation for the Blind's Child & Family Social Worker and orientation and mobility services. Really neat. We would be lost without them. I think they gave us the impetus to go on. And the Sensory Resource Centre and the Homai Assessment Service. That was the most encouragement of all. I came home from that feeling like there was really a dimension that we had been able to find. It's nice to finally come under an umbrella - we had something to work on. I'm all against labelling but my goodness it helps. Jarin doesn't have a label and I feel sorry for him. Labelling does actually work really well for the appropriate reason - funding.

We got introduced to PVI through the RNZFB Child and Family Social Worker. The Sensory Resource Centre teacher organised a night down here and we got to meet other parents. It helped in the things that they talked about, and the fact that they sat there and laughed about it and didn't profess to know all the answers. Often they didn't know where they were heading. And we saw this as really quite a significant turn for us as parents. I feel PVI is one of the few committees around that has actually got the ability to make changes in our children's lives. It's a really good learning area as well. I want to learn something that's going to benefit my child and hopefully, in turn, other children and parents. And this is the place for me to do it.

I thought PVI was a support group with some interesting things happening. I started to get involved in it around SEPIT (Special Education Policy and Implementation Team) time so there was some really progressive thinking which made me think. I think PVI has been instrumental in my personal growth and through them, I've learnt to think nationally instead of just locally. But it's changed. In those five years it has changed dramatically. PVI now is political, it's huge in policy making and it's huge in advocacy - I had never heard of the word 'advocacy' until then.

PVI are really into educating parents, they stand for what parents should be about. Other organisations have got some good policies, but they are not parent driven. I must say that you've got to thank the Royal New Zealand Foundation for the Blind and it's Board of Trustees because they must look at PVI sometimes and really put their head against a brick wall thinking "Why did we ever support them?" Because maybe something that was a very good idea in support, and a nice little warm, fuzzy thing has become, in some aspects, a big monster because it's questioning, it's asking for accountability, and it's suggesting alternatives. And that's the great thing about PVI, it just doesn't sit back on its laurels. We come from diverse walks of life, and have all diverse concerns with our children, and diverse disabilities within our children, but I think it's really unique that we actually come out going in the same direction.

There is also the realisation that you don't have to have everybody at the same level. It's kind of a multi-level thing with people working at both national and local levels. Its aspect now is in growing to make those multi-levels actually work for the greater good. That's why it's always going to be a very strong, parent driven group. What people are doing here in their local district is as important as the person that's doing it on a national level and working with the Ministry [of Education] and that sort of thing. PVI will never lose that vision of hands on - that's what people are doing at the local base, keeping their parents supported and strengthening them. I know one of the greatest things that it's done for me, is it's given me confidence, it's given me training in areas that I've wanted, and it's given me an encouragement to say, well I've gone this far now I'd like to see us putting these things into place. It's learnt the ability in working with professionals. So PVI, I think, in that respect, has been the answer for me. And I've been able to come back to be on the Board of Trustees because of what I've done in PVI. They're all interconnected. The fact is, it's not only what you know that's important, it's what you don't know, or need to go and find out. I think that if think you know everything and stop searching, stop questioning, you've lost. It's ongoing. I think that's what parenting is all about. Whether you have normal children or children with disabilities, it's the same job description. Teachers have personal development training and that's the same with parenthood. I wasn't born to be a parent, it's something that you learn.

(Lance) For parents that have got a child with a special need, sometimes a lot of their energy's taken up in just meeting the needs of the child, and they lose the 'oomph' for anything else. So you need people with the right skills to be able to just do some of the fighting for you, and take a bit of the burden off so that they can get on and be a parent to the child and meet the child's immediate needs. And I know one of the things we found, coming under the Foundation, was that suddenly we had someone else fighting for us, being able to have influences with different professionals and start getting some answers to questions, and decisions made. When you're trying to do it yourself and still be a family, it's makes the burden a lot heavier. So outfits like PVI can set up their own networks and get

the right information. One thing that's always struck me since Georgia's been involved in all of this is how all these different outfits hate giving away information. No one seems to be willing to release it. They don't like being able to say, "Right, it's this, this, this you need." They don't. Until you start kicking and screaming and thumping the counter you don't get anywhere. You need the right people that have got the influence, and it just seems the whole importance of the structure comes back to setting up a networking system. Parents that suddenly have a child that's got a disability need to be able to know that they can go to one place and get the information.

(Georgia) Our vision for Sarah is that we expect her to be moving out of home when she's a young adult. Parents of our age group expect our children to go on to something that's independent. But I think older parents, especially of children with intellectual impairment, don't have that incentive. They struggled like hell to get their kids into school, to get some sort of education, they struggled like hell to get some sort of workshop going, and some sort of after-College event, and never actually thought any further on about them living an independent life-style. That wasn't there years ago, whereas when we've become parents of a child with a disability, we immediately are thinking of her having as much of a normal life in whatever situation is relevant. They haven't looked that far yet, some of them. Some parents that I deal with have no expectations - they expect their child to live with them until they die themselves. They don't have an outlook, or maybe consider that there could be another way their child is living.

We expect Sarah to be productive. I think, for Sarah, as for all my children, the only thing that's going to stop her from reaching her potential is an outside influence, and that's by not getting the right resources at the right time, by the policy makers not acknowledging that children with low vision are just as important as people with no abnormalities. Society will let Sarah down, not herself. And I think that goes really for all children. I can't see myself that Sarah will let herself down and I certainly hope that society doesn't either.

With policy, I think that one of the biggest things is getting the education system right. The health system's always going to be a problem, there's going to be a continual battle there. But the education system is really, really important. So I think that if our education system can be re-educated to be multi-level and multi-functional, all children are on the way to being successful. But the education system doesn't work for a lot of children no matter what their race, colour or creed. The system lets down a lot of children - and it's the system, not necessarily the people within it. I believe that if education became multi-level and seamless, and was put together by not necessarily academics, you'd actually end up with a really good system. But the reality of it is that that would never happen. So for children with disabilities, for Sarah and for other children, it's always gonna be the case that they are going to have to work twice as hard to get recognised and accepted. And in a way, I think that's the making of them. It's a detrimental thing for them to have to do, but it's also a powerhouse for them too, because if they do it, then they're going do it on their own strength.

The vision for the kids and education is, we've got to teach teachers. I've come to understand that some teachers they have got no idea. I mean, you get some really gifted people in the teaching profession who are just superb, but on the whole - and principals have little understanding - they know how to get into their position but they actually don't really know what to do with it. They don't understand that they've actually got a motivational force to change a lot of attitudes.

Parents may not be able to change the system, like the health system or welfare system, or maybe they can't even change the education system overall, but they can certainly impact it greatly. I think every little change that's made actually adds towards the whole being changed. And first you change people's attitudes.

We never anticipated. You never expect to have a child with disabilities. Your expectation is that you get married, you buy a house, you start having children and they'll all be Prime Ministers, doctors, lawyers or big money makers. You don't say, now, I wonder how many of our four children we're going to have are going to have disabilities? And yet the reality of it is, the percentage of children born with some sort of abnormality is high. Paediatricians will tell you that to have a child that is completely normal, is abnormal.

When you look at Sarah she's actually pretty well normal in every aspect. To us anyway. It's certainly been a learning curve, and particularly to have got more assertive and more knowledgeable. You've got to re-educate yourself in different aspects. So I guess in that way it's been good for the whole family.

We didn't expect to become 'professionals'. When I had babies I thought, yep, breast feed them, take them to preschool, send them off to school, you know, just the usual run of things, go to cubs, scouts, you name it. I never anticipated becoming a professional in the education system, health system and welfare system. I didn't expect to become a professional advocate for my own children, although in one sense you'd always be an advocate though you just don't realise it. I didn't expect myself to end up living out of a briefcase, and having a filing cabinet at home. I always wanted to sew for my kids. So I've become a professional in areas I never anticipated, but I would never, ever change anything in my life, not with all the cost, and the frustrations, and the disappointments, and the greatness of it all, and all the exciting things that have happened, and all the little things that happen that just really add to the character of your family life. I wouldn't change one aspect of it.

I think it's really true when they say that out of any situation, something good always comes of it. Now, okay, our situation with Sarah you probably couldn't categorise it as being really difficult, but in all those things that have arisen, good has come out of it. Perhaps if Sarah wasn't like she is we would have never had those opportunities to be involved like we are. So the thing is, you've been involved in something worthwhile because you're doing it for your kids, and if anything, what better thing to be doing? What better situation to be doing it in?

Through PVI there's been the connecting and that's the uniqueness of belonging to this culture. There are meeting points where you can walk away and say, yeah, I understand where you're coming from, it's okay. And I think that is the richness, the aspects where your wealth is.

FAMILY PROFILE

Child: **Sarah**

Age: 9 years
Sex: Female

Visual condition: Myopia, Astigmatism
Low vision (6/36, 6/60, 6/36)
Condition diagnosed by doctor at 2 years
Level of vision is stable
Visual (print) mode of communication

Other conditions: Sarah's visual condition is part of the Ocular-Dental-Digital Syndrome which affects teeth, hair, hearing and also has social implications

Educational placement: Local primary school

Parents: **Georgia & Lance**

Ages: 38 & 40
Marital/Parental situation: Married
Vocation: Parent; Painter

Siblings:	**Jarin** (Jay)	**Amy**	**Kayla**	**Cousin: Daniel**
Ages:	15,	12,	7 years	17 years
Sex:	Male,	Female,	Female	Male

Family:

Time in present community: 15 years

Most important to family: Each other

Effective support systems: Family, friends, professionals willing to be 'bouncing boards', PVI, RNZFB Child & Family Social Worker

'Gift' to other families: "Love your partner and kids unconditionally. Take regard of other families' situations and don't impose own ideas, feelings and experiences. Just be willing to share as needed."

ANDRE'S FAMILY

Narrated by Theresa & Rudi

Society's different now. Look at the schools. A lot of schools have got a child with some kind of disability. I remember that when I went to school I didn't know anybody with a disability. ... There was very little opportunity for contact because people were often hidden away. People of our generation are just not used to it. But for my children when they are brought up with these children, they will realise that they are people in their own right and that they can do things. If you suddenly become a father of a disabled child you might think back to your schooldays and think, "We had Andre at our school and he was a neat kid and I used to love him." That's what I think mainstreaming's brilliant for.

In our family there's Rudi and myself, Theresa, Andre who is ten, Karl who is six and a half and Nicholas who has just turned five and started school. Our lifestyle has changed over the last couple of months in that we shifted onto a ten acre block. Life is hectic and stressful, it's always been like that really. We are on the go the whole time. But I think it's also because we are running our own business and that plays a big part in it. On the other hand even though the farm is quite a lot of work, there are lots of things that we plan to do, you come home, you see your view and a lot of that stress goes. The kids have got heaps of room and lots of things to do. We just love it. We think that having fun and getting on with other people is important. Sometimes it's a constant battle but we'd like each of the boys to be a nice person, someone that people like, that people enjoy being with. That means that they then also have good self confidence and a high esteem of themselves. Family life is the most important. Family life and socialising. Also, being able to do things apart, that is, you have got your own things that you like doing but then you come back together to the family unit. That's very important.

Andre, our eldest child, has cortical blindness and cerebral palsy. This means that he has got problems with fine and gross motor skills, for example, crawling and walking. With his vision he is for all intents and purposes totally blind, although some kids with cortical blindness are not. He doesn't even respond to colours. Andre was born on Anzac Day ten years ago. I had a normal pregnancy and normal labour. He was eight days overdue and it was only a six hour labour which was very good for the first one. Andre was a contented baby, drinking and sleeping well and we were a happy, although naturally tired, family. He smiled at five weeks. There was nothing apparent and it wasn't really until he started getting a little bit bigger and a little bit more awake that we noticed something. We didn't really know what it was but Andre appeared to look but not to see. The pupils of his eyes dilated and constricted and he scanned, but you could be in one position and it was as if he looked right past you and did not focus on you. Being first time parents we didn't initially think that there was anything wrong. As he got a little older I remember he didn't reach out to things. At four months you could feed him and he'd open his mouth but no way would he try to reach out for the spoon. Or if you had him on your lap and you were eating a biscuit he wouldn't try to take it. It was just little things.

His hand position was unusual too. His thumbs were inside his hands with fists made and very much held up. He was tactile defensive. We kept talking to my Plunket Nurse. She was only a part-timer and all the comments in his plunket book are 'beautiful boy, doing well, lovely boy' so she was no help unfortunately. A number of times I mentioned something to my GP who delivered him and he was really no help. He just kept asking what was making us think there was something wrong with Andre and saying that you shouldn't compare babies. So I said to him, "Well how do people who write books know what the average child should be doing if you don't compare them?"

Rudi and I were often thinking about why we had these feelings about our child. Our family were questioning why as well. Initially we thought that maybe we were being silly. But after a while we certainly did question why we were feeling like this when everybody else was saying there was nothing wrong. We asked, what's wrong with us? I know I felt that very strongly. We really loved this baby, it was a planned pregnancy, and we wanted children. Numerous times I had asked my GP what was wrong. But the questions remained - why did Andre not roll, sit up, reach out, and hold onto toys or food offered to him?

When Andre was about five months, a girlfriend of mine who I worked with, and who was pregnant at the same time as I was, came to visit with Robert, her little boy. We had had our first children within two days of each other. In the house where we then lived you could come in from outside through a sliding door from a veranda and this day both the boys were beside each other in the lounge. Robert was sitting and Andre, who couldn't sit, was on his stomach with his head up. Our cat walked in from the veranda through the sliding doors, past the boys and out to the kitchen. Robert's got cats at home and so it wasn't something new for him. Nevertheless his eyes sparkled, his face lit with excitement and his little hands were going as the cat passed by. The cat walked straight past Andre who ignored it and acted as if he didn't see it at all. Obviously we know now that he hadn't seen it, but that day I knew inside me that there was something wrong with his sight. We thought maybe it was short sightedness because Rudi wears lenses and all the boys in his family are shortsighted.

Andre was seven months old when I was at the doctors again and this time I burst into tears. I asked him to look at Andre again. I said, "You probably think I'm a bloody neurotic housewife, but I'm not leaving here until you do something about it." It was just so apparent - none of the milestones had been reached. He said that he'd send me to a specialist and a couple of weeks later we had an appointment with an ophthalmologist. He examined Andre and said, "Your child's got what they call cortical blindness but don't worry about it. Most children grow out of it by the age of three." I can still hear him saying it. So Rudi and I were really on cloud nine because we thought it was just a temporary setback. He said it would make Andre slow in his development as well because 80% of a child's development came through his sight. The next day we went to see a paediatrician who was semi-retired. He looked at Andre and told us that we had a severely multi-disabled child. So from one day feeling elated after having the lift from the eye specialist, we went right down the next. He told us to bring Andre back in three months time to see whether he had made any progress. We left feeling numb and devastated.

That same night we were due to host a farewell party for a friend who had visited us from Holland and was returning the next day. Our family and friends would be there and they all knew we had had an appointment that morning with the paediatrician. They would be eager to hear how we got on. Driving home from the appointment I didn't feel I could see or talk to anyone that evening. I just wanted us to be at home on our own and pretend nothing had happened. Selfishly I told Rudi we would have to cancel the party but knew that was impossible. Then I told Rudi he would have to host it as I couldn't face a lot of people. That, I realised was also not fair to Rudi who was hurting just as much as I was. We had the party and it was very difficult, but looking back it made us talk about it immediately with family and friends who did after all care. We didn't have to bottle it all up inside us before telling the same story twenty five times days later.

The next few days were a blur. Rudi took some time off work, we talked a lot, sometimes pretending there was nothing wrong and other times acting as if our whole world had fallen in. Telling family and friends in Holland was most difficult. They had never met our lovely little baby and not being able to talk face to face is always hard.

We did seek a second medical opinion after that and when Andre was ten months old we went to Princess Mary Hospital and had brain scans and CT scans done. They actually said to us then that he had medical conditions that later turned out he didn't have at all. We learnt all these long medical names off by heart but we didn't know what they were talking about.

The doctors also said that they couldn't find any reason for Andre's conditions and they didn't really know what was wrong with him.

The first paediatrician we went to had told us to come back in three months time, and when we returned he just asked us what Andre was doing now that he wasn't doing three months ago and we said, well not really much, nothing really - "Okay, well come back in three months time." This happened twice and Rudi and I felt this wasn't good enough. So then we went privately. This was in fact the same doctor who had given us the second opinion at Princess Mary Hospital. He looked up all the tests and told us that they were done by a young doctor in a hurry, that they were inconclusive. He ordered all the tests to be redone. We asked how this had happened. He was the same paediatrician but we were paying for him now.

We could really keep on going for a long time about doctors and people in the medical profession. We didn't have a lot of faith in them. In those days, and it's almost no different now, you didn't really get a result unless you went private. It was extremely amazing, the difference of response that we got from the specialist when we started paying for the service - it was like night and day. Today though, we're still with this paediatrician and we are pleased with him. We have got a very good rapport and we're almost like friends. He calls a spade a spade and there's no bullshit. He doesn't treat you're like you're dumb. He treats us as an equal.

We did go back to the ophthalmologist after about half a year. He said he couldn't tell us anything different from before. We were in there literally about two or three minutes. It was on a Friday afternoon at four o'clock and we had the feeling that he wanted to go sailing. I was so angry that I almost didn't pay him. It was the last time we ever went to this ophthalmologist. Andre's sight hasn't really changed so we just don't bother. If we noticed that he suddenly started going towards the light or going towards a particular colour we might have to go back to him.

We found some doctors very difficult to deal with mainly because of their condescending manner. But the first paediatrician we went to see put us onto the Crippled Children's Society (CCS) and onto Homai. That started the ball rolling and the RNZFB Early Childhood Adviser came to visit us.

Over the years Andre's conditions haven't changed but his development has. The cerebral palsy is no different really, it's only what Andre is capable of. As he gets older and bigger his capabilities change and you can get more out of him or less out of him. With cortical impairment you can sometimes start seeing more and more but Andre certainly hasn't.

For Andre I think it is very difficult because he hasn't got any sight and he has also got such physical problems. The two are linked together and impact on each other. If he had sight he would be encouraged to maybe move towards something, or to pick up something that he loved. Then he might be more encouraged to use the motor skills. There are a lot of children with cerebral palsy who are able to walk. But there again if he just had his cortical blindness and not his physical problems that would be different too. Andre's crawling now.

I think the family understands Andre's disabilities extremely well. Initially some of them said things like, "It does come all from her family, you know" or "We never had something like *this in our family." It's amazing what people say. Now they're really good, even Rudi's family overseas. When Andre was three we went overseas for three months. Then they all had the opportunity to meet him and get to know him. A lot of photos Andre takes aren't the nicest. You sort of see a little bit of this disabled child in some photos, so the photos that they did get weren't all that marvellous. They had felt really sad and they felt, "Oh, poor us, poor Andre", but when you meet him and realise what type of person he is, and the neat person he is, you stop feeling sorry for him. I think that was very, very beneficial for Rudi's family.*

So there's definitely good understanding by both sides of the family but mine more so because they live in Auckland. I'm very close to my family. They see Andre a lot. So do our friends. Mum and Dad used to look after all the children a lot but Mum can't look after Andre on her own since Dad passed away. My sisters have helped too. It's getting harder now though, we really don't want to ask them. They wait for us to ask them and I get sick of always asking. I think, why can't they offer it for once? But they don't think of offering it because they think as long as I am not asking I don't need it.

Rudi and I have quite a big circle of friends, we like being sociable. In the beginning, Rudi used to have his party trick. If we ever had a gathering of friends, especially males, and young people that weren't used to children, he would be talking to them and say, "Would you hold Andre for a minute while I get myself a drink?" and he wouldn't come back for half an hour or so. And initially you'd see these people thinking, what do I do with this? But then, you know what Andre's like - they'd warm to him. So our circle of friends have a really good rapport with Andre. And a lot of them will come and talk to him, pick him up and sing with him. And that's good.

I think a difficult stage for me was actually accepting Andre in the beginning. I don't know if you'd call it a problem but you have to overcome your fear of disabilities. My Dad had a problem with it. Initially he didn't want to know there was anything wrong. For me, I know I definitely went through a grieving process of what I didn't have or wouldn't have. I've always wanted my own children and I love the way how in my family you see the grandparents with the grandchildren. The enjoyment and pleasure they get out of their grandchildren. I did go through a grieving process knowing that I wouldn't have that. Rudi was a great help to me in working through that. It drew us closer together as a couple, because of Andre's problems. I think it's then that you realise that you have bigger problems, not all those little things you used to argue about or discuss before. They weren't problems any more.

Maybe it might have been helpful if I'd found out a bit earlier about Andre. I don't know necessarily at birth but we had months when I honestly thought something was wrong with me. If I'd known at birth then that wouldn't have happened. I still would have had to go through a lot of the process of acceptance. We really got to a stage of thinking, what's wrong with us? If all professionals and my mother and father who had five kids of their own, and grandchildren, were saying "Don't be stupid", there couldn't be anything wrong. What I find annoying is that there was obviously something wrong that could have been picked up so much earlier. I think there were a number of reasons why this didn't happen. For a start, my Plunket Nurse was a part-timer and was quite happy to do her job and go home. When she left, Andre was about nine or ten months and the next Plunket Nurse I had, it was her first job. She was straight out of school and she was scared - you could tell - she didn't want *to know if there was a problem because then she would have to deal with it. So as far as I was concerned, for Andre, Plunket was useless.*

I think one of the most difficult times was when Andre was just going on five. Karl was eighteen months - a revolting eighteen months - and Nicholas was a brand new baby. I had three babies really. And Rudi said to me "Theresa, I'm leaving work, I'm going out on my own." And that topped it all off. That was a very difficult time. It was also a difficult time when Andre was three and a half and Karl was seven months. Andre was waking five times a night and I was still breastfeeding Karl two or three times a night. Rudi and I were so tired we weren't speaking to each other because it was better not to.

I was surprised really how many people want to hide disabilities. I'll never forget when I enrolled Andre at Kindy. It was on his second birthday. At the bottom of the form after you fill your name and address, age and birthday, there is another section. I don't know whether it says disabilities but I wrote down that Andre had cortical blindness and cerebral palsy. The Kindergarten were actually amazed that I wrote it down. They said usually the parents won't say a thing about it. It's not until the child gets to Kindy that the teacher tells the parents. And I said, well I can't hide it. Why should I?

Society's different now. Look at the schools. A lot of schools have got a child with some kind of disability. I remember that when I went to school I didn't know anybody with a disability. In my family no one had broken a bone in their body and I'm one of five. So I wasn't used to it, and sometimes I think it took me maybe longer than Rudi to accept Andre's disability because Rudi was brought up with it. In the street where he lived there were two community houses just down the road. They were older men who lived there but Rudi used to go down and play at their place because they had better toys than he had at home. He loved it. They were people with intellectual and physical disabilities.

There was very little opportunity for contact because people were often hidden away. I think that's probably why there is an awful lot of marriage breakups in the disabled world. People of our generation are just not used to it. But for my children when they are brought up with these children, they will realise that they are people in their own right and that they can do things. If you suddenly become a father of a disabled child - and it's unfortunately most of the fathers that can't cope with a child like this - you might think back to your schooldays and think, "We had Andre at our school and he was a neat kid and I used to love him." That's what I think mainstreaming's brilliant for. It's hard in a stable relationship to have a child like Andre. I couldn't imagine doing it solo. No way. And there's plenty of them doing it. In the 80% range or something statistically. It's really high.

I think with the attitudes of some people it just makes you more determined to prove your point. We used to live next door to teachers who were both totally against mainstreaming of disabled children. Their attitude rubbed off onto their children who were only just young ones like ours. It makes you more determined to prove your point and to make sure Andre mixes with them. Sometimes you just say, "Oh well, it's their problem, they're the ones missing out."

We both make decisions about Andre although Karl and I are probably the two most concerned with people's feelings. He can't stand anyone being upset. Rudi and I take on different roles. We actually find that I do a lot of the hands on for all the children while he *does a lot of lobbying, especially with Parents of Vision Impaired. He's excellent with things like that. Where possible Rudi and I will attend appointments together as far as Andre is concerned. There have been a few obviously that Rudi hasn't been able to get to, especially follow up appointments, but certainly if there's anything important he's always there. Like, a couple of times Andre's had to go through an operation. But certainly any problems like that there's no way that either of us would make a decision on our own.*

I do feel a lot of times that I'd like to be more involved in something like PVI but I know that Rudi's really good at it. Rudi keeps saying I would be too if I gave myself a chance. Whether I would be or not I really don't know because I've never put it to the test. In some things, like issues to do with special education, I feel left behind in, but a lot of it is also because you get woozy in the brain from sitting at home for ten years. Sometimes you really have to get yourself into something again to get more contact with people. Ever since we've had our own business which is nearly five years, I have done more. But it's not only using the brain, it's also the contact with other people. For the first four years I had Andre, I was only in contact with people to do with special needs. I really needed other contact as well. I tried Parent Centre Play Groups and things like that but people were different to me because I didn't have a child like theirs. It was really isolating, the attitudes of other people who didn't understand disabilities.

Sometimes I'd say to Rudi that I didn't know what was going on in PVI or Special Education or whatever. And often when Rudi came home after a meeting he would have discussed it with others and would not really want to talk about it any more. He would just want to blob out and yet I'm at home dying for information. (Rudi) Your own partner you communicate the least with. It's true. You turn round and think, oh, you don't have to tell them about it. You just want to come home and relax and unwind.

(Theresa) When he was ten months old Andre started off at the Early Childhood Unit at Homai. He initially went for one morning per week and we gradually increased it until he was doing five full days by the time he was four or five. So Andre has been going to school for nine years. Every Tuesday, I remember, I used to go in and we'd do swimming and we'd spend the morning with him. Rudi spent quite a bit of time as well having a look and videoing different parts of the school.

The things that we did when he was young. We tried every bit of therapy that you can find under the sun. At that stage people suspected Andre had cortical blindness but they didn't know for sure. There were a lot of things going like the Glen Doman therapy. We didn't do that but we read all the books. We worked with alternative medicine, in terms of massaging, Bach flowers and cranial osteopathy. We went to a naturopath and a homeopath. We put things in his bath for a cure. I still remember, arnica lotion and eggs. We laugh about it now but at the time we were desperate to try and do anything we could, because imagine if something had worked and we didn't try it.

When Andre was about four we started off with a little bit of mainstreaming. That was on a Friday morning at the local Kindy with a teacher's aide. And when he was six we changed him to a local Catholic school. That was mainly because they told me that he was too big for Kindy and he was an over-age placement. I disagreed with that. It was once again going from a safe environment to something new.

Andre is still attending Homai and now, in the last four years, he's been mainstreamed as well, but only for between three and four hours a week. When he was coming up to five I went round about five different schools in the area - the ones with special units as well - just to satisfy ourselves that Homai was the best placement for him. You can't go saying it's the best place when you haven't checked out other places. But I'd be horrified if I had to send him to some of these other places I saw, even with the special ed. facilities. At the same time we also had a look at how they felt about having Andre for a few hours in the mainstream with a teacher's aide. Our local school was just appalling in attitude. But the principal of the school where he now attends said to us, "Well I don't know actually, we've never had anybody with disabilities in our school but I'll talk to the teachers who would be with Andre", and they came back to us in a couple of days and said, "We'd love to try." The rapport was just great. They sent some teachers to his Individual Education Plan (IEP) and to Homai to look at what his programme would be like. They were just brilliant. And they have been ever since. Really, really good. We have never had any difficulty getting Andre into the programmes we've chosen for him, though I think if we'd wanted to fully mainstream him we'd have had a lot of problems in a lot of places.

Andre hasn't got a lot of peers other than friends of ours who have children of a similar age group. Then they come, not for Andre obviously, but because of the family friendship. But the people who are in a similar age group are really good with him. Mind you, he's gone and spoilt a few of the friendships himself. There's a lovely girl near to where we used to live and she was exactly the same age. She'd always come and talk to Andre - she just used to pop over and chat. He's into this awful hair pulling at the moment and one day he really pulled hard and she was sitting there crying and she didn't know how to stop him. He was laughing and I couldn't get to her quick enough at the time and he just hurt her so much. I've noticed she's since kept her distance, for which I don't blame her. But I think it's sad. He really hasn't got any friends or any buddies his age but the children that do come to visit are really pretty good with him and his brothers are too. Sometimes they won't spend any time with him and other times they'll sit for ages. Nicholas will crawl into bed with him and they'll lie listening to tapes or one of them will read him a story or play games with him.

I've got home help from the IHC two afternoons a week. Rachael comes. She's twenty and Andre loves her. Every afternoon he says "Aechel, Aechel". He's got a couple of people, not necessarily peers, but a couple of people he has a very good rapport with. Andre loves them and has lots of fun with them. He looks forward to going to see them. What Andre needs is love and lots of one to one. He isn't able to keep himself busy. I think on the whole he does get it but we feel guilty if we don't spend time with him in the weekend in that way.

Karl and Nicholas don't know any different. As Andre is the eldest, he has always been there with his special needs. From that point of view I think it's been easier for them. But we do go through stages where they say, "Why doesn't he have to make up his bed?" and then we sit down and talk about it and we say, what do you think - because he can't see and he can't walk. And they know, but they feel as if everything is being loaded onto them. I think there definitely are some issues.

The thing that I'm worried about is that I don't want the boys to grow up and look back on their childhood and say they didn't have a good childhood because of their brother - or because of the problems. I don't want them to resent him. I definitely don't expect them to look after Andre either, because I know how tough it is for parents to do it let alone a *sibling. But I hope that they'd be quite happy to have him at home for a weekend or a holiday. So I'm hoping that we can get that rapport between the three of them and in that way they can support one another.*

A major issue has been spending time with all the boys and balancing their individual needs. It was years before they went to McDonalds. Now most children since the day they can walk have gone to McDonalds some time or another. I think Karl was three or four before he first went. Just those little things - it was easier to stay at home. It's too stressful to take Andre to wait on the rugby field or tennis court so the other boys missed out. But they don't seem to be saying, why can't we do this, or, why can't we do that?

I think a big issue for me is trying to cope with when I am becoming resentful of Andre. There have been times when I have been resentful of him. We don't do the same things other parents and other families do because of his disabilities. When that builds up and up, and your stress level gets high, you do resent him. Sometimes it may be because you think you can't do it, and you try it, and you find that you can. Or sometimes you do go somewhere like McDonalds and Andre has to sit there and be grumpy and scream and be unhappy, but the other kids are enjoying it. Then everybody else is looking at you and thinking, that poor thing, why aren't those parents doing something about him? For me, the major issue with the kids is that they are happy with us.

One of the reasons the stress levels get high is because we don't often go on holiday as a family. We don't usually take Andre. We may try to go away for the odd weekend but not for a really decent holiday. Andre hasn't been away with the rest of the family for a long time because basically we wouldn't enjoy it and therefore it wouldn't be a holiday. What's the point of going away from your familiar surroundings if you're not going to enjoy it?

Then when you do organise someone to look after Andre and go away you feel guilty that you're having a lovely time because he's not there and that's very high stress. Even if he is away for a weekend it is wonderful. I'm sure that he is having a lovely time too, but we do feel guilty because we're enjoying ourselves without him. It's so easy. Like the other boys don't mind if we say, "Oh goodness me, let's have a carrot for dinner", because I couldn't be bothered cooking. But Andre has to eat a proper meal or else he's sitting there crying because he's hungry. It's like with little babies when you have to be in a routine, but Karl and Nicholas are getting to the stage that it doesn't matter what time they eat, what they eat, and if you do pancakes for dinner they're rapt. If you want to go out sometimes it's easy to take Karl and Nicholas with you but it's not always easy to take Andre. Also when they get to this age they start staying at people's places - having a friend over and going over to their place. Andre doesn't do that. As parents we need patience and sanity time.

I've had a lot of people give us all these little poems about special parents and these type of things. To be quite honest I think they're bull. I didn't ask to have a child with special needs and I don't think I'm special. Rudi and I are very grateful and very lucky that we have been able to work things out together up to now. Who knows what might happen in the future and we are not special by any means. We have got a lot of shortcomings and yet we've got Andre to ten so we must be doing something right.

There are some incredibly strong feelings amongst parents about professionals. The professionals at Homai I think are all right. On the whole I think they've been really good -

all Andre's teachers and teacher aides. The medical professionals are really good too once you prove to them that you don't stand any nonsense. I think once you let them know, they treats us as an equal. In the beginning with our paediatrician we said, "Look we don't think it's good enough that you're the head of a team at the hospital and you can't give us satisfactory results. We start paying for you and we suddenly get the good results. It's not good enough - it's not good enough that you treat us like this. We don't want to be treated this way." We might not be a medical professional, but we are professionals in our own right. And he's really good.

As people we're quite vulnerable at this stage of our life, and the professionals are not perfect. A lot of them have never had any counselling skills, they've never had any people or communication skills, although some in our age bracket have. A parent with a deaf-blind young adult son always says that the problems were no different twenty years ago. So I think that a lot of that feeling centres around the lack of communication skills and how people are given information and how they are treated. I think that: a) professionals are under stress because of the case load they have got; b) they don't always have very good communication skills; and combine those two together with the limited time they have available, and then it becomes really difficult. Counselling skills never used to be there although now they probably are, they are working a lot harder on those.

So I see a need for some basic counselling skills in the training of professionals. The other thing is also that many professionals make a lot of assumptions. For example, you've got a paediatrician who is good at diagnosing somebody with brain damage and what physically their problem is, and they will then make a decision possibly in terms of what stage they will develop to, or how good they are going to be at school. There's a whole heap of assumptions that they will make and that's the bit that I find very difficult. But you mustn't forget that many of these parents are pressing for an answer on that as well when they get there. It's quite a difficult one. But I think with good guidance, having a good social worker or maybe a counsellor, it would work better. Maybe sometimes there are unrealistic expectations but there are definitely a lot of professionals around who don't have those skills. The thing that I find difficult is that a lot of those people don't believe that you have the knowledge. Just because you haven't studied, they believe you are incapable of understanding. That's the bit that gets me. Then, maybe we're no different in our professional line - we must be very careful in that. So, for example an engineer may talk about something and they may not bother explaining to somebody else either because they think you are incapable of understanding it.

Sometimes we haven't coped. Then we might cry or yell at each other. We get annoyed. We talk things over. Sometimes we've had to call in other people to listen to us and to help us. I remember before Andre ever went in for Parent Relief to Homai, I wasn't coping at the time. And an early childhood adviser at Homai said to me, "Do you know we can take Andre in for a weekend?" I didn't know that. Through non-coping you learn the coping strategies. But often just with minor things or just within the family, Rudi and I have managed to talk things over, or cry things out, and help each other. (Rudi) It's not always easy. I often get very annoyed. Very annoyed. That's my way of dealing with it. Theresa's way of dealing with it is crying, my way of dealing with it is just getting angry.

We also realise that Andre has to have time out and that's how we keep coping. I think if we didn't have the week or the weekends or something without him, some time to recharge *our batteries, I don't think we'd cope as well as we do. Especially because it's so full on with the other children at that age too.*

(Rudi) I get frustrated with other people demanding our time. It's interesting. There's quite a number of people who do make demands on our time and that's partly our own fault because we are quite social people. People come here all the time. We will just think, "Oh, we've got a weekend on our own", like last weekend, and then people turn up. All I really did last weekend when we had three days was shear one goat. That's all I did. I really get quite annoyed about it.

(Theresa) It's a bit difficult as well though because I love having people around me. My house is always open if someone wants to drop in, and if I constantly have a full house that's fine by me. I like having the time to ourselves as well, but it doesn't worry me. I don't get up tight if someone suddenly drops in, but if Rudi thinks he is going to have the afternoon to himself and it doesn't turn out like that, he is disappointed. It could also be because I'm home a lot with the children and I love it when others come in because it makes a break from the house. But Rudi, when he comes in, likes the peace and quiet.

(Rudi) I think a coping strategy for me is that I have got another person with a disabled child around, which is really important. We work together and spend an enormous amount of time discussing things. We are in a similar situation in terms of our partnerships really. Both our partners find that we are spending too much time doing these sorts of things in terms of lobbying and Homai. But they understand why we do it. So that's good from our point of view. But it is a way of coping when you feel you're doing something.

(Theresa) The main supports for us have been family, friends, and Homai, especially with the pre-school and the wider network as well. In the beginning there was Crippled Children's Support Group which I attended. Then we got more involved with Homai and the Foundation and were torn between two places. PVI now as well. Church has been available, we've just never taken it up. Rudi didn't want that type of support. (Rudi) No, I can't stand it when people come in and they think that you can fix everything with a prayer. That to me is just nonsense.

(Rudi) Homai was bloody good really. I must admit that. Especially in the early years. We don't need it as much any more because we know where to go for the information. But Homai is still good because if you need something you know that you can go there and at the moment we are wanting, for example, to do something about a bathroom for Andre and so I've turned to the occupational therapist who is pulling in other resources. So if we need something we know Homai will help, whether they can do it themselves or put you onto someone else. There's a pool of knowledge there.

I think what has made us able to go out and deal with the issues for our family has been sheer determination and good organisation. And I think also basically just to know that you have to carry on. Sometimes you want to walk away from it all but you can't can you? Well, we can't. We're the sort of people who believe that you can do it and want to make a change. It's a bit like a politician I would say. We would never go into politics, but there are people who have the same drive to go into politics because they feel they can make a difference, and that's exactly the same.

(Theresa) I never used to be like this and I haven't got confidence in myself, or never used to have. But then I think it's realising that if I'm at a meeting, or at an appointment - medical appointment or whatever - and it's just me with Andre and I feel something, Andre's not going to say it. He's not capable of saying it, or of saying how he feels. So if I don't do it, nobody's going to do it right at that moment. And whether you're scared to, or whatever the reason is, you have to say it because it's your child. That's what I've learnt - I've learnt that if I don't do it, that no one else will. I am trying to teach the other boys to speak for themselves. At rugby this morning, for example, Karl wanted his friend Brad to come and play and wanted me to ask. And I said, no, if you want him to come, you ask him. So I actually put that onto him because he's getting to the age when he has to be able to start doing things like that. But Andre, a few years older than Karl, cannot do it.

(Rudi) I do think part of what we do in terms of our support network, in terms of lobbying, is linked to ambition. I don't know in what sort of form or shape, but it's to do with starting something and wanting to finish it off. And knowing that it's worthwhile doing. That's what I call ambition, wanting to be part of that change. You need to have people who have got drive and a very clear vision. That's something I've always believed in very strongly. Whenever I've done anything in my life I've always seen the picture in my head. It's important that I can visualise it and see things happening. I'm not a great person in believing in planning to the nth degree but I believe that once you've got the overall picture, you'll automatically start putting things in place to make it happen.

(Theresa) Sometimes I had to go and find out for myself what there was out there for Andre. Riding for the Disabled I found, for example, by talking to other people. Often you're not told in advance. I do realise some people aren't ready, or cannot take the same amounts of information in at the same time. I suppose from a professional's point of view, how much they tell a family depends on how good a judge they are on the readiness of the family. But from my point of view, a lot of the things I've had to find out by searching for myself for Andre, rather than going to a spot and someone saying, "This is everything that is available, choose what you could use." We didn't know, for instance, that Alternative Care is shortly going to be changed. It's going to change to a needs based system - if you need more you can get more, if you don't use much you don't get as much. The 1st of July it changes and who knows about it? Nobody does. We only purely found out by chance.

(Rudi) I can't actually remember when we first became members of PVI. We just sort of seemed to be in it. I think we were so involved in Homai that it seemed to be just a progression. PVI, for me, became important once it was more focused on lobbying. I became more involved then. There was a time when it didn't seem to have a growing edge and it was quite hard to break into. But then again it's easy to say that, because even now we've got problems, because I really would like to get out to a certain extent, but who's going to take over lobbying? I can't see anyone yet who's got the skills to do it and I'll be buggered if I'm going to get out of it now and let everything that I've worked for all these years disintegrate. It's just at a very critical phase at the moment. So I don't know. Maybe I'm wrong in saying that - maybe it's the same attitude as the first people in PVI had.

I think the main function of PVI, in terms of the National Committee is lobbying - 100% lobbying and responding. Political lobbying, local lobbying and advocacy. We are thinking of setting up a group of a few paid members to become advocates to go round the country *when someone needs advocacy. On a regional basis PVI is a parent support group and a place for information sharing.*

With political advocacy at the moment it's mostly focused on education and health. Education was a big part of what we were fighting for but we have, to a lesser extent, spent time on health. But health has had a very good representation. I think the things in health like the Disability Support Services are moving reasonably well. But I might be wrong, we'll wait and see. In education the service provision has not been there. There has not been enough funding in it and the equity of services is a major issue. The diversity of the consumer groups in there trying to get money from each other, rather than getting more money, is ridiculous. That's the situation being fostered by the government - to allow that to happen is detrimental.

(Rudi) When I think of the vision for my family I've got a picture in my head. It shows lots of happiness, a big house, lots of people around, and one happy big family. I can see all the people doing things together there and that's really important. And I see Andre home for a certain amount of time, but not all the time.

(Theresa) My vision for the family is similar. I'd like a very happy, united and successful family in which the children will all stay together. That includes Andre as well as the others. And I would like to see Andre, the same as the other boys, at a certain stage leave home. I see that Rudi and I can have some sort of life together just for us two again. The natural progression will be no different as far as Andre is concerned. It will just be that his flatting or whatever situation, will be different from the other boys. Obviously. I hope that whatever he goes into will be a place that we are just as happy with - that you don't have to have those anxieties and worries that he should still be at home and what are we going to do? And I know that Rudi, especially, is working extremely hard because we'd like to be in a position where we are quite comfortably off. One day we want to have a vineyard. We are going to retire on a vineyard and we are going to make our own wine. It just depends on what you want. What's very important for me is family life and that includes seeing and enjoying Rudi's family in Holland. Unfortunately we have to be fairly well off to be able to afford to go there. But I'd like to be able to see them once every couple of years or so, and that takes a lot more money.

I still feel as a family we need some home support. We have up to ten hours a week but we realistically only use about four. That's not because we don't want to use any more, it's just reality. What happens with such young children is that it's not always that easy to get someone in after hours, over dinner time hours, that can cope with the children. You either get someone quite young who hasn't got their own family or else you get somebody a lot older and then physically it's sometimes difficult for them to manage Andre. Someone who's maybe similar to our own age group have usually got their own young family and so the hours that we need home support often are just the wrong hours for other people. Consequently we are not able to use it to the extent that we would like to.

(Rudi) We are planning to set up a Community House for Andre. I'm going to be setting up a family trust and that's going to be a major thing. I don't believe anybody else is going to provide for Andre and the insecurity of some of the other trusts that are around for the kids that are in the houses is quite major. I'm really aiming towards that for Andre - we might not be able to afford it - but one way or another I'm going to try and do that and there will be

other kids in there too. I'm not at all convinced yet that the education system, or social welfare is going to turn around and look after him. I'm not.

In Holland they've got community type houses like Hohepa. Now I don't know what Andre will be capable of doing in the future, but we didn't think he'd be capable of what he is doing now at ten. So we just keep going and see what happens at twenty. Andre has got a pretty good brain on him. He just finds it difficult to express himself, whether it's physically, or whether it's communication and language. I'd hate to see someone who's got a brain that they can use just sit in a house all day. He still needs to be extended and maybe at twenty he will still need to be extended as well.

What's out there for them? I think that is one of our biggest worries at the moment other than what's going to happen to Homai tomorrow. You know you look one step further and there's nothing out there for him. I've got a cousin in Holland who worked in a similar place to Hohepa and there are a certain number of clients who live there and they do everything from horse riding to growing vegetables and art work. All that you need is ten acres. So we're going to do it. It would be good to have something close to here - in the country but not too far away from the city. There are lots of possibilities and I think it warrants more investigation. Funding is always a pain in the butt.

(Theresa) I suppose in one way that's why money plays a big role in Rudi and my lives. Because if the funding is not there, maybe if we could afford it, we could set it up. I know someone said to us something about being people that want to be rich and what did we need money for. I said that it had to do with wanting to see your family and making sure you put your children through an education. We want exactly the same thing, but to see Rudi's family in Holland and to maybe see Andre set up for life. There is a vast difference in the amount of money needed, so sometimes in our situation we just have to push that little bit further. Okay, we need to be rich and it's not for us personally, but to do the same things as someone else might want. But they may only have to travel over to the North Shore to see their family and their kids might be able to go to varsity, which is pricey nowadays, but maybe not at the same level as Andre might need. The amount of funding that we require for a community home is going to be huge and some of it will come from the government and some of it will come through the trust, however we are going to get the money together.

For Andre's needs to be met we are doing our best. We make sure that we're on the ball, you keep lobbying and you keep up with what's going on. Being informed and knowing your rights, that's the most important thing. You learn more about it - it's the quickest way to do it. It's all linked in to Andre. We honestly wouldn't be in it if Andre didn't have his disabilities. And if anything happened to him and he wasn't there any more, or whatever, we wouldn't carry on, or certainly not in such detail. It's draining. We think about not getting as involved and then you look and say, yes, you're doing it for your child. That is uppermost, initially you do it because of your child. Then you see the wider needs.

FAMILY PROFILE

Child:	**Andre**
Age:	10 years
Sex:	Male
Visual condition:	Cortical visual impairment Congenital Visual impairment first recognised by parents, confirmed by doctor at 10 months No functional vision Tactual mode of communication
Other conditions:	Cerebral palsy
Educational placement:	Dual placement 1) Homai Vision Education Centre 2) Catholic integrated primary school (4 hours per week)

Parents:	**Theresa & Rudi**
Ages:	38 & 37
Marital/Parental situation:	Married
Vocations:	Company director; Company director

Siblings:	**Karl**	**Nicholas**
Ages:	6 and a half years;	5 years
Sex:	Male;	Male

Family:

Time in present community:	2 months
Most important to family:	Quality family life
Effective support systems:	Homai Vision Education Centre, PVI
'Gift' to other families:	"Trust your gut feelings."

SHAUN A's FAMILY

Narrated by Raewyn, Leith & Tania

I first started going to PVI because I believed very strongly that if parents meet together they come to understand that their situation is not unique. ... Other parents, even though their children mightn't have the same disability, have the same end result in view and by meeting together and actually understanding that there are other parents out there who understand you, it just made it easier to manage. Lots of things can be talked out and there are things to be learnt from the ways other people who have gone ahead of you have done things.

Leith: Sister

Eight years ago an event occurred that has dramatically changed my knowledge and perception of visual impairment and visually impaired people for ever. It all started in 1986 when my mother called my two sisters and myself into our living room for a discussion. She had received a phone call from the Department of Social Welfare asking if we would foster a child. There was nothing unusual in this as my parents had been fostering children since before I was born and it was just part of our lives. What was unusual about this case was that the child was totally blind and 50% brain damaged. He had been labelled a vegetable and was being placed in a foster home until an institution could be found for him. It didn't take long for my sisters and I to come to a decision. We would take him. My mother explained as much as she could that things would be difficult for the time that he would be with us and that we would have to be patient with him. None of us were prepared for the changes and sacrifices we would have to make.

Not long afterwards we were introduced to Shaun - a thirteen month blob. He couldn't talk; he couldn't walk; he couldn't even sit. I think all of us were at least a little taken aback at how bad he was. At the time Shaun came to us I was nine years old, my sisters Tania and Marianne were seven and six respectively.

We weren't expecting to have Shaun for very long but Mum started therapy with him anyway even though she'd been told it probably wouldn't help. Instead of registering him with the IHC as she'd been advised to do, she registered him with the CCS and the Blind Foundation. The kind of things that Mum did with Shaun were to walk him up and down the streets, making him use his legs. She was constantly told how cruel she was for 'abusing' Shaun in that way. This was because he screamed all the way. She made him touch things that felt slimy and rough and had different textures. For quite a while he was very resistant to things like that, as are most visually impaired children. Mum got him used to things by giving him things like playdough and rice to play with. She also put shaving cream on the tray of his highchair and kept putting his hands in it until he just played in it by himself. This was one of his favourite things to do. A lot of work had to be done to build up his left side as it wouldn't function properly because of the brain damage. There were a lot of mannerisms which are common to visually impaired people such as parroting other people which had to be checked as well. All this took hours of work and a whole lot of patience. I guess with all of the attention and special things that Shaun needed I felt a bit neglected. I had to take a lot more responsibility more quickly than my friends because Mum couldn't always take us to places like we used to. I learned to use a bus system to go into the library and to go swimming because Shaun screamed everywhere we went. The time that I started resenting him wasn't until Mum and Dad started thinking about his schooling.

By this time there had been two custody battles over Shaun. Shaun's lawyer had suggested that Mum and Dad become his legal guardians. We had won custody of Shaun so Mum and Dad were a lot freer to make decisions concerning his schooling and other things. Since we lived in Invercargill there were basically only two options for him to go to school. One was to send him to Auckland to board at Homai College. Mum and Dad didn't want him to go there as we'd only see him at holidays that way. The other option was to move to Christchurch and send him to a school with facilities for blind children. It was decided that this would be the best option. The house was sold and we moved to Christchurch in 1989. Unfortunately we didn't start school up here until five weeks into the school term. This was *very hard for me because I was a very shy person just starting Intermediate. I didn't know anybody and I didn't make any friends the first year I was in Christchurch. I really resented Shaun for making us move. If it hadn't been for him we would have stayed in Invercargill where I had lots of friends. I guess I never really got over feeling like that.*

Shaun started school in 1990 at a Normal School. We didn't know the extent of the brain damage so it was uncertain how much he would learn and retain. Through a lot of hard work from his teachers and Mum he has come a long way since he came to us as a "vegetable" unable to do anything.

Five years ago my mother got a job at a Visual Centre, learnt braille and became a teacher aide for visually impaired kids. She became a committee member for the Parents of Visually Impaired Children and spends a lot of time fighting for better facilities for visually impaired children. None of this would have happened if we had decided not to take Shaun, so I guess good things do come out of bad.

Leith wrote her story in 1995. It was entitled 'Good things do come out of bad ...' and was printed in the PVI publication Vision Newsletter (April, Issue 29, pp.18-19). While Leith participated in the interview, it was her preference that her written story was included unaltered in the study.

Raewyn: Mother, with Tania & Leith

In our family there is Leith who's seventeen, Tania who is sixteen and Marianne who's just on fifteen. And then Shaun who is ten. I'm separated - it's been a couple of years now and my husband is living in the same city. We live fairly quietly. We are a very close family. Togetherness is important to all of us. We like being with each other and I think that's really the most important thing. I had expected that looking ahead, when the children were little, by eighteen they would want to go off and do their own thing but they still don't want to. They will do their own thing, but they also want to do things together. I've come from a close family myself but most of us left home at about sixteen. The children haven't and yet they are very independent. I still have a strong attachment to my extended family although they are not here, they are all down south.

We have a very strong commitment to Christianity. I've tried to teach, not just Christianity, but the standards that go along with it. Caring for each other. They are very caring children. That was something always noted on their school reports, that when new or different children came in they would take them under their wing. The girls have always grown up with other children in the family and they've always had to care for them. They've seen a lot of different styles of living. That's been really good for them because they've learnt to make decisions and they've seen the consequences of things that children have done wrong from very early.

When I reflect on how we came to take foster children, it goes back to my work. My work life had been quite varied. I'd started off as a Karitane Nurse and I ended up working in a Children's Home. From there I went to work at a place further north as acting matron *at a babies' home. They were mostly Samoan babies whose mothers were single. That was twenty four hours a day and quite a horrific place. All through my casing work I preferred looking after disadvantaged children to children from advantaged homes. I tended to go towards that end, so fostering just happened. What started me off with it was the Social Welfare. They asked my mother to go in to a family and she wasn't able to at the time. I was working as a postie so I said I would go and do this job for them. Just as a volunteer. I was there for a year with these children, going in three times a week. They were there with their father. Finally two of the children ran away and I was out with the police looking for them all night. When we finally found them the girl said she wasn't going home again because the dad was sexually abusing her. They had nowhere to put this family of children so I said I would go into the family home and look after them. That was before I was married and after I had been there about three months, I got married. So it sort of just developed. I have always carried the responsibility in the family. One of the problems when I was married was that I always had to make the decisions. So right from the time when we got married and were in the Family Home with five children I made the decisions.*

We have been in Christchurch for six and a half years. For the children it's been a hard six and a half years. They left a lot of good friends they'd grown up with in Invercargill and found it extremely difficult to break into schooling at the ages they were. They found the sophistication in Christchurch among their peers was a lot higher, as they were pretty naive coming from a smaller town. It was totally because of Shaun's needs that we moved. There was no schooling for him at the time at Invercargill. The decision was either for all of us to come to Christchurch to live, or for Shaun to go to Homai. To us the Homai option wasn't acceptable. He would have lost what little family he had. We wouldn't have come to Christchurch otherwise and we still would go back to Invercargill if there was provision there.

Shaun was thirteen months when he came into the family. He had been in hospital, put into a family home unit and then came to me from there. At that stage it was on a temporary basis until somewhere more permanent was found. But this is where he stayed. I've actually never really gone into much about Shaun's disabilities because I didn't have the same problem as a natural parent in trying to come to terms with it. I just accepted him for where he was. I knew that he was blind but it didn't really matter how he was. I knew there was brain damage, but again, I didn't have to look into the why's or wherefores or anything else.

Before Shaun came we had frequently taken other children. In addition to the Family Home with the five children, I'd had other (foster) children on a regular basis. At the time Shaun came I actually had two other children and other homes had to be found for them so that I could take him, which I really wasn't very keen on. But that was the only way it could be done. We were told by the then Child Protection Team that Shaun was going to be what they termed, a 'vegetable'. It was the first child I think, in all the children I had had, that I ever said, "Let me think about it, I'll get back to you", because I wasn't really sure I wanted to handle it. But having decided, I then told them they couldn't take him away until they found something permanent, which they never did. They eventually decided not to take him away.

I decided to take Shaun because I thought there was something I could do. I think that if I had felt there was nothing I could do for him I probably would have said no. Having been a Karitane nurse I knew where I needed to get to, but had to learn how to get there. I knew if I could just find the triggers, that I'd learned from books I'd read, you could force the brain to take over other parts. When Shaun came he was like a three month old baby. He *was smiling but he was doing very little else. He never made any other speech noises like 'mamma, dadda' until he was over two. He was a very unsettled baby. He would scream a lot. The only time I could often do anything else, including having a shower, was when I'd put Strauss on and it would immediately calm him down. He'd lie on the floor and listen to it and I could go off and do the housework. But he often just screamed and screamed.*

We always have been open about the people in Shaun's life. We try to make it as good as we can and his birth mother has accepted now that this is where he's going to stay. For five years there were issues to do with Shaun's custody. It was very hard on everybody. I've got a couple of good friends that I could talk to and that understood. Other than that it was just a case of drawing on yourself and just hoping, just working through it. The kids got the brunt of it. But it was very hard because it was so long.

During Shaun's pre-school years there was an awful lot of hard work put in and because there were no resources in Invercargill I had to work through those myself. I would go up to Homai every year and get some more ideas of where I was going. Shaun got assessed when we went up there, and for knowing where he was, and where he was going in the next six to twelve months, the assessments were good. But it was also valuable for me being able to go into the school and see where he was going longer term. I went into the units to see how older children were behaving, to ask the staff and find out what they expected of children of five and that sort of thing. It was finding out what I was looking towards.

Then I would come home and work out how I was going to get there. I suppose because I had no resources available I sort of conned assessment schedules out of people. I worked on them and when I realised Shaun was getting too far ahead in one area I would try and bring another one up to the same level. I can remember when Shaun was about three the paediatrician saying to me that he had never seen a child go from where Shaun had been to the level where he was at then. He thought it must have been the way we were working with him. He likened it to a stroke victim and said we were doing really well. We felt we got things pretty much under control. Shaun went on like that until he got to school, I suppose. At about the five to six level he seemed to pretty well keep up with what was going on.

Shaun's first pre-schooling had been when he went to a centre at Invercargill. He spent a term there. I wasn't happy so I used to go in. I didn't work with him at all. I worked with the other children, but I didn't like the way that the children were treated. They sat at a table and puzzles were put in front of them and as one puzzle was finished they were taken away and another puzzle put in front of them. They sat at the table until 10:00 o'clock when they were allowed to get up and go to the toilet and then have morning tea. These were three to five year olds. If I got away with it I would let them use some of the equipment. They had some beautiful equipment there but the children never got to play with it. I actually complained to the management over it. I left there and I got him into a mainstream kindergarten setting with a teacher aide. It was reasonable. The teacher aide was very good. She was very understanding but I did find there were issues that came up in that setting that were totally ridiculous. Things like, he bit a child when he was three and they told me I should take him to a psychologist. I thought that if he was sighted they would have just told him off and sent him out to play again. But because he was blind and the other issues that went with it, he was supposed to be sent off to a psychologist. But it was reasonable. They did try.

When we came up here to Christchurch I got Shaun into a mainstream kindergarten again with a kindergarten teacher as his teacher aide. It was a good kindergarten except that they were all very scared of him and I had a lot of input - like to get the understanding that he was quite safe climbing up the slide and you didn't have to have your hands around him the whole time. All those sort of things. They are real issues in the kindy setting.

We didn't really have bad behavioural problems with Shaun in the early part. The difficulty was more with understanding. I was looking back on letters I wrote when Shaun was three and four and it was apparent even then. He's got the language and he does the things, but he hasn't got understanding of what he is doing. That was my biggest concern, that on the surface people thought he was doing great, but he never seemed to have the understanding of why anything was happening. And no understanding of consequences. The thing that stopped the behaviour problems was that I had control. To me, that had to be, and yet it wasn't the best thing. When Shaun was at school the behaviour problems did come in quite markedly but as long as I was in the room, and he knew I was in the room, there wouldn't be a problem. The moment my physical control went off, he just fell apart.

Shaun couldn't seem to control himself. So when he got to school he had an awful lot of problems with teacher aides, mobility instructors, and teachers who, because his language was very good, assumed a lot more. Also they thought he was rather cute because he is not like a lot of blind children with all the blindisms. He manipulates and they wouldn't realise that they were losing control of the situation, but once they lost control, everything just went completely haywire. He would fight - he belted the O&M round the legs with his cane, he just didn't have any self control. And a lot of behaviour problems came in there. It really started at kindy where they didn't deal with him properly. They just sort of put him outside the circle, or the other kids got in trouble. If he was having a fight or something other kids were the ones that got punished.

When I think back, other people must have thought I was very strict. One psychologist wrote that he thought that rather than being a mother, I was a teacher. He also put us in a situation of saying it was either a Maori-Pakeha situation or it was a socio-economic situation and it was neither. It was just that if I hadn't done anything, and my choice wasn't to do the things I did with him, we'd have got nowhere. But it was that sort of thing you were working against all the time. Trying to make them see that if I didn't do it, this child was going nowhere. This psychologist had never seen a blind child before, let alone a blind child with brain damage.

But there have been a lot of behaviour problems, a lot of them outside the home, that I've had to try and fix. Because you still have to try and work with O&Ms, you still have to work with TDLs, you still have to work with classroom teachers and teacher aides and there have been teacher aides leave over Shaun. The consequences I've tried always to make very clear so that he has got very obvious boundaries that he must stay within. It's outside the home that people actually don't make those clear boundaries for him and he doesn't know where to stop. And once he's over them and people have let him go over them, they don't know how to bring him back. And he doesn't know how to bring himself back either.

Shaun's been to school just on five years. When he started school as a five year old I didn't realise that I could have had him at a local school but I looked at where my children were going and decided there was no way he could go there anyway. And so I really decided right *from the start that he would go to the school with the Visual Resource Centre based there. He was mainstreamed there for the first four years of school and went into the Visual Centre for his braille and maths. He started off not too bad with lots of input from the Visual Centre teacher. But the progress deteriorated and we found that he just could not cope. He couldn't figure out when the teacher gave instructions - he couldn't figure out what she wanted so he would sit there and do nothing and then they would say he was lazy. Or he'd get very frustrated and he'd throw a wobbly. You know, it seemed like when he was in the mainstream he just sat, simply because the teachers did not have the time. He had no understanding. I think a problem with all disabled children is that the teacher aide becomes the teacher and I think it's wrong. They don't recognise the teacher as being the teacher because she is teaching the rest of the class.*

So Shaun learnt while he was within the Visual Centre but the rest was a waste of time. Another problem was that the teachers didn't understand how specific they had to be. I could never get that through to them, how really specific they had to be. We had an instance one day where Shaun was in a music group. The children were doing a rehearsal at twelve o'clock and the teacher let them go out early for lunch so they would be on time. Now I had a little girl rush into me in a panic saying that Shaun was screaming and yelling down at the other end of the school, because I worked in the Visual Centre too and the children would come to me. When I went down to find out why, he was in a real state. I said, "What's going on?" The girl was actually trying to haul him and he wouldn't go. And he said, "I'm not allowed to go. The bell hasn't rung." But you see the teacher hadn't told him. They have a quarter of an hour to have their lunch and then the bell rings and they're allowed to get up and go. Because he'd got out at a quarter to twelve, the bell hadn't rung. And the teacher didn't understand when I took him into her. I had to go back later and say to her "This is what you did, this is what you caused", because it just threw him. He couldn't do music, he couldn't do anything. And it was just silly things like that, that happen in the school systems unless the teachers are very, very aware. Teachers aren't aware because they only have one child who is blind and maybe that's all they'll have for the rest of their school teaching life. I think some training in special needs should be undertaken nowadays as so many special needs children are mainstreamed.

Shaun's programme was reversed this year in that he is now in a Visual Centre classroom with four other children. The class goes from 9 until 12:30. In the afternoons, with the exception of the five year old, they all go into their mainstream classroom. Shaun goes in about three days a week. The others go in four or five days a week. I'm getting less and less of a belief that mainstream is the total answer. I never did believe it was fully the answer. There's never going to be enough money to do that properly. It would take vast amounts of money. And where Shaun has a Visual Resource Centre Teacher every morning, all morning - a specialised teacher with the teacher aides - you could never have that in the regular classroom. We hope that the current arrangement is going to be ongoing but it's very iffy. At the moment we've borrowed a classroom from the school but the school needs it in the third term and we've got to be out of there by then. We've been given permission to build onto the Resource Centre but it's when it's going to be done, that is the problem. There are about thirty pre-schoolers (with visual impairment) and there is at least one a year coming in that will need that sort of situation. So hopefully it will be ongoing. I think Shaun doesn't realise it, but for me, it's quite unsettling. Not knowing where he's going to be. We realise how unsettling it is for the kids when that sort of thing happens. With new environments, just physical spaces, the whole thing, it does become quite an issue.

Socially, Shaun tends to isolate himself. At home here if we gave him his tape recorder and his keyboard and put him away in his room and left him there, he'd be quite happy. He would probably just listen to endless tapes interspersed with his keyboard and sit talking to himself and his 'friends'. The other children are very good to him, his peers. But he tends to turn them off. He doesn't talk the language they talk. He tends to talk a lot to imaginary friends. He wants to play imaginary games and of course ten year olds are pretty well past playing imaginary games. Shaun gets on quite well with the Juniors and the classroom he is in at the moment is situated right in the middle of the junior block. He likes the other children in the Visual Centre classroom because he's the oldest and he gets on well with them. But socially he hasn't got a wide range of friends. Shaun's academic and social level would be around about the same, about six years.

The major implication now for Shaun is the brain damage rather than the blindness. It is the brain damage that is actually stopping and hindering him from going any further. We have been discussing things at school like how we will keep braille up and whether braille is going to be Shaun's main subject because he cannot retain it, or whether we should be making more use of computer technology. He can't get past that basic level. Maths is another area he just can't retain and that is an area where you are moving on all the time in the different areas. Once you let go of basic additions, for example, and move on to multiplication Shaun's lost the basic additions, which means you can't go on any further. Generally, retention of things is really difficult. Shaun's very good at doing music and he likes music composition. We're going to have to look at other areas where we can actually get onto something to retain the music so he can bring it back. I can't write music so we're looking at maybe getting that onto computer. I think in the future that's going to be the major issue for Shaun, how far academically we can get him. So I think, when I look around at other blind children, the major implications relate to his brain damage, not the blindness. The blindness is a disadvantage obviously, but I don't think that's his greatest disadvantage now.

We're even looking at the school programme being more lifestyle based rather than academic based. It's going to take quite a bit of working through. But it's been more settled this year. Other years it's been a major disruption to him every time he's come back to start the new school year. Because you've had six weeks off and you've had to restart at scratch again. When you are looking at things like braille where you're having to go back to ... well, he's at Hungry Lambs now and he was at Hungry Lambs two or three years ago. We're looking at how to get past that, and even having to go back beyond that at the start of the school year. The disruption of being in a mainstream classroom just added to that problem.

The teacher that he has got this year is extremely good. All the Visual Resource Centre teachers are. She is particularly good in that this is the second year she has worked with him and so she knows him very well, she knows where the boundaries have to be and she sticks with them. That's for all the children in the class. It's just not for Shaun they're being put down. I've noticed the academic things over the last six months are staying very much the same. Shaun seems to have plateaued out at about the six to seven year level and we can't seem to get him past that. Even socially, he's over there now playing with a four and a five year old. That's where he's happiest. Those kids he can cope with. When he gets to his peers he doesn't talk the same language as them and they're not interested.

I think at ten we should do something now. I don't really see Shaun getting to Intermediate. I'd prefer that he stayed at Primary and then to go on to maybe a sheltered type classroom *at the High School. Primary's not going to hurt him because it's got the Visual Centre there and so he's got that very secure environment. But, I think now we've got to start looking at something. I wouldn't have liked to before this because I hoped that he might have plateaued out for a while and then gone on, but I think that we've been so long here now. We're still going to keep working through the issues involved, but I think more and more we're going to have to look at what other options there might be.*

(Leith) One of the difficulties we have is the level of understanding of Shaun's disabilities. I think most people outside don't realise. It depends how close they are. (Raewyn) When we talk about the extended family we are talking about three extended families here. Shaun's father's family have never had too much to do with him. My family have more understanding of where Shaun is at and have always been very good and very supportive. His natural family don't know how to take him. We have had lots of promises made about what they were going to do but none of it seems to come through. I make sure I get everything about Shaun in writing and when I get a report through I get a copy for them. I always get a copy of the IEPs too and I usually go and try and explain to the mother. I don't just give her the copy on its own. If any other information comes in, like where we are trying to go with school at the moment, I tell her that's what we're doing and the reasons why. But until you admit there is a problem you can't actually work through the issues. That has to be - everybody working towards the same goals for Shaun. But it is sometimes very, very hard.

There is generally an overestimation of Shaun's capabilities. Most people outside of the family get fooled by the language. (Leith) Because Shaun comes across as quite normal. It's not until you see him with his peers that you realise he's so far behind them. (Raewyn) His language is amazing and sometimes even I think, am I doing this? Am I putting this on him? I found I really had to think. So I think that those outside are fooled to a large extent. They certainly have no idea of how it is living with Shaun.

So that's what I find with people outside. I usually say, all right, Shaun's got good language, he's doing well and that's been my stock answer, "He's doing all right." But I'm finding more and more it grates to just say, oh yes, he's doing well, when I think he's not and where do we go? Is he still going to be dependent on me at forty? What are you looking ahead to now? The paediatrician wrote in the recent report that he wondered whether Shaun would reach independence and I object to that because I do believe he will. But by the same token I've also got to look at what if he doesn't? Where are we going? I try to be realistic. I think for Shaun's sake you've got to be because it's no good going off with some airy fairy ideas that he's never going to be able to achieve.

I don't think Shaun's getting entirely what he needs. Within the family he's getting what he needs - he's getting the structure, but even within that we need a lot of TDL which he's not getting. There are things I can't teach him because I don't know how to. I get very angry about that because I believe there ought to be TDL instructors to teach the children. There is a lack of personnel that know how to work with children.

O&M is a real problem. We have no O&M for our children down here now. Within a short few weeks of not having O&M Shaun loses a whole lot. When they start seeing him again they will have to start right at the beginning which means he never gets anywhere. He's never got any further than going round the block because as soon as he gets on all right they say "All right - we'll give him a rest now." And he's lost it. I had the mother of another *blind child call in the other day and ask me how she could get some O&M for her son. She said that he was doing all sorts of strange things. He's had O&M for six years and she said he's tripping over things and he won't use his cane properly. He's a child, and that's really where he's at. He needs O&M constantly. But it's just trying to get the O&Ms to come down to a child's level. Trying to make them see that they have to reward children instantly. I've said to them so often "I'll give you the money" - even if they take them down to the shop to buy something, you're doing O&M with them all that way. Then there's some purpose. And I can see for an adult, what I would call the mindless technique and learning the skills of cane would have some purpose behind it. They know the purpose because most of them have gone blind as adults and they know where they want to get to, like, to the shops, or to find their way to the toilet. For Shaun to go round and round the block and the best thing you can do is to look at the numbers on the letterboxes, was no incentive whatsoever. We have had one O&M that was really good, but they don't stay.*

Shaun's got security which is probably one of the most important things he can have but there are so many things that are lacking. I've reached a stage now that I don't know how to get beyond and somebody has to step in and take him that much further. At the moment the Visual Centre teacher is trying to do that job. It's just about impossible for her to do all the jobs that need to be done, so there are things he's not getting. I'm working through the ACC at the moment to try to see if I can get something through them but it's a case of knowing where to go to and how to tap into things.

The only way, I believe, for Shaun to get what he needs in education is for the parent to actually step in and demand, and keep on demanding until everybody is so sick of them. Very strong advocacy is the only way. Nobody else will care two hoots if the parent doesn't do it. I haven't come across one person who would actually take it on if a parent didn't. And for those whose parents are not doing it, the children are not getting it. I think it's an unfortunate situation, but that's the way it is. It's constant and so it's a heavy load for the whole family. Because the whole family become involved. I don't think that there is any other way because at the end of the day no matter how caring the professional - and I've been in this profession, as a Karitane nurse and an advocate for foster children and all sorts - they can all walk out and go home. The parent has to live with it.

What's helped me to cope has been the support of other parents that understand. The support of parents who have actually been through the system. Getting involved in other areas, the RHA, for instance, I found very enlightening. I've been able to tap into things that I never knew were there, which has made it easier. I've got big hopes for the Disability Support Sector. I've been to all the meetings and I've been on the committee for the policy for the visually impaired. I think that they are really willing to make changes, and the fact that there is going to be someone that is responsible as facilitator to see that the parent gets what they need, I think, is a big change. There's never been anybody responsible and if the Visual Centre teachers didn't take it on and make it their responsibility then nobody did.

We are working towards the girls and I being able to spend more time together at the moment. We've never been able to get Alternative Care. We don't qualify for that, or Disability Allowances, or anything else. But, I have, just in the last two or three months found that ACC can provide. The Social Welfare, to be fair, would have found another foster home. Now that was not what I needed or what Shaun needed. So in the last few months we have actually realised that we can tap into ACC and they are going to provide respite *care, probably most of the school holidays and some weekends. We are really looking forward to that. I think all parents of disabled children need a break and we had a week in the May holidays which is the first time we have actually had Shaun away for more than two nights. (Leith) We were able to go to the movies. (Raewyn) It's as simple as that. We went to the movies as a family. I hadn't been to the movies with the kids ever. We would like to spend more time together but it becomes very hard. You can't do anything off the top of your head. It's those sort of things. You've got to plan ahead so far.*

As a parent, I think the major issue has been the constancy. It actually becomes very draining. With the girls, who have always been quite independent, I could say, well, go and do this, and I could just have a few moments to myself. But with Shaun that few moments is never there because when he's here, he's demanding the whole time. I've got to continually be aware of where he is and what he's doing. It's not having any other support, I think, having to rely totally on the girls or myself for everything. I go to PVI meetings and I work at the Visual Centre. That'd be about it though. I don't do anything else. I'm too tired.

(Tania) Leith and I have got jobs on Saturday nights and even just for mum to come out and get us - there's got to be someone home. It carries on because there is so much time and effort needed to be put into Shaun. It has a big impact on how you relate to your peers too. Having to do those things a lot earlier than some of my friends changed things. I find it hard to relate to them because they're at the stage that I was a couple of years ago, so it makes it more difficult that way. People think that I'm a lot more strict or grown up than I am.

(Raewyn) There are very few people who can cope with Shaun. (Leith) It's frustrating with other people when they think he's really cute. They're not prepared to listen to what you have to say about him and then when they try to look after him or anything they get really frustrated because it's so hard. (Tania) They get angry that you didn't tell them that it was going to be this hard. (Raewyn) It doesn't bother me quite so much with the community, with those who have nothing much to do with us, but it does bother me when it comes to people like those in the Foundation. I really get hot under the collar when I get people I feel should understand and they still have those attitudes. Then everything blows up in their face and they wonder why. They are not listening. I make a very great effort when I have anybody new. I always try to get with them and talk about what they can do to stop a situation developing or how they can handle situations. I've had probably three people who have listened to me in all those dozens of people I've worked with. That really frustrates me. I feel like I should be getting support and understanding, but they actually have none.

When I say anything it is taken very personally. I've always got on very well with the people - I've not got a problem with any of them - but I do have a problem with how they are dealing with Shaun. And I'd say so. But then it comes back to me that it's become a very personal thing. To me that's just total arrogance, that they know best and I'm only the mother. In fact I've had that said to me, "We are the professionals, we know how to treat these kids." And I said, "We live with these children" - and we weren't just talking about Shaun - "I think you will find that we do know what we are talking about." Then they started talking about irrational parents and I said, "You might look at us as irrational, but if you had to live with our children you might become irrational too. And you might even become demanding of what we know", because if you're looking after that child for only two or three hours a week, then there's no way you know what's going on.

Our coping strategies centre around discussing issues ourselves because we do at times, all of us, get uptight and fed up. I tend to go to the Visual Centre a lot and discuss it with them or to Kathy at the Foundation or anybody else I think can help. So I'm very much into the mode of going off and talking to people about what I can do. I didn't use to be the type of person you would think would become a strong advocate. When I was at Karitane I was so shy that I walked home about five or six miles every day after I'd finished duty in the morning so I wouldn't have to walk into the lounge with the other girls. I was that shy. But I guess it started before Shaun. It started with the foster children, or even before that with the baby sitting where there were just dreadful conditions. I suppose it's been really a case of having to. If I didn't do it nobody else was going to. So if I didn't go out and read up books and find out where to get to, or how to do things, then nobody else was going to help me.

(Leith) Within the family we have always talked about things. We all have talked with each other so we know what is going on and there have never been any secrets within the family. My youngest sister and I get on really well so we talk quite a bit about what's going on. Probably Tania and I don't talk as much because we're too much alike. In our family, our strengths are each other and the biggest is our belief in God. (Tania) I've been lucky - I've got music so I can get time out. I'm in countless bands, orchestras and choirs and things like that. I play the clarinet and tuba.

(Leith) There have been positives for us too. I'm teaching Sunday School and Shaun's in my class. I've had to learn to work around him. And I'm working with other blind kids, and kids with disabilities, so I've had a lot to do with them. I help out with homework and practice. It is different working with blind kids. (Tania) I do Shaun's music practice with him. I can sometimes get by playing the piano, so I help him out doing that. (Raewyn) There have been a lot of positives. We have really enjoyed Shaun over the years and he has changed our lives a lot. We've got into things that we'd never have got into. Leith's got into Alternative Care with very disabled children and is thoroughly enjoying it. She's going school teaching which she may never have looked at. Certainly she's had to develop an awful lot of skills. Tania's become very good with Shaun. She'll take him out to town for the day and that's something he does enjoy. He'll go off with her and it's the one place I can leave him and know he's okay.

A number of support networks and service systems have been available to us. One has been family. In Invercargill when I was living down there my family would babysit for me. There was support in the fact that I could go and talk with them. They were there - that was the thing. They may not have understood but they were willing to listen and I think that was the main thing. There used to be neighbours too when I was in Invercargill. My neighbour was great and in fact we used to swap babysitting. I would have her children and she would have mine. That was in the early days when Shaun was a pre-schooler. It was great because I would never have been able to leave him otherwise. In the early days I think it was the blindness used to scare people off. They just didn't know what to do. Now it's the behaviour problem. People have no idea of how to react. Nowadays I don't have that support from neighbours. Shaun will go to the neighbour but she really has nothing to do with me because I go to work all day and she works at nights.

Friends are great, and the Church - I couldn't have done without that. The Church has just been there. They may not have understood but they were there. They're even willing to take Shaun if I really felt it was necessary. I know a lot of them couldn't cope with it, but they *would be willing to do it. Again, the Visual Centre here has been a lifeline. They're doing a very, very good job. They understand Shaun's needs very well, I believe, and I spend a lot time talking with them which has been marvellous.*

The health system has only been of value in that it has assessed Shaun and I've got a report. I've had a fact in my hand when I've gone to do something else. The Welfare System has been, in this instance, for Shaun and myself - and it doesn't apply to everybody because I have heard of others that have had fantastic support from them - absolutely no support. The social worker that he has now he has had for four or five years. She would probably have seen him about three times. She certainly has not seen him at all in the last two or three years. Now there is a reason for that. She says there is no reason for her to get to know Shaun because he doesn't need another person in his life and I can understand that, but the only contact I have with her - and remember who the agent is for the guardian - is if I have an account for her to pay, or if I have a problem that needs to be addressed with his natural family. There is no support there otherwise.

I first started going to PVI because I believed very strongly that if parents meet together they come to understand that their situation is not unique. I was in a foster care support group before I had children and the big thing I found there was that parents all thought they and their situation were unique. And nine times out of ten, it isn't unique. Other parents, even though their children mightn't have the same disability, have the same end result in view and by meeting together and actually understanding that there are other parents out there who understand you, it just made it easier to manage. You didn't feel like you were on your own all the time. That's what actually brought me into PVI. I do believe that if a lot more parents got motivated and got to know other parents they would find that their situations weren't unique. Lots of things can be talked out and there are things to be learnt from the ways other people who have gone ahead of you have done things. Most of the people you come across don't have any understanding of what you're going through. In my normal every day life I would never meet up with any other blind child or any other brain damaged child for that matter. It's only when you seek them out that you realise that there are shared experiences.

Earlier, when Shaun was smaller, because I had been a Karitane nurse and knew where I wanted to go, I spent some of my time helping out other mothers. Most of them had no child care basis to start with. You don't have any child care training before you have a child so you are trying to work through those things, let alone with a disabled child. There was no Early Intervention or anything like that. It's extremely hard and you become very isolated. So I think the main function is to get those parents talking together and getting them out of their isolation. PVI, the National Committee, is becoming more political and to a large extent I see that as its role if our kids are going to survive. Changes have to be made.

The vision for this family is that they'll all become independent and do their own thing. I just want my kids to be successful in whatever they do. To be able to be good, independent people that can be self-sufficient and have the resources and the strength to do it. And that includes Shaun.

From now on it's out of the realm that I've ever worked in. I'm at the stage now where I guess a lot of parents are at the beginning. Not knowing where to go and not knowing how to get Shaun from here to where I see his next step is. I don't really know what to draw on.

I don't see the resources there to help me. Maybe I'll have to look at them myself but I don't have the time or the skills there to do it. I haven't got the amount of time I need in a week now and because I'm on the DPB (Domestic Purposes Benefit) I'm having to do more and more just to keep the family going. I'm hoping to start at Training College in July and that will cut down my time even more. But, for myself, I need to do it simply because I need some training behind me. It's not going to help Shaun in the short term and it's what I do with him in the meantime that worries me. But there aren't the resources there to call on.

Policy makers I think just have no concept whatsoever. They talk in riddles. They talk in paper, in theory, and they just have no notion whatsoever of what their policies are actually doing to parents and to children. They have become very much removed. The thing I am looking at the moment, and I don't know whether it will come in Shaun's time, is the National Body. The National Education Body where we may be able to employ or contract our own O&Ms, our own TDLs, our own living skills people maybe, or whoever is needed. I see the places like the Visual Centre being able to contract in the services and then putting them out to children through the IEPs. We can't do it now under the law. The Act doesn't allow for it. At one stage when I first started going into this I thought that we would have it in place but now after seeing the Ministry recently I doubt it very much. It wasn't negative, but they're looking at maybe the end of next year before coming back with any sort of policy whatsoever on Special Ed. There's a feasibility study being done by SES (Special Education Service). Now I'm asking how can SES do a study on vision when they have no expertise? And even when that's done they're looking at maybe having some sort of policy in place by the year 2000. But that's not to say that it's actually going to go ahead then. That's just to say that the policy will be in place so that they can look to go ahead. When I really started thinking about it I thought it might benefit the next generation if they ever get their act together but I don't think it's going to do any good for Shaun. Not that I will stop fighting for it. I think it's important. But it worries me - where do I now take Shaun? Where do I get those resources? What is the future for him because so much of his future depends on what we can get pushed into that head of his now.

The Foundation don't know our children and they're backing off. That's fine, but if they are going to back off then somebody has to pick it up. All of our children are in the education system somewhere, either connected with Homai or in a Visual Centre, so that's the place for those things, Braille, O&M, TDL - those are educational things. They are as much a part of their education as maths. When these skills are denied to the children then they're being denied the world. Sometimes you go from one Act to the other Act, and it seems like whichever which way you turn it's always put in front of you, "Well we can't under our Act." It seems to be the stock answer to everything. No one would take responsibility for O&M - not ACC (Accident Rehabilitation and Compensation Insurance Corporation), not Education. You know, if that's not part of Shaun's education, what is? If he can't get from one place to another then what's the point of all the rest of it? We made very strong representation to the RHA (Regional Health Authority) because O&M was one thing that was falling down and that needed to be provided and they did actually pick it up and run with it in their Draft Policy Document. But how much clout that will ever have and whether they will try and push that across to Education, I don't know. But there are so many issues where, the moment it looks like it's going to cost anybody any money, they just say, "Well it's not ours."

I think most parents are reasonably realistic about where they are going for their kids and if they have a good teacher going with them, or if the teacher can get the parent on board, then a lot of things can happen. Blind children are one sector of the disability community that can actually become perfectly good tax paying members of society. Given the right resources they can hold down a job, a normal job, and pay their way. There's a big wide world out there and Shaun's got to live in it.

FAMILY PROFILE

Child: **Shaun**

Age: 10 years

Sex: Male

Visual condition: Result of neurological impairment
Onset at 9 months
Light perception
Tactual mode of communication

Other conditions: Neurological impairment

Educational placement: Class within Regional Visual Resource Centre with partial mainstreaming at base school

Parent: **Raewyn**

Age: 45

Marital/Parental situation: Separated
Shaun entered the family at 13 months as a foster child
Contact is maintained both with his foster father and his birth mother and her family

Vocations: Teacher aide working with children with visual impairment
In July commenced teacher training at College of Education

Siblings:	**Leith**	**Tania**	**Marianne**
Ages:	17 years;	16 years;	15 years
Sex:	Female;	Female;	Female

Family

Time in present community: 1 year

Most important to family: Christianity, close family life

Effective support systems: Kindergarten, Visual Centre, PVI

'Gift' to other families: "Don't excuse behaviours because the child is visually impaired. Sometimes you have to be (or seem to be) cruel to be kind. Visually impaired children need endless input - things don't 'just happen' for them."

NUULELEI'S FAMILY

Narrated by Nuulelei, Katarina, Tafale, Feanu & Tinoa

In thinking about Pacific Island people the difficulty is that they don't come forward with their problems. I think they try to solve their problems themselves. They are sort of shy to tell some other people because they think they might think that they are the cause of their visually impaired children. So there's not many of them that come forward. Sometimes it's because maybe they don't know that there is help for them from the Foundation. And sometimes it's because people have a colour bar - they don't treat them the same.

Nuu

My name is Nuulelei. I go to Intermediate School and I am 12 years old. I have a visual impairment. At school I am able to see some of the things in the classroom. If the writing on the blackboard is big and in white chalk I am able to read it. Otherwise it is too hard. I have got a magnifier for reading books. I'm okay moving about outside unless there are steps. They are hard to see. If I'm in a place I know then it's okay but if it's a strange place then I need to be careful. I get teased a lot at school. I don't like that.

The eye specialist and doctors are helpful and explain things but I find it hard to ask questions. It's embarrassing. Once a teacher (itinerant teacher for learners with visual impairment) came to my school to check out how I see. We went to a special place. She had those little cards with pictures on and stood miles away and I blocked one eye. Then she visited the classroom to look at where I was sitting and if the lighting was okay. That was helpful.

In the future I would like to be a musician. I like playing the instruments and would like to be in a band. Drumming is best - I like to do drumming. I guess I'll have to work hard.

Katarina & Tafale: Sisters

(Told by Katarina)

I am Katarina. I am 15 and I go to College. My sister, Tafale, is eight years old and she goes to Primary School. I like being with my friends. Me and my friends we just hang round and do anything.

With Nuu I sometimes truly think he takes advantage of his disability. Like, you know, a person with a disability should strive to improve. But at home he acts like it's really worse so that he doesn't get to do all the chores and things. He should try. I mean, like, you have a disability and you try to be normal so people won't tease you, but I think Nuu takes advantage of it. It's always back to his eye. I really think his eye is normal, it's just the way it's facing.

We were talking about how Nuu has to feel for things. When my parents are out of the house and his watch drops or something he just goes and picks it up and when my parents are here he goes "Oh, where is it?" I think Nuu can do more of the things like I do. Not in every way, but you know, washing the dishes or something - he can wash them clean when he feels like it.

Sometimes we argue. If you ask me I don't think it's got anything to do with his disability. I think it's just normal. When I go to school with my friends we always get together to relate our story about family and everything. And they tell me stories about how they fight their brothers. I think it's just normal.

For the future, I'm not sure, but I would like to travel. I enjoy travelling. And I would like to get a business or something, but I'd hate being stuck inside.

Feanu & Tinoa: Parents

(Told by Feanu)

We are Feanu and Tinoa, the mother and father of the family. I work as a teacher aide at the Intermediate School, the same school as Nuu goes to. I work with other students, not with Nuu.

I think the most important thing in our family is our religion and our customs - that we have to stick with it. We show this in our surroundings (referring to garlanded portraits of ancestors on the walls of the room) and the environment inside our family, and between us as a family and other people in the community, or our other relatives. As an example we don't let our kids speak in English in our family. They can only speak in English when they go to school. When they come home I tell them to speak in our own language so that they won't lose it - so that when they grow up they still have our own language. Then when they go back home sometime to Samoa they can talk to our people there and understand what's going on. It is also my own belief that if you can read or speak properly in your own tongue language it will be easier for you to learn other languages. I think it teaches them how to respect other people. They can learn other second cultures.

The Church is important to our family. I do believe in God and His grace. We have to teach the children when they are young. As they grow up they will follow our steps. Because we know, these days, lots of street kids and they don't go to church. So they start from the beginning. We have prayer every evening and go to church and read the Bible. I try to teach them to memorise some of the verses in the Bible. 'Cause that's how I was brought up.

Thinking about our family, when Nuu, our vision impaired son, was born we were really lucky that we didn't have to go and look for help or assistance because from the day he was born he was registered with the Crippled Children's Society by the doctor that was delivering him. She was a lady doctor and she was also a paediatrician. She also referred him to the vision impaired social worker. So he was getting the handicapped allowance from the day he was born and every sort of assistance that we got we didn't have to go and look for.

Nuu had problems before he was born. When I was eight months pregnant they found out that there was too much water inside so the doctors tried to reduce some of it by giving injections and taking out the water but it still came back again. I didn't have pain and when it was my nine months they advised me to come to the clinic. I stayed there for two weeks before the birth. When I was in labour they said that I had to have a caesarian because his head was a bit bigger and sort of soft. So I had a caesarian with him. About two days after he was born they took him to another hospital. They found out that he had cerebral palsy and the doctor said that the fluid inside his brain was not flowing properly - it was sort of blocked somewhere. So he was going to have an operation. But as we got there the brain specialist did another test - an EEG (electroencephalogram) - and he found out that it was not good to have an operation. He said to leave it because as Nuu grows up it might get better itself. He had to measure his head every three months to see that it had stopped growing. But as Nuu grew up he was sort of floppy. He was taken to many physiotherapists and he was taken to the home at North Shore - Wilson Home.

I stayed with Nuu 'cause they wanted him to live there by himself but I said, no, I can't leave him by himself. They had to find a house there for me to live in so we stayed in the house with two other parents. We stayed there for two months.

It was hard. Nuu was about eight months or so but he was taken nearly every week to the physiotherapist at the centre. When we came back from there he was still floppy so the physiotherapist came to home and did exercises with him every day. And even the speech therapist, they always came and tried too. When he was two years old he was still floppy and couldn't walk. He could talk but couldn't walk properly. So with the help of the physiotherapist, and all that, he started to walk. He was nearly three then.

Nuu had problems with his ears as well - he got tubes put in his ears. He had all sorts of problems. The doctors told us that he was going to have fits sometimes as he grew and we had to be aware of that. That only happened once. That was in 1988.

Nuu's vision seems not changed. It is stable. If he drops something or if you ask him to pick up something he always sort of feels with his hands or feet instead of looking direct with his eyes. He did that when he was taken to Homai College. Homai College was his first pre-school. He was about two years old when he started and the taxi picked him up and dropped him home. The early childhood social worker arranged that. Nuu still had his problems.

He had an operation for his eye - to straighten it but not to change his vision. The doctor says that his vision won't be changed at all and glasses are no good either. So the reason he had an operation is for appearance. His vision is 12 point something.

It was hard when all this was happening because we had to take Nuu to the hospital nearly every day. But Tinoa was good to support us because he stayed home with Katarina and I went to the hospital with Nuu. It was sort of difficult at first because she had to have someone to look after her while Tinoa went to work too. And I couldn't work either, I had to be with him.

It was helpful that Nuu was registered with the Crippled Children's Society because they could get us a lift and take us to our appointment and that didn't interrupt Tinoa while he was going to work. We only have one car so if he uses it for work we get support from the Crippled Children's Society to help us get a lift. Back and forwards to the hospital - every week he has appointments to go to the hospital. It's either one hospital or the other.

We got support from our relatives. Our family was grateful for their help. They live close by. And the services were good. The paediatrician was very good. I think she was there when I was in labour and she did all the referring to the Crippled Children's Society and to the Social Welfare for the family allowances. There was good networking. I was just lucky that those good people were doing it from the beginning because from what I hear now some parents are struggling. The eye specialists were good too.

With Nuu's education he went to Homai College from when he was two years old until he was about seven or eight. I pulled him out of there then. The Homai bus picked him up and dropped him home each day. One day the bus missed him - they forgot to pick him up but he wanted to go, so he asked us to drop him to school that morning. So we went and dropped him off at Homai. When we got there the class was having reading and the teacher *told Nuu to look for a seat to sit down. Nuu's vision impaired but not that bad. Some people don't recognise that he's vision impaired and he looks like a normal boy. So what he did next was something I didn't like and the reason I pulled him out then. He was acting like a blind person. He was closing his eyes and feeling the chair - finding the chair by touching. I expected him to be better while he was there - to use his vision. He's not blind, he's just vision impaired. So I said to the teacher, "Excuse me, why is he doing that, does he always do that every day in here?" She said, "Oh yes." I said, "Why?" "Oh, he's only copying other blind children." I said, "Oh well, that's it. I don't like that." The reason why I bring him here is to teach him to be independent so that he can stand on his own and use his vision. But what I see now he's getting worse. No wonder when he comes home he always crawls and feels like this when he looks for something. So after that day I didn't take him back.*

I took him to a normal school. I tried the local school and I'm glad that the headmaster accepted him. The itinerant teacher from Homai visited him at this school and now comes to the intermediate. I still ring them and ask them if someone can visit. I asked someone to come because they could tell the teacher about Nuu. After she came and visited the school, his class teacher from intermediate went to Homai for a course and when she came back she was crying and talked to me and said "Thankyou Feanu, I just recognised now how bad it is for (people with) impaired vision like Nuu." She just learned in the course that it is hard to put yourself in the position of the visually impaired. She didn't realise it before and she said she was too hard on Nuu. But she cried that day because she felt sorry for what she was doing. She said, "Oh, I know now that it is hard for a visually impaired child." So she's trying her best to do everything - to enlarge the homework sheet and all that, and the tests. So that's one good reason for an itinerant teacher to come.

It's hard when there's just one child with vision impairment in the class because there's not much time to take just one child and to understand. That's why it's hard for me to decide for Nuu's next school. I know in our area, there's hardly any vision impaired kids and so that's why I think I will take him to Manurewa High School (where there is a Visual Resource Room). I am going to visit. The itinerant teacher can take me around to different schools. I've been talking to the parents in our meeting last week at the RNZFB open day at Parnell. They suggested Manurewa High was the best for him because they have all the resources and there are about twenty vision impaired students. He can have the same sort of friends instead of having just normal ones. He would have both and he won't be teased a lot. There won't be a problem with his transport either. We'll arrange for transport to take him to school and bring him back.

I think differently to Katarina about Nuu's vision. It is because the specialist told me that he can't improve his vision. We don't talk about it with him. We have to help Nuu with things. But I do think in some things that he could improve if he tried. With our family - our relatives - when they come here or we go to their places and they hear me talking to Nuu the way I like him to be, they always say "Oh, don't do that, he's sick, he's ..." I say "Don't tell him that because he relies on that and that makes him worse." He thinks that if he mentions his eyes he won't be told to do that and that. That's why sometimes when my relatives ask me if they can take him I say no, because I know that they spoil him and it doesn't do him any good.

A big problem for us now is how to get the children working together. It's not such a big problem that I need help from outside, but it's between them. Trying to get them to work together. Arguing and fighting, it's a problem now and I'm still thinking to myself that I can ask the adviser or specialist. I don't know whether it's because we have a disability in our family - because the two girls work together - whether it's because of the difference like being a boy and a girl, or because Nuu's vision impaired.

Our main vision is, and I think it is the same for any parents, that our children grow up healthy, and have a better education and get jobs so they can be independent and look after themselves in the future. We're trying our best to support them with their education. We want a good life for the future and we work hard to get something for our kids, to get them off to school.

In thinking about Pacific Island people the difficulty is that they don't come forward with their problems. I think they try to solve their problems themselves. They are sort of shy to tell some other people because they think they might think that they are the cause of their visually impaired children. So there's not many of them that come forward. Sometimes it's because maybe they don't know that there is help for them from the Foundation.

And sometimes it's because people have a colour bar - they don't treat them the same. Right now I heard about the difficulty some parents have getting benefits. They can't just go to their doctor, they have to go through a specialist and all that. But I didn't have that problem with Nuu - I told them that he got everything from the beginning. But they don't treat all the people the same and the process is hard. Some people who work there they just sort of look after their friends and all that. It makes it harder for some people. They should treat all the people the same - not bring their personal feelings about people. Leave their personal feelings at home and then when they come to work, treat it as business. The consumers they sort of expect more - needing more than what they get. Or not understanding the process.

For our own family I think we all have to work together and try to achieve our goal for the future by respecting one another. Also respecting other people's feelings. Our kids behaviour should be respectful of other neighbours and not just inside our family but outside, in the schools because, that's what we teach them. Not just to behave in front of us but to respect the teachers and neighbours and our extended family.

FAMILY PROFILE

Child: **Nuulelei**

Age: 12 years

Sex: Male

Visual condition: Optic Atrophy, Nystagmus
Congenital
Visual impairment diagnosed at birth by doctor
Low vision
Visual (print) mode of communication

Other conditions: Cerebral palsy

Educational placement: Local Intermediate School

Parents: **Feanu & Tinoa**

Ages: 47 & 48

Marital/Parental situation: Married

Vocations: Teacher Aide; Process Worker
Towards the end of the study Feanu started a full time Nannying Course

Siblings:	**Katarina**	**Tafale**
Ages:	16 years;	8 years
Sex:	Female;	Female

Family:

Time in present community: 9 years

Most important to family: Children's education, Religion

Effective support systems: CCS (Crippled Children's Society)

'Gift' to other families: "Be patient with your child and try to understand by putting yourself in their place. Try to treat the same as the other children."

TONI'S FAMILY

Narrated by Alison, Daniel, Toni, Rebecca, Annemarie & Sarah

The best way to ensure that Toni gets what she needs in education and other areas of life is to bang on the desk. You don't have a choice. If you've got a child with special needs ...you have to advocate for them or your child gets nothing. And I know of some parents who either don't have the skills, or don't do it for whatever reason and their kids miss out.

There are six people in our family. Myself, Alison, Daniel, and our girls, Rebecca, Toni, Annemarie and Sarah.

Toni

I'm Toni and I'm a visually impaired person. I enjoy watching TV, movies and going on trips away. I liked the holiday we had in Australia. My friend Jane has a bach up at Te Anau. I stay with her sometimes. I have a lot of friends. I enjoy doing things with them like going to the movies or them coming round home here. I also belong to theatre sports. I like people and talking. In growing up what I think is important is just to be yourself.

I don't know that much about my eye condition. I've got coloboma in both eyes. And in the left eye the optic nerve is not connected. The whole bottom half of my left eye does not work and parts of things are missing. My right eye is not as bad. Everything from eye level down is seen okay but eye level up is black and in the left eye there's nothing. It's hard really to explain because I have nothing to compare it to. I just see people and I know what they look like from my whole life and I don't really know any other way to say it because I've never ever known any other way. I'm taking part in a study about coloboma. There's a guy doing research into it at Otago. I got a letter through the post.

In class it depends on how far away I am sitting from the blackboard as to what I can see. I usually sit up the very front of the class, or near to it, and it's no problem if on the blackboard it's yellow chalk and on the whiteboard it's black marker. But if it's blue or red on a sunny day it's very hard to see. If I'm sitting back further I can't even see black or white - it's very hard especially if the teachers write small.

My vision is really affected by glare. It gets better and worse just with different conditions. At one school it was light with all windows and that was very hard. When I went to one school they learnt to close the windows and shut the blinds. In the very beginning I had to have a CCTV and then I went down just to a magnifier. I'm getting a lot better and I can even read some things without my magnifier. I go to the Low Vision Clinic.

When I first came to New Zealand I wore glasses and nobody seemed to care. At two schools I went to I got a bit of teasing but that's only because I was new I think. But when I went to Intermediate I got more friends and people realised that I was just normal. Now I'm at High School nobody even cares and the people that do say anything get screamed at by everyone else. It's just that when I first fought back, other people started and then people realised that it's not worth it any more and that I'm no different really, at all.

Looking back, the teasing was hard to deal with at first. I was wanting to actually ask mum for someone to come and help at school. Annemarie had the Deaf Foundation and the Crippled Children's Foundation to help her and I was very upset because she didn't get teased any more after those persons had come and talked to her class. So I asked if there was anything and mum said there was the Foundation for the Blind and so that's how I got involved. They came and it was helpful. The first time there was an O&M instructor and she was very good. She took me around and taught about traffic, how to reach for drinks, and other things you need to know. She came to my class and talked to my classmates and *had these wee goggle things. After that I got lots more friends. They started talking to me and asking things and I didn't mind because they were talking to me, not about me.*

I'm beginning to take more responsibility for decision making. I don't have mum and dad telling me things, like reminding me to do my homework, all the time. I get by. It's not really major decisions that I've needed to make but I'm taking part in my own IEPs now - the meetings we've had at school with all the teachers. I get a chance to tell my teachers about my needs. Like, my Japanese teacher doesn't really seem to understand. Every single lesson I remind him that I cannot read the book and I need a large copy and he goes, "Yes, yes", and he hands the rest out and he forgets. Then the next session he hands them out again and at the IEP he said, "Oh, there's no problems really, I don't think Toni has anything." And yea, I just get a chance to say.

There are some things that happen that are not helpful. One day the science teacher was writing on the overhead projector, and I can't read overhead projectors, and my friend who helps me at school was reading me out what he was writing. He said, "Oh, shut up Jane, everybody can read here." And he looks at me and goes, "Oh, no we can't. Sorry." And then he spent the next five minutes just changing feet to try and get himself out of it. I just sat there looking at him over the top of my fingers.

At school the most important things I need would have to be a photocopier that can enlarge things very well to the right size, and my friend, Jane. Some things are too small to start off with and can't be blown up to the right size, and in that case I need her to help me with that stuff. Also I'd like teachers that actually know what they are doing. But there are some teachers who know to shut the curtains or use the right coloured felt and get the stuff for me beforehand so I don't have tests half an hour later.

I'm able to speak up about my needs at school now - probably since about the third form. It's just that some teachers don't want to hear it when I do. And if they don't, I make them because I don't find it very fair that if somebody couldn't see because the curtains are open that the teacher shouldn't close them. I don't see why my stuff shouldn't be enlarged or the proper chalk put on the board. I mean, they'd speak louder for a deaf person so I don't see there's much difference.

Sometimes there are difficulties with relievers. There was one reliever and he was saying to put safety glasses on because even if you lose just one of your eyes you can't do anything - you can't drive a car, you can't ride a bike, you can't have a life, you can't do anything. He didn't believe I couldn't see properly and said that I would definitely not be in this room if I couldn't. My friends really got into him and he believed me then, still I had to go to the principal and the reliever does not go there any more.

(Alison) There seems to be no way of the schools telling the relievers that come in about the needs of students. In Australia they used to have big rolls, at primary school anyway. In the front of the roll would be, say, any children who suffered from asthma or whatever and the teacher, as they marked the roll, had this there to refer to.

(Toni) When I have relievers at school they just don't do anything and so I do nothing for the period. I get the notes from somebody else later on in the week. I go up to the teacher if she's handing some worksheet - we usually have worksheets to do because the teachers we

have don't always do the subject they're relieving for - but I say, do you have an enlarged one for me? And they go, "Oh no, should I have?" and they said, "Well we have nothing about it on the roll so I'll have to check it out with another teacher after." So I don't get it done and it is seen as my fault and I have to catch up later on.

Then there are things like when I was doing the typing module. I couldn't read any of the typing I did but I could see the keys no worries. I was just typing away but my proof reading was useless because I could not read what I had written and I got a really, really, bad mark for proof reading. The teacher didn't seem to notice that. She knew to put me up the front of the class and she blew up all my stuff but she did not realise about everything, like the proof reading.

(Alison) There were a couple of years that were very unsettled and very difficult. About the time they were moving up towards standard four from the larger print to the smaller print Toni went through a really difficult period. She thought she was actually losing her sight because she couldn't see any more. We went through a stage where they were querying hysterical blindness and it was basically that, although there was a slight change in her sight, mostly it was the move towards more blackboard work and that sort of thing.

(Toni) It was complicated because I'd moved from a school that had just started accepting that I was there, and understanding, to a school where no one knew anything about it. So it was very hard. It wasn't hard at all getting new friends because the teacher who was there the first year, Form 1, made me stand up in front of the class and talk about myself. I didn't feel very comfortable about that. From that people did not understand anything because he asked all these stupid questions that didn't help at all. Like, "What is that thing that you read your stuff with?" That didn't mean anything. But later on in the year we had speech competitions and I did it on myself. I was asked to represent the class in assembly - but I decided not to. But that made people more aware in my class at least. That wasn't too bad.

Because my eye condition is noticeable, it's not all that bad. My friend's got cancer and she's bald. And a small boy came up, tore off her hat and felt really, really bad about it. But with me they know where they stand - they avoid talking about it to me. They hardly ever bring it up, but if I do, they don't want to talk about it. But my special friends like Christine and Jane and Ruth, they don't mind. They're really nice about it because they've known me for a long time.

I don't like it when other people ask my older sister about me. I just don't think there's any need for them to know because it's not going to affect them in any way if they do or don't know. If they really want to know I don't see why they couldn't just ask me. But they don't think to ask me. It'd be a lot better than getting it from someone second hand, from someone who wouldn't know, and might be saying things that are not exactly true.

When I got my contacts there was this fifth form boy who kinda liked me and he looked at me and he goes, "Oh, you've fixed your eyes." I said, "Excuse me, I don't know what you're talking about." And he goes, "Oh you used to have funny looking eyes." I said, "No, you must be talking about my twin sister." And he goes, "Oh do you have a twin sister?" "Yes, yes, she's in the third form and just like me but she's not as brainy as me, you know." It was quite funny. We had him walking around and he goes, "Where's your sister today?" I don't know. It was really funny.

I have had some contact with other young people who are visually impaired. We used to do lots and lots of things with a guy who's my own age and their brother, and there's another person too. We all got together sometimes and did lots of fun activities, like go down to the Police Station or to the pool and it was really good. But we haven't been doing much since I've been to High School. I've had things on. There's only one other wee girl who's got coloboma.

(Alison) I would have to say that there is a lot of anger sometimes inside Toni, frustration and anger that comes out. Sometimes she might have had a really bad day - someone might have teased her - and she comes home and she's really frustrated and angry.

(Toni) Well, usually at the beginning of my life not very many people really cared enough to listen. And so I've learnt just to keep it in. That's what I've always done. (Alison) We could always tell when Toni would come home really pent up and angry and you'd say, "What's the matter?" "Nothing." And she wouldn't say and it might go on for a week or two until in her own mind she'd sort out her own answer. And then she'd get back on track again. But even from the time she was a little toddler, she would never share, or say, this is what's happening for me and I'm really angry, just leave me alone. So we could never say, or give her a cuddle. You just knew it was happening.

(Toni) I can talk to my friends now. I don't know why, but family is a bit different. My friends, when I first came over here, were not too smart. I'm not being rude or anything. My friend, Jane is in my class now which is the top band and she knows how I'm feeling and she can understand. She's known me for a long time since Form 1 and she's very good because she knows about parents and things.

Rebecca, Annemarie & Sarah: Sisters

Sarah

I'm Sarah. I'm the youngest and I like sports. Being together is important to our family. We went ice skating the other week. Sometimes it's been annoying because Toni throws a psych when she doesn't know where things are. She kind of takes it out on you and she gets things wrong sometimes. It's hard because she's bigger than you are.

Annemarie

I'm Annemarie and I like sports too. I like day trips. We take day trips every so often. We went up to Gore to the ice skating but we also go to Te Anau. We went to a Venturers meeting. I think it is important to be honest and I think that education is important.

Rebecca

I'm Rebecca. I remember one time when I wasn't wearing school uniform and I was at school with Toni. Some people tormented her. It was the only time though. And sometimes I used to get asked if that blind person was my sister.

Mum goes away a lot, sometimes to places for Toni or sometimes Annemarie. It isn't that bad, it's just that she's not here. She's away with committees and stuff. Or else when we go away somewhere, sometimes mum and dad get all freaked out because Toni does something dangerous like try and jump off a castle because she doesn't know how far away the ground is. It's frightening but it's also funny because mum and dad are nearly freaking out. Toni climbed over the top part of Larnach's Castle. She said she was just leaning over the edge to see how far down it was. Mum grabbed her. Dad had a camera around his wrist and it hit her in the head when he tried to grab her. She said for ages that Dad hit her in the head with a camera.

Another time Toni tried to crawl off Mt Buller. It was a ski resort. We walked off up in the summer with a whole lot of friends and it was a 200 foot drop below the chalet and Toni climbed out over it to see. She was about four and when mum's friend came back it took us about half an hour to calm her.

People ask about Toni and she gets freaked out when you try to tell any of your friends about it. Most people though are just curious - they don't mean anything. I don't know everything. I just say that she doesn't see very well and if they want to know any more to ask her. But she doesn't say anything anyway. I don't see any problem with it. I only tell them the stuff that I know. I don't say, "Oh, she sees this, and when she looks at this, it looks different." I don't know that.

Alison & Daniel: Parents

As a family we enjoy doing things together, going on picnics and that sort of thing. I guess eventually we'd like to have four responsible adults. We've tried, as the children have grown up, to teach them about right and wrong. That sort of thing. Whatever they choose to do is fine, but hopefully they'll be responsible.

Daniel and I tend to stress the education side of things. We try to get through to them the importance of getting a good education, something behind them. I guess we're never going to be really wealthy and so we figured when the kids were all little that the best we could possibly give them was a good education which would provide a solid base to make their own future from. And so most things go into that.

With Toni, bullying and teasing have undermined her confidence over the years. Around the house there are not a lot of implications other than being aware of her needs. Things like positioning the television so that there's no direct glare onto it, and being prepared. Toni very rarely opens the curtains in her room. Her room remains dark. When we have a lovely sunny day we are used to saying to the kids, "Quick outside, it's a lovely day", and this one comes back inside. But other than allowances where it was necessary for her safety, Toni's basically been just brought up exactly the same as the others. So other than allowing for glasses, and now contacts, at home there hasn't been much.

Daniel prides himself on being the first one to notice Toni's visual impairment. He actually got to cuddle her first. After she was born they put her on my tummy and once the cord had been cut they wrapped her up and handed her to Daniel while they stitched me up.
(Daniel) Now, I noticed it immediately she opened her eyes. In the days following, Toni had

conjunctivitis, she slept a lot, and in the hospital they didn't want to wake her. So they just kept saying, "It's just conjunctivitis don't worry about it", and very few people saw her with her eyes open. (Alison) Daniel kept saying, "It's not the infection, it's the eyes." Eventually they had a look, and at the postnatal check it hadn't gone away. The GP expressed concern and went away and rang someone on the spot to say, "I've got this child with these funny eyes," and they must have said, it's coloboma, because he came back with it written down and showed me. Then we saw an eye doctor and he explained that it was coloboma.

The eye doctor was rather rude and he was rough. They put Toni under an anaesthetic at eight months old to keep her still and just to see the extent of the damage in the eyes. We afterwards found out that there was no need for them to have done that. The doctor basically came out of there and said that she was blind in one eye, half blind in the other, she'd probably have to go to a special school, and that there was nothing we could do till she was five. Then he went away again and Daniel came in to pick us up. We were told to come back in a week and we were allowed three minutes to ask everything we wanted to know. We went away and I thought, there's got to be something we can do in that long time and I rang the RVIB - Royal Victorian Institute for the Blind. They had someone like Homai's Early Childhood Adviser. They sent someone out within the next week who said that there was heaps we could do and recommended a second opinion. That's when we went to Dr McLeod. Toni was about eight months old at the time and he was really good. He was the head of the congenital abnormalities section at the Royal Victorian Eye and Ear Hospital. He was a Scottish bloke and he had all these little wee children, and he looked after his wee children, and his wee children loved him to pieces. He used to give them smarties and all sorts of bribery and he was really good. He said that there was lots we could do and we just stuck with him until we came here. But that's about it - it was noticed at birth. Daniel picked it up first.

Because we've grown up with Toni we accept the way she looks. It's not normal if you've never seen it. The number of people that have come up in supermarkets and gone "Aahh", grabbed her and pulled her and said, "What's wrong with your eyes?" is unbelievable. I wouldn't have a clue whether Toni's condition is understood by the extended family. We don't have anyone that interested. They know she doesn't see and that she needs enlarged print. When we initially found out, the first thing Daniel's mother said, was, "It wasn't from our side of the family." And that was the first thing my mother said too. Daniel's father basically said to put her away somewhere where no one would notice. Then they just got to accept it.

There is really not much known about coloboma. We were told originally it was genetic and then they said they were not sure. Daniel's convinced it's to do with pesticides because we were living in a rural area and they sprayed at about the time I got pregnant. But when we first came over to New Zealand the ophthalmologists down here had never seen a coloboma kid and now there's four. So I wonder if it's on the increase.

(Daniel) Having an accurate diagnosis was the first major issue for us. We had a lot of trouble with figuring out what exactly the problem was. But once we got onto Dr McLeod that was good. Toni was pre-school then and he went right through with her until we came over here. Next after that was getting the appropriate considerations at school. The appropriate facilities. And first finding out exactly what they were. Alison did most of that really. It was just a matter of figuring out what. We had advisers and once we understood

that the glare would be a problem for her and that she needed to have slightly larger text - although that one didn't matter until later - then it was a case of educating the teachers and making sure that they would make allowances. Other than that there have been a few positive things too. Toni has had access to some very good services and she has had a lot of fun with friends - with other people who have had visual impairments - as a result. Skiing and various other things.

(Alison) In a way you tend to move with people that accept the disabilities, not just Toni's sort, the others as well. If you meet up with friends who are uncomfortable you tend to move away where you do not have as much to do with them. It was hard coming over here too. Some of our first contacts were linked to the disabilities. Like, with Annemarie she had a hearing aid, so one of our first contacts was the Deaf Children's Association to tell us about batteries because the school automatically notified them. So we made some friends there and then through the Foundation.

My friends that knew us when Toni was born just automatically accepted it because that's how Toni was. I guess some of the kids now they are getting older ask things about Toni's condition which may make her uncomfortable, but most of our friends who have been our friends for years accept that this is how it is, because we've always had Toni. She's always gone with us - we've never left her. When Toni was little we tended to forget because around the house she functioned well and we'd go somewhere like bush walking and a branch overhead would hit her because she didn't see it and we thought it would be high enough, or whatever. I remember once when she was little we went kite flying and we were at an oval where they had a fence with railing round the top. She saw the uprights but not the railing. She went running with this kite and went smack and bruised her head. That sort of thing.

But Toni makes adaptations too. The speed with which she will adapt is amazing. Round home, we often forget. It's not till someone walks in, or you go out and she walks into a door in someone's place, that you remember. Decking is a real problem. She thinks it's steps. We'll go somewhere and all of a sudden you've got this thirteen year old who's still falling over. I always remember when she was about three and we went to a friend's place in Australia. They'd just put on a new deck and Toni came out of their house. At that stage she used to drop to all fours and she'd feel her way. Daniel was down on the grass and he called to her, "It's all right, love, it's decking, it's not steps." So she up and she ran straight at Daniel. At the very end of the deck there was one step to the grass and she just fell straight off. Daniel realised as she got to it and he yelled and ran. She stood up and she said, "You bugger", and took off. She blamed him for that. Poor old Daniel's face. We were with our friends and they all looked. When she was with this group of friends they would ask if she could cope with things and she would say, "Of course I can", and get quite narked. Now, everyone ignores it. So they adapt themselves, and yea, you sort of have the hiccups but there's nothing major.

There's a lot of frustration sometimes which we probably treat more as turmoil. I have to say that having children with special needs certainly puts a lot of stresses at various times on the marriage. Perhaps more so than normal, but that is an assumption because we haven't had a lot of normal kids. But I must admit there's been some times when things have been really stressed.

(Daniel) Alison and I haven't always agreed on the best course of action. And that's caused a bit of stress sometimes. I guess I'm a little bit more inclined to leave Toni to her own devices. Let her sink or swim so to speak. Alison's much more an advocate for her. But by the same token I think there are times when we've been strengthened by that actually.

(Alison) Our coping strategies have been everything from blind panic to behavioural counselling. All sorts of things. About two years ago things really got bad. We had Toni picking up a knife and threatening - things like that. Then we got to the stage where I ended up in hospital and we had to do something. But a lot has come with maturity and it's continuing. We might have had back then, five bad days out of seven and now I think we probably have one bad day every five or six months. Toni's very strong willed, very stubborn, and she's one of those kids that had to test the limits. She wants to know the boundaries are there. I can remember one of the early childhood advisers coming out and Toni was just terrible. The adviser gave me heaps and heaps of stuff on time out and that sort of thing. She rang up after about two months and said, "How's it going?" and I said, "It doesn't work." She told me I was doing it wrong and that she'd come out the next week. Out she comes. She actually arrived when Toni was having a really bad day, which was good from my point of view, because people often don't see them. Half an hour later she came into the kitchen and she said, "For God's sake make me a cup of coffee, I don't know how you survive." She could not get Toni to do anything. Even at two years old, if she didn't want to talk to whoever arrived that day she would sit and face the wall. And she'd do something wrong and you'd take her away and say, "If you do that again you'll have to go to your room," or whatever. You'd take her to her room because she'd do it again and she'd say, "Thankyou mummy I needed a sleep", put herself into bed, and go to sleep. Then she'd get up, be out of bed an hour later, come out, and do exactly the same thing again. So she's always tested us right out to the limits. And that in itself caused stresses because by the time six o'clock came when Daniel walked back in from work, I used to sometimes be swinging from the rafters. He used to say, "I don't know why you yell at the kids", and "You should do this and you should do that," and I could have just about killed him. Coping strategies - I don't know - I think we've just muddled through. We've never really had any. That's probably half our problem. I honestly don't know. I guess just going with instinct and sometimes you really wonder if your instinct's right.

(Daniel) We've tried probably any number of things in a half hearted fashion but we've never had any strategy behind it. We just muddle through.

(Alison) I guess, you try something and if it doesn't work you try something else. When I go away to PVI I'll chat to the others and someone will say, "Look I tried this", and I think, oh yes, slot that one away. And someone else will say, "I tried that", and you think well, that won't work for mine and it's really bitsy but just talking to other parents is helpful, because I think Toni, whether she had a visual impairment or not, would have always been very strong willed. She doesn't cope with change, never has, but that's not the vision impairment. And sometimes it was really hard to think, how much latitude do I give because of the visual impairment or how much do I attribute in the behaviour? You sort of sit back and you think, oh wait a minute, she would have done this anyway. You try to keep an even balance between treating her the same as the others and making allowance for the vision. At one stage we started having real problems with Sarah because Rebecca wears glasses and of course Annemarie and Toni have problems. Sarah thought she was abnormal because she

didn't see any doctors. It's trying to say to her, "Look you're fine. You're the only one that is normal," without then implying that there was something wrong with the others.

It used to be quite funny. Toni always had to wear big, bright, wide sunhats. In Australia it wasn't so much a problem because by the time she was at school hats were almost mandatory. Now I believe they're just standard. She always had to wear dark glasses and we went through the usual toddler stages of hiding everything and trying to find these wretched glasses that cost a fortune. So I automatically had sunhats for everyone. And Sarah, whenever she walked out the door put on shades and everyone would say, "You're a real cool dude." But they just grew up expecting to do it. It was probably better for their skin now they're older. So everybody just put on hats and dark glasses and Toni never looked out of place. I guess that's the hardest, trying to treat her the same and trying to teach her that she's the same. When she has to have things differently she doesn't always like it, but she can achieve what everyone else can achieve. She just might need things a little differently to get there. Just because she's going out on this path doesn't mean it's any less than going another way, or whatever.

At one stage between Toni and Annemarie going backwards and forwards to Dunedin I was away about every second week. Rebecca and Sarah basically mutinied because, "You don't love me any more because you're spending all this time with them." And trying to find time - sometimes I just found it extremely difficult. And Daniel's always been away a lot. So I don't know whether we had any sort of definite strategies. I guess the only strategy we had was trying to keep everything as normal as we possibly could within those circumstances that we had and just working out things as you go, to that end. I think any parent with either a visually impaired or handicapped kid faces the same sort of thing. You adapt as you go. You get a problem and you think, right, first of all is it the vision or is it normal behaviour? And if it's normal behaviour you do this, and this, and this, and if it's the vision what do I need to help it?

For example, we had a new house in Australia and Toni wouldn't go outside. So we basically borrowed money from parents to put up this big pagola with shade netting on it and creepers and things. And all of a sudden we had a child who would go out on a sunny day and play. Of course we had to pay that back. We wouldn't have to do that sort of thing if Toni didn't have that need. Doctors don't think anything of saying to you, "Oh, just zip up a pagola, or wack up a car port, or buy the child $300 worth of sunglasses or something," you know.

I must admit education's been a nightmare, both in access to schools and with teachers. You say your child is visually impaired and they just automatically assume blind. The most significant thing I think, is lack of tolerance. For both Toni and Annemarie. A lot of people also seem to think that if a person's visually impaired they are also mentally handicapped, or deaf, or dumb. There's an awful lot of both intolerance and ignorance, there really is. I must admit, Daniel and I had never really thought about it. I've done my nursing training and never thought about disability until we actually had children in that situation and we just realised how poor the resourcing is and how ignorant people are.

My ability to advocate started the day I went to enrol my child, who was five, at the local primary school in Australia. I went in and said, "I've got a visually impaired child who sees and functions pretty normally and I was told that I had to come and tell you that she's *starting next year." The principal said that he was sorry but he couldn't take that child in this school unless he got extra teacher hours to cope with it. I said that Toni was not blind but he said, no, sorry. So I went home and I rang up Daniel in tears. Then I decided to ring Toni's eye doctor. I actually managed to get him and I didn't know at the time but he was on the Advisory Board to the Minister for Education in Victoria. I rang up and said that they had refused to enrol Toni and I asked if he could give me a letter saying she was perfectly okay. He asked for all the details and I thought, oh yea, just for my letter. And so I told him. Twenty four hours later I had a letter from the Ministry saying my child was welcome in any school in Victoria. I had the school principal ringing me up asking me if I could attend the school at half past two before I picked up Rebecca who was already there. And I go up and out goes the red carpet - <u>do come in</u>, sit down madam, dust off the chair - your child is more than welcome in my school. It was unbelievable. Then I found out that the doctor had gone straight to the Minister and said that this wasn't good enough. And the principal had had the Minister for Education ring up. After that I thought, gee, parents have power. I realised then that if we weren't going to go out and make the opportunities for Toni, initially, until she could do it for herself, she was going to be let vegetate because people were ignorant - and I don't mean stupid ignorant - I mean uneducated ignorant. So we had to go out and do that for her. And then when we came over here they accepted her fine at the first primary school and then wham, the second primary school when we moved up here from Tiwai the same thing happened. That's where we had the teasing and stuff. I then realised that if we don't say something and do something nobody else will. I mean I don't care if people think I'm stupid or neurotic. I'm sure the principal sees me coming and thinks, "Oh my God, here comes that woman again", and shuts himself in his office. But if that's what it takes to give them the opportunity to get somewhere in the first place, so be it.*

A major difficulty has been the nature of Toni's visual impairment because she seems to see adequately one day and then doesn't the next, so there's frequently been misunderstanding. Because Toni functions reasonably well most times, teachers just don't make allowances and then they think the parents are neurotic. Then something happens, like they sent her out to play cricket and she got a cricket ball in her face which shattered her glasses and they said, "She sees ok, she just stood there and let it hit her." But she didn't see it coming. That was the first time. She's had her glasses broken a few times.

When we went to enrol Toni in a High School she was again refused acceptance. So education has been really difficult all the way through because of lack of understanding, ignorance if you like, not wanting to understand. The school she's at now is fine but when I was trying to enrol her one of the high schools here refused point blank to have her. They literally said, when I went for the interview, that it would be a bloody nightmare to have a child like that here. "Would you please take her elsewhere."

(Daniel) The best way to ensure that Toni gets what she needs in education and other areas of life is to bang on the desk. (Alison) With a hard bit of four by two. You don't have a choice. If you've got a child with special needs - and it isn't just the visually impaired kids because we have the same problem with Annemarie - you get labelled basically as parents who are trouble makers and you have to advocate for your child or your child gets nothing. And I know of some parents who either don't have the skills, or don't do it for whatever reason, and their kids miss out.

I think inservice training for teachers is important. We've been trying to get yearly courses from Homai but we've only ever had them two-yearly. Hopefully now we've got a teacher coming down here ourselves she'll be able to organise it. Once the child gets to High School level I would like to see the resource teachers go into the staffroom in the lunch hour and do the simulated glasses on all of them.

(Daniel) I always had the belief that Toni's vision wasn't too bad. I still believe that. Therefore she should be functioning effectively normally. But she does have a problem with glare. To compensate for that we ensure that her work is blown up a little bit. She has a magnifier as well and the degree of magnification she requires can be achieved with those magnifiers quite readily for most texts. Maybe newspaper clippings are a problem. Certainly the phone book is a problem but in general she manages all right.

(Alison) Now she's in the older forms some of the reference books like the Britannica we have to read. When she has to do assignments I probably know as much about them by the time we hand them in as she does. Because we don't have access to an enlarged photocopier at home it basically falls to me to read it to her, or Daniel.

The support networks we have used have been the RNZFB here, RVIB (Royal Victorian Institute for the Blind) in Australia, and Special Education both here and in Australia. PVI, locally has been a good resource. And I guess family when we were in Australia, but that all disappeared when we came over here. There's only Daniel and I and the four kids. That really was hard at first, not knowing anything or where to look for it.

We first made contact with services when Toni was at primary school. She was being teased to the point of having nightmares. I went up to the school and, as much as it hurts you inside, you have to allow for a certain amount of teasing because that's always going to happen. But when it gets to the point of the child having hysterics and nightmares and having to be literally dragged back to school, I decided enough. So I went up to the school and I had the deputy principal turn round and tell me, "Yes your child is being teased. Yes, they are pulling off her glasses and throwing them in the bushes so she can't find them, and dancing around her and that, but it's character building and we will do nothing about it." So I came home, sat down and had a howl for about an hour and then I went through the phone book from A until I found Royal New Zealand Foundation for the Blind. I didn't know what it would be called. Because they are all different. I tried Blind and I tried Institute of the Blind because I'd known it as Royal Victorian Institute of the Blind. Then I tried New Zealand Institute for the Blind and I went through all the R's until I found Royal, and then I found it. I rang up and the social worker came and filled out a temporary membership and it went from there. I wouldn't say the person who came was terrific as a first contact, but she got us in and we saw the ophthalmologist fairly soon.

The social worker also told me to contact the parent rep for PVI and it sort of went from there. Then we had a few near misses with Toni on the road and at that stage we got an O&M. She came out and did some work with Toni. After she left Toni's flatly refused to work with anyone else. But originally that was how we got onto the Foundation and we just got involved. The RNZFB Child and Family Social Worker from Dunedin comes down regularly and we've become friends. We've been to a few camps and that was really helpful.

(Daniel) We have not experienced difficulty accessing services once we found out about them, but there have been some problems with the usefulness of a couple of the services. Perhaps because of the people, or perhaps because of their perception of Toni's needs. Because at the end of the day, she's not blind. She actually sees quite well. Her problems are to do with the environment that she's in at the time rather than any specific inability to see, as in blindness. For that reason it's not always appreciated that she has a need to be associated with the Blind Foundation. But I think on the whole we've been reasonably happy. There have been ongoing problems with getting sufficient services down here and there has been some dissatisfaction where you could say we have found them unhelpful. They were either not down here often enough or not terribly effective at the time they were here. I'm sure they mean well, just sometimes the message doesn't get across perhaps too well.

(Alison) Rightly or wrongly, Homai is seen by everybody else as having all these wonderful, terrific resources and you can't access them, especially if you've got a Resource teacher who doesn't want to ask on your behalf or bring them down. I don't know whether a parent writing direct to ask would solve the problem.

The way the children's sight is assessed has to be changed. We go into a room at Homai, and at the Low Vision Clinic, and they know Toni doesn't function well in glare. So they immediately turn off all the lights except one little lamp on the eye chart and say, "Hey, this kids got 6/6." Then when you're walking out the door they say, "But don't forget she won't see like that in normal lighting conditions." One ophthalmologist assessed her vision at 6/6 and said that this child should be out of the Foundation now. 6/6 in half an eye. But functionally they'd got her vision at about 6/38 and so deregistration was not recommended because there were still some problems there. Glare showed up in everything. But even when she had her functional vision tested it was in a darkened room and they said that of course she was glare sensitive, she wouldn't see so well in glare. Why the hell do not they test them in normal lighting conditions either at home or in a school room or something? Toni's never been tested in the classroom. Every parent I have ever spoken to has said the same thing - they maximise the lighting conditions for that child. That's fine, that gives them an idea of what they can see, but life isn't like that. Life isn't a darkened room. So I think they need to alter the way they test the children and how they work it out. I'm not saying Toni needs all the Foundation's services, she doesn't. She sees a lot better than many of them. But every time we've moved around the country with PVI, meeting other parents, all of them say the same thing. The way the child's vision is tested isn't an accurate reading of what this kid sees in everyday life.

(Daniel) I think that there was some frustration there on the part of the doctor because Toni did appear to be pretending sometimes. And we were determined that we were going to get to the bottom of this. That pretending wasn't going to be believed. Her vision isn't that bad, but she does persevere with her magnifier to the extent that I expect she really does need it.

(Alison) I would like to see the Homai Assessment Unit tour the country and do all the vision testing in the areas where people function. I know it's probably terribly impractical of me but that would be my ideal. I must admit, too, that a lot of eye doctors haven't seen coloboma. It's not that rare but a lot of them haven't, and certainly almost no GP's.

I must admit I find with the different networks that are around, like the Visual Resource Centres, and Homai, and Special Education, I get so sick of the professional jealousies and *politicking between them which stops them all working together effectively. One of the mothers here has got two boys, both severely hearing impaired, and they've both got really bad eye conditions. Now the ophthalmologist will not allow for their hearing impairment when he tests them for their visual acuity. The teacher for deaf children will not allow for the sight impairment when he's testing how they function in a class. And the teacher for the vision impaired and the teacher of the deaf children did not work together to maintain teacher hours from coming out of the deaf children's budget for these children. And this happens more than once. You often are in contact with half a dozen agencies for one kid, especially the multi-impaired kids. And be it professional jealousies, plain ignorance, or whatever, they will not work together.*

(Daniel) Sometimes they just feel they're not competent to do the other piece of work.

(Alison) But this happens all the way especially with multi-handicapped children. They're seen as 'eyes', 'ears', 'brain problem' or 'IHC'. They're not seen as, hey, this kid's Jo. Jo's 'kid' first and foremost. They're kids or they're adults first and then they've got these impairments. You can't treat one impairment separate from another. With Jill's kids you can't say optimum eye level they need this and this to function, for their hearing they need this. You have to take into account that, hey, this kid's sitting there and it's missing out on 80% of its hearing, and I think at the moment one of them's down to about 70% of their vision. But this kid's not getting a lot, we need to look at the whole. And sometimes it's professional jealousy, sometimes it's ignorance, sometimes I don't know what it is.

Sometimes I think the Resource Teacher's job is left to the parents. It's my understanding that these people are there to advocate for these kids but it doesn't work that way. The parent advocates and gets the name for being neurotic and they distance themselves. I get annoyed when Special Ed walk in and say, hey, this kid needs this. Special Ed down here deem all the teacher aide hours. They've got no idea at all of vision or sight yet they've got the right to say, this visually impaired kid gets nothing. But they will not say, hey, we don't have this expertise can you come in and give it to us?

If the RHA's new Needs Assessment does get off the ground and does work, and I'm not too sure it will as it's very idealistic, I think that's going to go a long way. They are going to take each person as a person, and have one key worker who says, "Right, this person has this need, you come in and advise; she has this need, you come and advise." You're going to end up with a lot of people talking, but at least they're going to treat the person as a whole. That's my soap box - I'll come off it now.

I think it was a hunk of four by two wielded by another parent that prompted me to become involved with PVI. Representation was needed from the south. So three of us sat down and worked out how to share the roles. Lucy was on the Resource Centre Committee which meant a trip to Dunedin monthly, Jill's on the National Executive for Deaf Children and they both also sit on the SES Committee that do the teacher aide hours as advisers for these kids. We worked out who was going to do what to spread it around so that everything was covered. PVI was mine. We always got together to do letters to the Ministry and stuff like that, and we worked it all out.

I would say the main function of PVI is to educate parents, both parents of visually handicapped kids and other parents. Also to advocate for services, education and whatever *needs any child has, and to advocate for the needs of visually impaired children on behalf of the parents. Like a spokesbody for the parents to get the services and the needs met.*

In looking towards the future, the way things are going we will probably have to win lotto to put all the children through university, and they're all heading in that direction. I can foresee problems with Toni at University level. Even now at High School level there is a problem with the extra costs involved in photocopying everything for her. Everyone's on such tight budgets. The school she's at now got around that by setting up what they called 'Budget Toni' and that's a pool of money for any faculty that she's taking. For example, if she decides to do Japanese or typing they apply to that budget for the money to enlarge all her material rather than it coming out of the curriculum budget. That has stopped anyone saying, "Well she could do physics, but try chemistry, dear", and stuff the chemistry budget. One of the schools I went to, the one that refused to take her, the first thing they said was that it would be a photocopying nightmare and it would stuff everyone's budget and no one would want her. Whereas this school sat down and said, "Ok, we'll set aside this pool of money." I think the first year they were flying by the seat of their pants until they got an idea of roughly what the cost was. Once they had that, that was fine because they knew how much more it cost to send the kids through each year and they would just add that to her budget. I don't know whether they would do that at Varsity level and the way things are going I can see them saying, "Right you have to pay this much extra for your child to be educated." With Toni, I think, as much, perhaps if not a bit more than the others, she will probably need that grounding because it's going to be hard enough for her going for jobs with the visual impairment. Someone at a PVI meeting told me that the unemployment rate amongst visually impaired people was something like 80% because they just can't get the jobs.

(Daniel) Even so, I don't think Toni's in a position where she'll have trouble getting a job because of her vision. Except maybe as a traffic policeman or something like that.

(Alison) There will be heaps of things she can do. I think she's probably the brightest of the four and they're all fairly bright according to their teachers. But Toni's in the top band, so she can do it. I just hope that her vision doesn't limit her. Her greatest limitation will be other people I think. She lost confidence for a while. Since she got her contacts and she's not being teased as much we've noticed a big difference in her confidence. But I think her greatest handicap will be other people's perception of visual impairment. And I see the same for Annemarie. We're going through things with her at the moment. She's at that early teenage stage where they're quite cruel. She had a birthday party not long ago. She asked six kids and one of them came back two days later and said, "I really want to come to your party but my mum won't let me go because she won't let me knock around with cripples." Annemarie was a bit upset but the other five came so it didn't matter. And that's exactly what it is. It's other people's perception of them. They see the handicap not the person. And I think for any special needs person, or challenged person, that's their greatest handicap, other people.

(Daniel) I'm a bit concerned about the number of changes that have occurred since we got to New Zealand. We haven't been here that long and the system seems to be being dismantled. Of course, probably some contraction was necessary because the country is over committed. So, okay, it's unfortunate when it turns out to be a health area that's being chopped, but I also have looked at the services that are available to people such as Toni and Annemarie and provided there is someone prepared to make the effort to find out what is

available and to use it, such as Alison does, then there isn't really a significant disadvantage for those kids. There's no automatic safety net. There's no spoon feeding any more. So somebody has to look out - and if not to the Department of Health or whomever - the parent or somebody has to look after the needs of that kid. I can't help thinking that's the way it should be. It shouldn't be confined to the health area. It should be applied also to social welfare and employment and everything else. As far as further policy changes in the future, I don't know enough about them.

(Alison) The draft policy on disability support, the Needs Assessment one that I was talking about before, I think is an excellent policy. But I think the way government policies are going it's too idealistic. They'll chop too much out of it and it will not work. There's going to be problems with it. But if they keep it's concept right it should work well. Unfortunately governments tend to syphon this bit off, and take that out, because of cost. Then you're left with a half hearted thing that doesn't work at all, like they have with ACC and places like that. I don't have Daniel's niceties towards the government. It's because of going through SEPIT and things like that, to have them wipe it and start again.

The way the government works you end up with too many administrators and not enough hands-on people. You've got more money, in effect, going into it and it's just not working. I see that all the time at the hospital. Working with occupational therapy you see a lot of people out there who are really hurting and there's just no relief. I don't have a good feeling about the future at all with the government. I think even what we've got's going to go. The way they're going with the user pays and the way they tend to be moving, especially in education, it's very much like it was in Australia before we came over where they started dismantling the likes of Melbourne's equivalent of Homai. They said, "We'll take all this money back. You mainstream your children and all this money will go out." That money went back and none of it went back out. There was no specialist school, there was no back up. Effectively they chopped RVIB off at five and said that the advisers for visually impaired children would take over, but no money went in. So there were all these teachers who had the expertise that weren't put back like they were supposed to be. It was terrible. You'd enrol your child and you'd go to a meeting and there'd be someone from Psych and Guidance, and someone from Vision Impaired, and someone from somewhere else. And they'd all say, "Sign this, sign this, your child must be registered with us", and the more children they had the more money they got. I got into a great fight with one of them because I maintained Toni and Annemarie didn't need a psych assessment. They had a straight out visual or hearing problem. They didn't need it. So the way they are talking about breaking services up here, you are going to have to get parents who have got, say a vision-hearing impaired child, to decide whether they want hearing to administer it, or vision to administer it. And again, you're dividing - you're not looking at the child. You seem to lose the perspective. I keep going back to the whole person and that's how I see it. They're not an impairment, they're a person. But I don't have any faith at all in the government.

(Daniel) I'm a little bit in favour of the concept of user pays. And if that means that special needs kids are forced to subsidize the additional services that they require, okay, then I can understand the logic behind that too. It makes it hard when the resources aren't always there but maybe with subsidy or part payment or something, that would be the way to go. Because it's a fact of life that if you make it all free, it gets abused. Then you end up with not enough money, no matter how much you've got in the pool. Now, I've often felt that we've been using more services than we should have, for Toni in particular, because her vision isn't that

bad. We've certainly had a lot of assistance going along. We've had a lot of people taking an interest in her development and her needs and so forth. Annemarie, yes, to a lesser extent, because we haven't had so much intervention in her case perhaps, or assistance. So I can understand how the government is trying to spend less and the logic behind it. I don't see any particular flaws in it. It's just that the administrators are also only people and it's very difficult to keep your finger on the pulse all the time.

(Alison) That's where we differ. Daniel can sit back and he can see the budgeting constraints, that there isn't enough money. He looks at it logically, whereas I look at the people. (Daniel) Right. But it's not the government's fault that we have a vision impaired child. Okay, so I pay taxes, but if I really wanted some help for Toni then I should also have insurance or something like that. And we do. Or if I could get resources some other way, such as my employer, for example. I recognise that not everyone's going to be in a position to do that, but I don't think the cake's large enough for everybody to access those services simply because they are in the country. Because they pay tax doesn't mean that they should be entitled to whatever services they need, irrespective of what their special case might be.

(Alison) We haven't actually accessed services for a couple of years now with Toni because there's been no need. There may well be in the future. But we haven't used them. I sometimes get really narked because both of us pay taxes and then because we're supposedly bracketed with the wealthy of the country, we pay for all the doctor's visits and things like that. We don't get any services through outpatients, they're all private. So you are paying there and you are paying for all the scripts and everything. Some of Toni's equipment, like the magnifiers, might only be seventy or eighty dollars, so you don't qualify on that. Sometimes it's means tested and I think, somebody's who's on a benefit is getting all of this free - all the equipment and everything, and they're not paying any taxes. Whereas we are and it's like you're paying twice. I occasionally get narky because sometimes it is difficult to make ends meet.

(Daniel) Our vision for our family is for them to grow up and leave. We're trying to give them an education so they'll be able to make their way in life and that's really all we can ask at this point. We're not going to dump a pile of money on them, that's for sure, the way things stand. But by giving them the education we're trying to ensure that they get, they'll be able to do that. And where it's necessary for some extra help to be brought to bear as in Toni's case and in Annemarie's case, then Alison, in particular, is trying very hard to ensure that that happens. I'm quietly supporting them.

(Alison) I think I share that in common with Daniel. We've tried really hard and I'm still trying on the education side to give them a really good grounding so that they can make their own way. Also I think a stable home life is important. You know, a good base from which to go out. Hopefully they will have learnt the difference between right and wrong and be responsible citizens who realise they have to keep the laws. You can't guarantee that but I guess we've tried and done the best we can. Hope - just the same as all parents - and to provide a stable base, that's what we've tried for.

FAMILY PROFILE

Adolescent: **Toni**

Age: 14 years

Sex: Female

Visual condition: Bilateral coloboma
Congenital
Visual impairment first recognised by parents at birth
Low vision
Visual (print) mode of communication

Educational placement: Local High School

Parents: **Alison & Daniel**

Ages: 40 & 41

Marital/Parental situation: Married

Vocations: Home duties, Occupational therapy assistant; Specialist metallurgist

Siblings:	**Rebecca**	**Annemarie**	**Sarah**
Ages:	16 years;	13 years;	11 years
Sex:	Female;	Female;	Female

Family:

Time in present community: 6 years

Most important to family: Providing a safe, secure environment for the family, and providing a good educational basis for the children's future

Effective support systems: Parents, friends, RVIB, RNZFB, CCS, Homai Vision Education Centre, PVI, Royal Victorian Eye & Ear Hospital, two specifically named doctors

'Gift' to other families: "You (the parents) know your child best. Always hang in there until you get what your child needs - you are the best advocate your child has. Listen to the professionals/'experts' but if it is not right for your child or you, don't do it, and persevere until you get what you need."

HANNAH'S FAMILY

Narrated by Gloria & Cloan

Knowledge is power and I think some of the most wonderful people I have met in the professional field have been people who have been prepared to sit down and form that true alliance - not sitting there judgementally saying that you're a parent, you know nothing. That is absurd, because even a parent who may be deemed to be the most dull witted of persons, can't fail to see something happening with their child. They will pick up something. It's about applying that professional knowledge to the knowledge that's gained practically. It's a team effort.

In our family there is myself, Gloria, Cloan, my children, Justine who is twenty five, James, nineteen, and Hannah, fourteen, and Cloan's children, Robert who is twenty four and Dylan who is nineteen. We are a 'blended' family. Of the children only Hannah is at home now.

Our lifestyles are pretty crazy. We're two people that are both working, and I think that impacts upon our life. So things are pretty hectic and disability forms a large part of our life. We're in the throws of probably having to change that, or else we won't survive. Because it's disability, disability, disability. A lot of energy goes in especially at the level that we've been operating.

(Gloria) Hannah is vision hearing impaired. I think with Hannah, my pregnancy was such, that I knew there was something wrong before she was even born. I had been sick and I'd obviously been sick with rubella, but it wasn't picked up because it was thought I had glandular fever and a doctor had given me penicillin. Sometimes when you give penicillin to someone that has glandular fever they come out in a rash. So when this happened, they naturally assumed that that's what I had. In retrospect I think I probably had both, the glandular fever and rubella. But I definitely knew there had to be something wrong with this baby, having been so sick. I didn't think of rubella or anything like that, I just knew that I had been sick, and I thought, well, that's going to affect the foetus. Hannah was born very tiny, she was about four and a half pounds.

I think that because I thought there was something wrong, I was probably looking for it. Before we left the hospital they detected a heart murmur, so that was suspect right from the word go. Then when we got Hannah home I used to drop pots and pans to see if she was actually hearing, because I didn't think she could. She was too good a baby. She could be in a noisy room and not react. Then I noticed that she had something wrong with one of her eyes - it was sort of like looking at a photo negative for some reason. It was unusual. So we went to the paediatrician that had detected her heart murmur and he had tests done. He said that they thought Hannah was a rubella baby, so it started from there.

Hannah's birth had a large impact on her father. He'd actually been badly burnt in my first month of pregnancy and nearly died. He was a heavy drinker and I think being badly burnt didn't help. Then when he actually had a disabled child, which was his first child, it wasn't very good for him. So that had major implications for him, and I think also my parents were affected. My father was a social worker for IHC at the time and he was extremely upset. I think he was upset not for his own sake, but because he knew the trials and tribulations I would actually have to go through with a disabled child. I think he could see the future better than I could. I tended to prop them up because they were upset, and I think you probably forget about yourself.

You really don't know. You have no idea what it really means. You've got a little baby in your arms and you don't see the disability there at all. They may not be able to hear, but you can't see that, and their eyes are fine and they look all right. So I guess it's an ongoing thing and I think it always will be. I liken it to people with Usher Syndrome. It's an ongoing grieving situation. As the children get older you think, oh, what a pity, she would have been doing this, or she could have done that, or she would have looked really pretty in that. You know, they talk about people having dreams about their children. You have an image of what your child's going to be like, and that dream becomes shattered when they're not like that.

But as I say, you don't see that initially, and perhaps I don't really have a dream, I don't know, but I guess you do have wants and needs for your child.

Hannah had a cataract operation when she was three months old. Both her eyes were done and they were very good. The retinas were fine and the cataracts were removed. But the rubella was active and so the cataracts kept forming somehow. They had to be needled three times, and it wasn't until the third operation that she actually lost the sight in one eye. That was negligence, I've been told, which is a real pity. It's also very scary because she could lose the sight in the one good eye and that would mean she would be literally deaf blind. To someone who's had sight that would be pretty horrific I should imagine, and particularly for Hannah. She's pretty stroppy at the best of times and I know she'd be very frustrated.

Hannah still gets floaters as a result of the needling and that can be very frustrating. There are a lot of late manifestations of rubella. Also Hannah pokes her good eye quite severely, especially at night. She's pushed it in, and condensed the fat behind it. That worries me because it means pressure on the retina and the blood supply. For all intents and purposes, her eye looks reasonable healthy at the moment, but it is definitely recessed, and with cataract operations glaucoma can be a consequence. So it is a very real problem. Maybe if Hannah had had both the eyes, if she had then lost one later she might be able to last the distance with the other one. I guess sometimes you resent it, sometimes you worry about it and you think, "if only, if only." You go through that sort of thing, and you try to actually not even think about it, because you're spoiling the moment, you're spoiling what's happening now. You have to just go from there and hope that it doesn't happen.

I guess those first five years, for me, and for Hannah, were pretty hard going. It was twenty four hours a day, seven days a week. It was also compounded by the fact that I had a husband that drank a lot. And then I guess another difficult time was when Cloan and I actually put our families together. It was quite hard doing that because there were a lot of physical needs there with all of them. Hannah was about three then.

The major implications for Hannah have been in relation to her education. It's been a hard one really because it's so difficult to teach someone like Hannah. The profound hearing loss just has such an impact on everything for her. Concept development has been a major, major thing. There's not a good understanding of how the congenital aspect impacts upon someone that's vision and hearing impaired. Any changes in anything to do with her education we're a bit wary and a bit scared of. You have expectations I guess. I just know that Hannah has been particularly bright. I think she was bright enough to be perhaps further on down the track. I don't know. You can say things like, if I had learnt sign language when she was nought or one, then it would have made the difference, and I think it would have. It's like anything. You can invent something different, but you can only say to someone, "Well yes, if you could get that off the ground then it will make a lot of difference to their lives." If she'd had the two eyes, that would have made a lot of difference to her capacity to learn, because she may have been virtually just a deaf child in that respect. But you don't know because rubella is terrible. It does some crazy, weird and wonderful things. You don't know whether there is brain damage or brain lesions. But for all intents and purposes right from a little one Hannah seemed to be bright, on the go, and motivated.

Hannah went to Homai College when she was about four and a half, and she went from then on. Prior to that we attended the Child Development Centre and she went to the Crippled

Children's Kindergarten a couple of mornings a week. Then she attended the McKenzie Centre in the Waikato where we lived. I used to go as a volunteer there but they didn't know a great deal about what to do for a deaf blind child. But just that interaction was really good. I think I pushed her right from the word go. I knew that she had visual problems. I also had input from the social worker from Homai, so that was good. I don't know whether you would say I had a lot of input, but there was input from various people, particularly at one stage when I was trying to get a suspensory loan. The loan was to get an extra room on my home to accommodate Hannah so that she wasn't wrecking the other kids' room and so there was some place she could sleep without disrupting the rest of the house. Hannah made a lot of noise and it was her lack of sleeping during the normal sleeping hours that was totally distracting. You'd find Hannah out on the trampoline at one o'clock in the morning or else she'd be sitting on the stove or turning on the switches. She had no concept of night or day and used to sleep sometimes only two or three hours a night. That was a big problem and we learnt to sleep fairly lightly. So we wanted to build a room that was big enough to actually accommodate her being able to do lots of things and where she would be warm and safe and would not disturb the world in doing it. They wouldn't have a bar of that. So that's essentially why Hannah went to Homai. But not withstanding that, I think that she's had a lot of excellent input at Homai. There were some excellent teachers that have recognised Hannah's potential and not been limited by it.

Those teachers, I think, have an understanding of deaf blindness and treat that disability. They are people who care right across the board. However, in residential care and education staffing has had its difficulties. We are currently involved in setting up a Community Trust Home and we've seen it there - that the people looking after the young adults don't really understand. They haven't had children of their own for a start, so don't have that sort of comparison, and to actually enskill them into that nature of deaf blindness, is really difficult. Then there's the transient nature of staff and things like that. I think there has to be that continuity across the board.

(Cloan) One of the aspects of Homai that they have not come to grips with at all is that the hostel should be on an equal par with the classroom as a learning part of the child's life. Teaching in the hostel is where it all should have happened when the children came back from school. Now they've tried, but it's never really been as good as it might. (Gloria) It's the values placed on people - whether that staff in the hostel has the same value as the professional teachers in the classroom. It's that power thing once again, rather than a focus on what happens for the child. And okay, I guess there is the problem that some of the staff aren't trained in that aspect, but perhaps the hostel has to have equal value so that the staff there are just as trained as the teachers over in the school. (Cloan) The thing is that if you've got trained people it gets down to a matter of economics and you're going to have to pay the people that are trained. And, hey, we only want to pay them a small amount because caring for children is the least valued role. (Gloria) It's like the person that's at home actually caring for a disabled child that's allowing the other person to be out there, perhaps gaining the kudos for what they're doing, because that has more value than what the person in the home is actually doing.

(Cloan) In any western society there's only going to be, by definition, so much money to go round. It seems that the essence is to actually get as big a part of that for yourself as possible even if that means denying some part of society. But in spite of that I do believe that

New Zealanders, if they were brought to an awareness of how it was for some of these people, would rally because essentially I think there's a relatively decent amount of people out there.

Attitudinal change is really important. The thing is though you can have change happening almost at a legislative level - like this Disability Bill that they're putting through at the moment - but you can't legislate people's minds. People's attitude is the difficult part and that's where it gets geared to education. The bottom line is, who the hell wants to learn about disability anyway? It's not part of the essential curriculum as far as getting out there and doing it for yourself is concerned. That's been our argument with Hannah in a mainstream class. Essentially if Hannah goes into a mainstream class, everybody in that school will have to sign, because that's what inclusion means, not just a few of the class signing. If you take it to it's logical conclusion everybody in the wider community should actually be signing and you start this convoluted, philosophical argument again. So it's very difficult to keep the thing at a realistic level, and what is realistic? Who am I to say this level, or that level, or that Hannah in an inclusive classroom should be happy just to have a teacher aide who can sign. There is a heavy lobby for inclusion. But I think it's easier to put some children in the mainstream than perhaps it is with someone who is deaf blind.

(Gloria) We both make decisions for Hannah and advocate on her behalf. I'm more involved in the day to day hands on. In terms of who is most concerned with people's feelings in our family, I guess it's probably me because I'm considered the more emotional one. I'm just the nurturing one. But then Cloan's not without feelings, it's just that he's able to control them a lot better. We're both involved in getting things done and problem solving. But at times it is a difficulty. Because of what's happening in our personal lives a lot of things aren't happening. A lot of things are actually going by the wayside because we just don't have the time to do them, even things like paying the bills and deciding if we stay living here. A lot of those decisions are forced on us almost, rather than us actually coming to an agreement and having a strategic plan for what we want to do. So that's been a problem, to actually find the time to discuss the things that we need to discuss in our personal life.

Because we're so busy, at home we get back into a situation of doing things for Hannah rather than her doing it for herself. That's a real danger, particularly if we're up at six in the morning and have to be gone by seven, and Hannah might be cruising or just taking that much longer to do something. That's a real problem in terms of time - to reinforce some of the skills that she needs to know. Hannah wants to do a lot of things - like cooking - and if you take the time during the week to actually go through that, then you're looking at ten or eleven o'clock before you get to bed. So the practical nature of that is a problem, and the fact that we live so far away from our jobs that cuts out being able to do that. And I think we don't do a lot of things because Cloan is a workaholic - he works all day and all night and all weekend. There isn't time for a lot of things to happen unless I do it myself, and that's okay, I do do a lot of things. I take Hannah swimming and she comes shopping and things like that, but there's not a lot of fun things. We should be doing a lot more and that's why it's going to be a phasing out of some things over the next couple of years.

Hannah actually gets exposed to quite a few people in many respects. She goes where we go, and that may mean to every meeting that you attend, which is not much fun for Hannah, but she's actually quite good in that respect, she's very adaptable. I think we've been lucky. But I think more could happen for Hannah if we had the time and the energy. Hannah needs to *be involved with Special Olympics, she's got a good ability to swim. But the practical nature of actually taking her on Wednesday night and maybe Sunday afternoons, is difficult. If we made that one small shift in our lives it might make a difference because it wouldn't be such an onerous task to actually go back down into the city again, but you come up here to our home on Friday and you don't really want to return. Some of those things would make a difference to her life and need to be tidied up now. Hannah hasn't been to the pictures, which seems ridiculous when she's fourteen years of age. Now she might go to the pictures and hate it, but she's never actually had the exposure. You have to keep reminding yourself what a normal fourteen year would old be doing. It would be a hell of a lot more than what Hannah's doing. And okay, Hannah can't do all of those things, but she can do some of them. We used to take the boys surfing, we'd take them round in the van. And I think as parents, you have to go out of your way for your children.*

Hannah's not unhappy, generally. I do think she's aware of what she looks like. A dilemma we've got at the moment is in terms of what to do with her teeth. But I don't know whether Hannah knows how disabled she is. Hannah's quite able, actually. In a lot of respects she's quite normal, very normal. There was a stage when she withdrew into herself. It was like, one day she was out there yahooing on the trampoline and then that just stopped and she became a housebody. That may have been a normal sort of developmental thing, but you never know. There are heaps of variables there that you never know what has actually happened beneath them.

We've talked to people who have had young girls who have gone into that very hometype behaviour and it's quite a normal thing for young girls. But the only problem with that is, a normal teenager might go into their bedroom and they'll be listening to the radio, talking on the telephone, or doing something, whereas Hannah's withdrawing and doing nothing. So I do think Hannah could be exposed to a lot more and she could actually be doing more in terms of what she can do for herself. There's a lot of guilt involved and there's a lot of emotion for myself, particularly if I know that Hannah maybe isn't doing a lot of normal things. I don't mind her folding paper sometimes, because I see that as a valid form of recreation that she enjoys, and that's fine. But to be actually doing that all the time is a real worry, I don't like that, and that makes you feel bad.

I'd like to look at what Hannah needs in her education because I don't know what's happening for her at the moment. Maybe she doesn't need to be at school. I don't know what alternative there might be for Hannah, but they're looking at putting her in workshops now, at fourteen. I think maybe I could have an alternative program for Hannah where one day she goes to school and another day she does something else, rather than her just going to school everyday and maybe spending a day in a workshop - there'll be heaps of workshop time for Hannah later on. But then I don't envisage that happening for her, because I don't want that to happen for the people down in the Community House either. I don't think it should be automatically that they go off to a workshop because that's a normal thing, people going off to work. They don't even have a concept of the $5 that they get at the end of the week so it's neither here nor there. They don't really need to be in that workshop situation constantly. They could have maybe one day at a workshop, which might be on their own premises, where they make something which the next day they take to sell. The following day they may be doing recreation all day long. Why do they actually have to spend the rest of their life in a workshop for five days a week? That's ridiculous.

(Cloan) We objected quite strongly when it was suggested that Hannah should go into transition education. Essentially transition education was going to workshops. To my mind that's not transition education, that's basically saying, "Well, here's what you're going to be doing for the rest of your life so we'll introduce it." My understanding of the transition education that I've been involved in at the high school, is that it's giving people tastes as to what is out there. Then they can say, "Well, I might have that, or I might do that, or I might try this." That sort of thing. But transition education as it was mooted in this case was basically workshops. And we were saying there's the possibility that Hannah will be going into one of those for the rest of her life, so how can you talk about this as transition? It's like accepting, "Hey lady, that's what there is for you for the rest of your life."

Education continues for life. This concept of seamless, continuing education is becoming the norm out there. Education is something now, they say, that you'll never, ever be without. It'll be part of an ongoing process, and if you're not in there, if you're not in that mode, you'll be one of the also rans of this society. But for a normal child there's all the stepping stones that they can go from one to the other, and for the rest of their life they can be in and out of employment and into education and training. But these ones here with disability, when they turn twenty one, it's "Sorry you're out." I know a family who have fought tooth and nail to keep their deaf blind son at high school after he turned twenty one. He has managed to get some time at the local high school. It's only one or two days, but that's part of his richness of life. When I was teaching at a high school we had adult students in our class and they were getting paid to be there. And yet to keep this deaf blind boy in school after he was 21 was going to cost the parents something like $1500 a term. I think, under the present rules, education has to have a payback. Up until about the mid-80's, education was seen to a large extent, as almost a recreation for some people. I remember lots and lots of people went back to varsity to do psychology degrees. They often didn't intend to do anything with it but just wanted to learn a few things. But now it seems to me that the philosophy is user pays. I think that comes through very strongly.

(Gloria) Hannah's got better as her brain has matured but you do run out of energy. I think you just keep going, and now perhaps, we expend more energy on going to work and living this far from the city, than perhaps on Hannah. But it is the constancy. It's like having a small child for a long time, I guess. I've been lucky having someone like Cloan. He's been a tremendous person in my life, for my development, and also for Hannah's. He's out there advocating for Hannah, and that's pretty amazing because Cloan's not her natural father. He's done more for her than a lot of people. I'm lucky too in that I've had good parents. I come from a large family, although most of them are scattered throughout the world now and we haven't been able to utilise the extended family as such. In the early days, my mother and sister were particularly supportive and Hannah's father's mother was extremely good. I sometimes needed time out because of the constancy and also the difficulties of my husband, at that stage. But we didn't have an extended family that could look after Hannah. That's always a problem with someone who is deaf blind, particularly because of communication. Not everybody knows how to communicate with Hannah, so that's a real dilemma in terms of getting people that can actually look after her.

That has impacted on what we have been able to do in terms of socialising and that sort of thing. You blame yourself sometimes for not getting off your butt and getting a better network out there, but it's a real catch twenty two because the more you don't take the time to deal *with those things, then the more it impacts upon your life. I think what happens sometimes is you see other people doing it and think, well, why aren't we doing it?*

(Cloan) For all our children, I suppose, basically what we have wanted for them to learn is independence. If our kids are out there and they are being independent and not having to rely on other people, from my point of view, that would be the major thing. If they come home to stay for the holidays or something like that, that's okay, but independence is a big one and I think they're all out there independently doing their own thing at the moment.

(Gloria) Justine's pretty resourceful, she's out there on her own and has been for quite some time. She was really forced into it in a lot ways because I was on my own with Hannah and she helped me a great deal. Probably James missed out a bit and was a bit more dependant on what I could, or couldn't, do for him, though he's actually out there now surviving basically on his own. Cloan thinks I overcompensated with James. It's not so much that you overcompensate, it's just that you fill in because it's easier, because you're too busy doing for the other one. I think also that he had my undivided attention for the first five years of his life, and then Hannah came and that was it, just cut. It was a big change for him. Then to accommodate him I used to do for him as well as doing for Hannah. You had to be pretty much organised to cater for Hannah, because you didn't know when you were going to be out of action for an hour or two while she threw a wobbly. Everything was organised at least a couple of hours ahead. It was quite difficult for James, but today, of anybody, James is probably the most sympathetic towards Hannah, which is really quite interesting. He's fairly sensitive, and fairly soft in that respect.

(Cloan) I believe any family that's got a disabled child is going to be somewhat dysfunctional. I believe that is the reality of it. Dysfunctional in as much as the disabled child takes away a lot of the energy and attention that would otherwise be spread evenly over those other ones. In actual fact I think our kids have handled it rather well.

(Gloria) I think there have been some resentments and problems in coming to terms with it. I know that Cloan's boys particularly were a bit upset at his total involvement in disability, and I think in some respects that took away from what they'd already had, and what they were used to. And I guess that's understandable, that's a normal sort of reaction. I think now, they've just accepted it - that that's the way it is. Whether they like it, that's a different story. I don't know whether they particularly like it still.

(Cloan) I think, when you look back on it, that having Hannah, in some respects was quite a levelling thing for us really. It sort of takes the bullshit out of your life. If you lived in an unreal world with a disabled child I think things could only go from bad to worse. We had five kids and they all had their needs and wants. And I think, you know, we didn't do too badly. The trendy term in those days was to have a blended family, and there were people who only had a boy and a girl, or two girls, or something like that they were trying to blend together, and they had major traumas until the whole thing blew apart. Now we had Gloria's two, and I call them normal for want of a better term, and my two normal ones, then we had Hannah. And that's what I mean, I think Hannah was a great leveller in there. (Gloria) I think they actually just worked through it, because there wasn't the time for us to work through it with them. (Cloan) It was more than that in a way because if things blew up you couldn't afford to trauma. If there was a problem, "Right they've got a problem, right let's get the thing sorted out", because there wasn't the time and the energy to enter into trauma.

That's the way it had to be really because with the way Hannah was and with her needs, we couldn't afford to have a whole lot of this other junk on top. We would never have survived as people.

(Gloria) In actual fact we had some good times with the kids and they often look back on those times when we were all together. Every holidays we were together, and we would have these sessions where everybody would sit around and talk about things. If one was having a problem, then everybody would help. (Cloan) It was mean stuff. It was like family therapy, but the family were doing their own therapy type thing. So you had to get to the basics pretty quickly because you couldn't afford to keep going on that way. (Gloria) But I think the kids have come through it pretty well. I don't really worry that much about them, I think they've got a survival instinct now, and I guess it may be because they've had to survive - independently, emotionally, a lot of emotional independence there really.

One thing that really pulls us together is when there's a crisis as far as Hannah's concerned. Then you can guarantee we're all rooting together. I guess that's part of the strength of where we've been. If it's Hannah involved, then it's everyone to the pumps, type thing. (Gloria) Especially the kids. It's quite incredible, they're very protective of Hannah. I think, looking back, in those first five years, Justine particularly, gave a lot of practical and emotional support to me. If it was a hard time, she'd be there for you. I think that's the difference with my relationship with the kids, or in particular, my own children. I guess since then we haven't had a lot of major traumas in terms of Hannah.

(Cloan) We had some pretty steep learning curves and I think another thing was that we both came out of broken marriages. We virtually had to start in our financial aspect all over again. And we're still sort of starting with our financial aspect. (Gloria) We had to work hard because we had to look after Hannah, there had to be something for her. It was head down and butt up. In fact I think we've got to a stage where we need to look at what we're actually together for, what we're doing, and what our needs are at the moment. You can always project out to the future and I see people that have done that all their lives. Then they've actually come to the future and they have nothing, because there was no guarantee that what they did previously was going to get them anything. I think you've got to start living in the here and now and take advantage of things at the same time.

I think that probably the worst part of being a parent of a disabled child is the question of what's going to happen when you're not there. I think that's the worst one, worrying about what will happen, because you know that no one will love and protect the children as much as you do, and that's the reality. You can't rely on the siblings or anybody else for that matter. You can only ask people to oversee their care and hope that they take a genuine interest. When you work with people, and you see what happens to them when their parents aren't there, you know that those are the possibilities. So that's the only thing and I guess that's why you get so involved - you're planning for that person's future. I know it's the reason we've become involved with the trust house. But whilst you're doing that, I think it has to be in moderation. There has to be that balance because you can spend all this time hoping to shore up your future and there is no guarantee. You can only hope for the best, and not negate the fact that they're in the here and now. You give them as much as you can in the time - just balance it, just make it normal.

When Cloan and I first got together we thought we should ensure that there would be a trust or something to cater for Hannah's future. And I think what has happened is that Cloan can see the greater picture. Instead of being in one part of it, he's tending to want to be in all of it which is reasonable because they impact upon each other. But as one person you really can't cover every area.

What you're actually trying to do is make society become aware. People with disabilities are less value in any society, that's the reality. And there are swings in the pendulum. Probably in some societies, particularly nomadic ones, they'd have left children with disabilities at the river and carried on. Or they would have been left to die somehow. But we're, I guess, civilised. It's a bit of a worry. But that pendulum swings every time. The children need a fair go. We laud the medical profession for keeping a baby the size of a pound of butter alive but what does that mean? With something that big alive everybody says, "Wonderful, marvellous, it's just fantastic." But then they give that little thing to the parents, and say, "Yours now." I used to say that it takes the radicals to actually make the differences. Like, with the feminist movement and the burning of the bras. It needed something really shocking to get the attention but I guess that if society valued everything just because of the mere fact that they are here, that wouldn't be necessary. But that doesn't seem to be the case and so always it comes back to resources. It always comes back to money. As long as we operate on the current economic model then I guess it will never change, because as we've got more money then it gets better, and as we've got less it get's worse again. That'll always happen.

(Cloan) We took virtually a year and a half out of our lives and devoted it solely to advocacy. A lot of our personal money went into our advocacy, which was basically to stop the special schools closing down - not so much closing down, just the closing of them willy-nilly, that sort of thing. There are a lot of people out there who have got some fabulous ideas, in theory, but practicality has to rule in all cases. That's where we put most of our energy because we recognised that there will always be a need for a special school.

The debate's still going on. At the moment I'm involved in a national group called SPECC - Special Education Consumers Coalition. The idea there was that we'd all come together and front up to the government and say, "Do something about the situation or you'll feel the wrath of the combined disability group throughout New Zealand." But the group I belong to at the moment has eighteen member groups that have come together, and IHC says they don't want a bar of it because we happen to be advocating for a range of options. They have a single philosophy of inclusion. I believe any straight philosophy does not work in real terms. I think in all aspects of our life philosophy has to be tempered by a good measure of reality otherwise life wouldn't go on the way it does. Some would say, "You're self defeating, you're defeated before you even try." But in actual fact that's not the case. You have your ideals, but I think that most successful people in this world have been people who have had their ideals, but have been prepared to actually adapt and be malleable. That's just life. So we're staunch in as much as we believe that there should be options and choice. We haven't been able to agree with the philosophy of the IHC who have disestablished some communities of people with disabilities. In other walks of life like-people congregate together, but people who are disabled are not allowed to do that - they're different, they're special, and therefore they've got to be spread throughout the wider community where they're not going to have this contact with each other. (Gloria) I think you also had an organisation that was doing that en masse, rather than looking at what was happening for the needs of people within that small group. (Cloan) And so it became an imperative.

When we first got into advocacy Gloria and I did a trip. We got out there and we visited. We visited units, we visited all sorts of places to just see what was going on. We'd hear about great examples of inclusion and we'd go here and look at them and we'd say, "What?" and they were being put up as models. And people were saying, "Look how wonderfully it's working." We went right round the North Island looking at different placements because I felt that if you were going to start saying things you actually had to be talking from a knowing position, rather than from speculation or hearsay of what was happening.

(Gloria) Much of it was the same as what they were trying to replace. There was good and bad in that, but they made a blanket approach, and that was a real pity. They didn't take the good from one philosophy and meet somewhere in the middle, it was just either, or. (Cloan) We don't have imperatives in our lives, imperatives that say, "You will go out there and you will meet so many of these kind of people and so many of those kind of people." If you want to stay at home and be a recluse, that's fine. No one says that you have to go out there and do what I think is being forced upon a lot of our disabled community.

(Gloria) I guess there are swings and roundabouts in the new community homes and some are actually getting better as they progress along. But a lot of the people, at the stages that I saw them, didn't have a van, didn't have a swimming pool, which they may have had at Mangere, and they were wandering round the house doing absolutely nothing. But it's the same at another residential facility. I've seen residents just recently there and there are thirty odd people just standing around doing absolutely nothing really - no programmes for them at all.

It's developed that Cloan has become more of the person that is actually involved. I've become his sounding board at home and a way that he can talk about what's actually happening and get some feedback. I guess my work (paid employment) has come about because of my fourteen years hands on experience with Hannah. From my point of view, because of our pretty busy lifestyle and our involvement with disability, my skills haven't developed as well as they perhaps could have, because you tend to be a bit fractionalised.

(Cloan) I don't agree with that. When I was out there being the mouth Gloria was my research officer, and that's the reality of it. A lot of the ideas and a lot of the basic information Gloria was actually reading while I was out there. So while I was the high profile of it, Gloria was the one that was doing a lot of the research behind the scene, particularly when it came to deaf blindness. Gloria says I'm a person who is single minded and focused about things. I think if you really believe in something, if you have a belief in a set of principles, it helps a great deal. I've always had drive and energy in whatever I do, I've always been a doer.

(Gloria) It's not always easy to be in the supporter role. I met a woman the other day whose husband is high profile and she said that he would not be able to do what he did without her at home to keep things running. And I thought, yeah, well I guess that's right. Often, you know, you see people out there - high profile - but the nuts and bolts of the situation, like the washing and the ironing and just getting the groceries or whatever, still need to be done. And often that doesn't allow the other partner to do some of the other things that they might like to be involved with, and I guess I feel that myself. I suppose it's a partnership, and it's okay as a partnership as long as there are balances in there, as long as you come together at some stage and do something together, or be appreciative of what

the other does. I think that's what it is. You have to make sure that those balances are there. It's not only women. Recently I met a male partner and he was saying the same thing. Basically he was doing the hands on and he said that often you don't know what's going on, you're not always included in some of the dialogue. That's actually quite fractionalising for people at home, because whilst you're there supporting, you may not know all of the things that are going on, or maybe to be involved is just as important for you as it is for them.

(Cloan) Sometimes you've hashed it over so much that you don't really want to come home and hash it over all over again. You get saturated and you just want to come home and leave it. (Gloria) Maybe it needs to be shared. Perhaps you need to allow the other partner to be able to get out there, if they so desire, to actually become involved more. It's a hard one, it's certainly an issue for me.

(Cloan) At the moment we're saturated with involvement with disability. It's my second job and Gloria's first job. (Gloria) I don't know whether you can have disability in the home, disability in your job, and disability as your hobby which is basically what the advocacy has become, because you don't have any other hobby at all.

(Cloan) There comes a stage where you give out so much and then you say enough, you've given enough. I think we're getting to that stage now. (Gloria) There has to be a moderation there. What happens a lot of the time with people that are totally involved is that you forget about what's happening on your own home front and why you're in there in the first place - and the reason is normally because you have a disabled child. So the child tends to miss out, and your other children probably miss out as well, because your focus is on the one that's disabled. You can get to a stage where you've given out so much that you're depleting your own resources, resources that are being taken away from your family. I think that it's necessary to take stock and I think that for us that time has come now, otherwise the reason for being there in the first place won't exist any more, and that's a bit crazy really.

The trouble is that it is difficult to pull out of some things especially in terms of credibility. Like, with the Community House there's a lot of lobbying and a lot of work that's been put into that, but we do have to moderate involvement in everything. Two professional people working with a disabled child is a hard thing anyway, so you maybe have to look at different ways of working that out. You get into a bind. It's all very well to be able to go out there and be successful at what you do, but you end up with a dilemma. There'd be nothing nicer than for me to say there is a group of people there that would be able to carry through with things, understand the philosophy, and put in place all the structures, systems, and policies, that are required to actually make the thing happen in the way that it should happen, but there's not. So you've got to remain in there. It's the same with PVI and the National Body for SEPIT. You take it up and you start running with it and you can't just get part way through it and say, oh, I'm bored now, I've got to do something else. There is the integrity and you've got to keep on doing it until it has some satisfactory conclusion.

(Gloria) Part of the strategy I think, is that you actually have to train up other people that can take over. You can become the catalyst and move on, rather than just having to stay in there year, after year, after year, because you're the only person. (Cloan) Then there's the question as to whether others want to be enskilled, or are they quite happy for you to be there leading the charge, as it were. Do they really want to take it over and be the ones out front

leading the next charge? I find that the easiest thing for me to do is advocating for people of children with disabilities. It's easy, because you know at the basis of it, you're right. I find it very easy to be hardline too, when it comes to that. It's something that you know no one can attack you for your morality, for your ethics, or anything like that. It's easier than being religious.

(Gloria) For Cloan, he has been a professional, and worked with professionals, so they have never intimidated him. He hasn't been at that stage as a parent of a disabled child working with professionals who have intimidated him. For my part, to have actually come up through the ranks in that respect, and dealing with professionals, it's been a difficult thing. When you're trying to advocate for your child, you believe the professional, because the professional is the one that may make the difference to your child's life. So you're not necessarily going to kick them in the shins or do anything wrong. (Cloan) The rocking of the boat syndrome is a reality. Whether professionals like it or not, it's not necessarily just the squeaky wheel that gets the most oil, sometimes the squeaky wheel can act in the reverse, and I've seen it happen. And that's a modifying thing, particularly with your own daughter. It probably sounds strange, but to advocate for someone else's child - no problem, go in there boots and all and swing an axe if necessary - because if there's the anger you know it's directed at you and not at those parents. But for Hannah, I feel if I go in there too heavy, that it is going to have an influence on her welfare and wellbeing. What the professional holds over the parent is knowledge, "I know something, and you know nothing. I've got my fancy degree and I've got all these bits of paper and God knows what, and I've been here, there, and everywhere, and how dare you come and question my authority." It's not true of all professionals but I've mixed enough with teachers to see it operating on a grand scale within the teaching profession. And if it goes on in the teaching profession, it'll go on in every other profession. The teaching profession's nothing special.

Knowledge is power and I think some of the most wonderful people I've met in the professional field have been people who have been prepared to sit down and form that true alliance - not sitting there judgementally saying that you're a parent, you know nothing. That is absurd, because even a parent who may be deemed to be the most dull witted of persons, can't fail to see something happening with their child. They will pick up something. It's about applying that professional knowledge to the knowledge that's gained practically. It's a team effort.

The quality I as a parent would look for in a professional is compassion. This is something that I think a lot of professionals don't really even think about, "What the hell is it like for that person?" "What is it really like?" And the way the professional treats that person sitting there who fronts up as the parent, I mean, what is it really like for that person? I feel a lot of professionals do not have compassion. Just like when the guy came down the corridor and said, after he stuffed up one of Hannah's eyes, "Well, you know, she's got another eye and plenty of people have only got one eye", knowing full well that she's deaf, she's got cataracts, and the other eye's never, ever, going to be perfect. How insensitive, how dare that professional even presume to be so insensitive.

It's about being aware that the person sitting there is going through something that's a trauma. It's an ongoing trauma. You treat them like people. I've seen professionals go in and treat parents like dirt. Far too much head stuff and it's an arrogance, but then, I shouldn't say that is a fault of professionals alone. It seems to be humankind's folly. So to *say arrogance per se is the domain of professionals is probably being a bit unfair, but when you're in a situation like that, the arrogance seems to be a bitter pill to swallow.*

Professionals also need to be competent in what they're actually doing. So, I would say that as far as professionals are concerned, be compassionate, and realise that they are talking to someone who's going through a major trauma in their life, and an ongoing one at that. It's not like an appendix that can be fixed up and the patient sent out the door. But it's not only professionals. Your local Social Welfare front-desk person is exactly the same, asking the most diabolical questions of parents. And I suppose even the forms you get from Social Welfare. "Is your child still deaf blind?" I mean, surely there's got to be some point where they've got to say, "This child is deaf blind." But it's asked every year. It's a system that's applied in its rawest terms and there's no latitude for having a human face to it.

Disability is the real arse-end of the world. No one, in their right mind would choose to have a disabled child. In New Zealand there's a funny attitude towards us. If you have a look at OECD countries, we lag severely behind in the amount of funding we actually give, for special education, for example. Substantially, we are just a little bit down the track, but not round the corner, not even into the back straight yet. I find it strange that in a colonial country where people depended so much upon each other, they can be so blasé about the whole thing. But I honestly do believe if the whole thing was raised up to a level of consciousness of the population, that they would demand that something be done. I believe that it never really reaches a level that actually strikes home at people, where they can say, "Well that's not right." These things should be basic rights. We shouldn't have to walk around trying to get the funding together.

The policy makers know what's going on but they can't come out and say, "Well you're dead right, but there just isn't enough funding out there." There's no way that they can sit there and take the line that they do and not know the truth. We get all sorts of subliminal type messages, but they've got to be staunch. There are times when the facade just drops, in that flickering instance when you pierce in there and you see the real thoughts that are going on behind that person, but that's about as much as you'll get. So I believe that those policy people are aware. It's like there's their public job and their private person, but their private person will never, ever, break through in a situation like that, because their jobs are down the line if they don't tow the party line, and that's the reality of it.

There are times when we get really frustrated with the slowness of things. We want solutions now, not ten years down the track when our kids are out of the system. I must admit, I have sometimes given it full barrel to the policy makers. After all they are the Minister's agents and if they can't get up there and plead a case to that minister, then they're not worth the salt that they're on about. You call upon the real self in that situation. You've got to get to that real self, cut the bullshit of all this facade that's put up. I make no apology for attacking people at that level. They put themselves out there, they put themselves up for criticism. I get quite emotional about that.

When we consider our needs, I think Gloria and I have needs that are no different to a normal family in which mum and dad work. Essentially we're no different to thousands of families out there. But there are added pressures. For example, come the holidays, adolescents of Hannah's age might possibly go down country to one of the relatives to spend some time on the farm, or they might go into town. At fourteen years of age, I would say *that a child would be quite capable of hopping on a bus and going somewhere - round to their mate's place to spin a few yarns or cruising for the day. And where I'm coming to is, essentially to be normal we do need a support system. For example, we really enjoy Twenty Eight Day Care because it allows us at least to fulfil our requirements of what we want out of this life, and not have to fork out from our own pocket. What I'm saying is, basically, I would hope that there would be at least some support structures that would allow us to act as a normal family. We have aspirations no different to anyone else. One of Gloria's sisters said, "Oh, you should be staying at home and looking after Hannah." It's almost like laying a guilt trip. "What the hell are you doing out there working when you've got this disabled daughter?" I mean, it's instilled into us these days that to be a whole person you have to have this independence of income. That's almost an expectation. But then you can have someone turn round and say, "Well, you should be home looking after this person." Nobody would actually wish themselves into the disability end of life. It's an exhausting thing, not only the day to day practicalities, but the whole emotional thing and dealing with those things in society that are not right as well.*

(Gloria) The attitudes of others impact. It's quite interesting when you've got staff that have never experienced having someone disabled around them and they are having to cope with the wider community and their attitudes. They get very, very frustrated with people staring at them, and that sort of thing. The staff in the Community House are just coming to terms with attitudes in the community, they've never been exposed to that before. (Cloan) You tend to forget, when you're with Hannah. To us, Hannah's just Hannah. But then you can walk through a place like St. Lukes and you realise that there are a thousand eyes staring at you. But overall, that's what it's like, it's a bitter realisation. (Gloria) And that's part of the frustration for people, particularly if you're having a bad day. You can tend to want to lash out, and that sometimes happens. You might blow your fuse and get very short with people like, "What are you staring at?", that sort of thing. And I've noticed it with staff, they actually feel the same way, and yet they're not the parents of those young adults, but they want to lash out too. So, it's quite interesting that.

How have we coped? We're really quite emotional people, both of us, and we can lash out quite badly at times at each other. It sort of peaks and then there's this period of calm. Then it starts again. But all great artists have been like that. We tend to keep it amongst ourselves. It does affect the others in the family when we're having a bit of a bitch at each other of course. As people, we've actually had quite a lot of stresses, whether self-induced or not, and I think a lot of them have been because we've chosen to go down some routes that had the potential to put off any normal, sane person, and we've actually survived them. I think we're quite strong people in our own individual right.

(Cloan) For myself, essentially I identify with the underdog. I have always been cast in the role of the underdog. And people say, "Look at all your abilities, how can you be an underdog?", but in some respects it's because I've got the abilities that I'm cast in that role anyway. I identify with being purposely put down. And that's given me strength.

(Gloria) For me, I've come from a large family and I probably role-modelled my mother. I've seen her operate, and it was just something that she did because that's what she had to do. And I guess that's what you do, because that's the job you've been given, so you get on with it. I've probably been able to get that much further down the track than her because I've got back out and got myself a job. Maybe that's the difference between me and my

mother, but I think she's an extremely good person and an extremely strong person. I guess too, I've got good organisational skills. It's hard to know because I really don't see that what I am, is any different to what anybody else is. In fact, I see myself as probably being less than some, so that's a problem that I haven't come to terms with. I guess it's to do with where I've come from educationally, that I haven't had the education that I should have had, or could have had. I've always seen that as being a stumbling block for my progression. The knowledge I have has been born out of having Hannah and doing a lot of reading on Hannah's disability. I think I could be further down the track in my career if I hadn't been quite so fractionalised. But then I guess I wouldn't be in it if it wasn't for the fact that I had Hannah. So it's a real problem there. I suppose, with our involvement with disability, and this being probably my only career, I would have liked to have done it really well and become more of an expert than perhaps I have. There are a lot of gaps in my education so it's very difficult to put it together because you can't go out and fill all those gaps, not in one lifetime. It's hard when you come from the position of life experience. I found it difficult working in the Foundation for the Blind, because there are professionals who are threatened by someone coming in that has those life-skills as a base, rather than having acquired them by going off to study. I guess having both is probably the ideal, and that's why I'd like to have extended what I should know academically and built on what I know in my life-skills. But there hasn't been a lot of opportunity to do that, so it's been learning on the job once again, and just doing all my own reading. At one stage I did go to varsity for a year, but when I went back there it was hard. Your concentration span is something like ten to fifteen minutes because you've spent years with a child where you had to go to-and-fro. But I've done lot of reading and I may not have actually internalised and remembered it all, but some has obviously rubbed off and made a difference.

(Cloan) Something that we have gained through the advocacy thing, is that we've got to know a lot of good people, interesting people. (Gloria) For me personally, the social worker from the Foundation for the Blind was a good person to have as a contact and I was lucky that I had an amazing paediatrician to start with. He was brilliant. I was lucky, too, that there was the McKenzie Centre in Hamilton. In those early days, they were all worthwhile.

(Cloan) The social welfare system's a minefield. The education system just boils down to the fact that if you've got a child who is disabled, you're starting right at the bottom of the cliff. And quite honestly, there are very few occasions when the people in those systems and services will reach down, take you by the hand, and give you a leg up, that's if they want to know about you at all. It's not made easy. A lot of these systems are only operating with you because they have to. If you are entitled to some funding because your child has a disability, you generally have to scrap and fight to get it. (Gloria) It's as if a lot of people in those places are trained to take it personally, that the money's actually theirs. You actually have to fight. It's very demoralising. It's not a user friendly system. How have we negotiated these systems? Just out of sheer bloody mindedness a lot of them.

(Gloria) We need more time out, I guess, but it's a dilemma. It's back to finding someone that you're going to be comfortable with to look after your child while you're having your time out, because there's nothing worse than having time out and worrying about it. But then I think if we cut down on some time elsewhere then we may be able to look at that situation.

(Cloan) I think we're pretty lucky in a lot of respects. After all our gripes and groans, as a unit, we are pretty well catered for, except for perhaps, as Gloria said, just the time out. And we're a good team. When we're working totally as a team, we'll cream you. When we're actually focused and doing it together we're just totally directional.

FAMILY PROFILE

Adolescent: **Hannah**

Age: 14 years
Sex: Female

Visual condition: Cataracts, reduced visual fields
Congenital Rubella Syndrome
Visual impairment first noticed by mother and diagnosed by doctor when a baby
Low Vision
Visual/Manual (signing) mode of communication
Other conditions: Profound hearing loss (deaf-blindness)

Educational placement: Homai Vision Education Centre

Parents: **Gloria & Cloan**

Ages: 45 & 44

Marital/Parental situation: A family which 'blended' over ten years ago and is comprised of Gloria and her three children and Cloan and his two sons
Vocations: Vision and hearing impaired co-ordinator;
Documentation specialist

Siblings:	**Justine**	**Robert**	**James**	**Dylan**
Ages:	26 years;	25 years;	20 years;	20 years
Sex:	Female;	Male;	Male;	Male

Family

Time in present community: 1 year

Most important to family: Openness, honesty, friendship, wellbeing

Effective support systems: Family, other parents of vision impaired children

'Gift' to other families: "Don't expect anything to be given to you as of right because you have a child with a disability. Be proactive and make sure that you talk to other parents who have been through the experiences."

SHAUN B's FAMILY

Narrated by Violet

... there are a lot of issues that I found as a parent I needed the opportunity to be able to talk about - your guilt, your shame, the whole bit - without having to continue to carry it, to be able to say, yes, I felt guilty, and angry and the rest of it. There is a need for someone who can find the thing that you are really asking for within the conversation, someone with the right listening skills. I think a person that has a good listening ear is going to achieve more than any other person.

Kia ora tatou, kia ora tatou katoa
Ko Violet taku ingoa.
Ko te Orewai (Ngapuhi) taku iwi.
Me wha tamariki.
Nau mai haere mai, tena koutou tena koutou katoa.

My name is Violet and this is our story. Shaun is the youngest of my four children. He has two sisters and a brother. He was born nearly three months premature and was a very tiny baby. At one stage he was given too much oxygen which caused total blindness, brain damage and hemiplegia of the right side.

Shaun doesn't have very good communication. He appears to understand a lot but his expressive language is not very good. Although he can tell us his needs, he sometimes gets frustrated because he can't always tell us what it is that he does want. Consequently we all tend to get a bit up tight, but we are working through it. Today Shaun can ride a skateboard sitting down, he loves to swim, and enjoys going to the beach and long walks. Like a typical teenager he does not like picking up after himself. Shaun's not too bad at dressing himself but he still needs to be supervised and assisted in many of the things he does.

Looking back to our family's beginnings we come basically from a working class family and at the time that Shaun was born my husband was working and I was part time working and we were always involved in sport so we took Shaun along to all of our sports. My husband played rugby and I played netball. In the summer we followed the surf around and we'd go up to Mahia. There used to be a whole group of us young parents. Our husbands played rugby as well as surfing and so we were all sort of close knit. The wives played netball for the same club. We'd all go off for holidays together and that used to be a lot of fun. We did a lot of that when Shaun was younger.

Then of course things changed. My family were all back in Auckland. It was just mainly James' family there and they were quite supportive at the time. Shaun was born at 6 months - they think he just might have made it to the 28th week. He wasn't quite the weight of 2 pounds of butter - he was only tiny and then of course he lost a lot of weight. He went down to 700 grams. There were complications prior to the birth. I had a kidney infection. My temperature went up and I was also haemorrhaging because the placenta had come away from the uterus. I didn't realise what was happening because I was at home and the next day I rang the doctor and was consequently rushed to hospital.

The doctors were unsure of the effects and when I had a scan to check out to see if the baby was ok everything seemed fine. Well, from the time I came back from the scan to my room my temperature had shot up, and I just proceeded to get worse and worse and I had everybody thinking, what's wrong with this woman? That's when they found out that I had a kidney infection. By then the baby was getting stressed and he was constantly kicking and moving and I remember the doctor saying to me that through the drip he would feed the medication that develops the lungs to make them stronger. He said, "I know that you are in a lot of pain, but we have to try to delay the birth." That went on for 48 hours. And then it was time. The GP had said to me, "We're not sure whether he will cope." He was a forceps delivery and when I first saw him being yanked out he looked quite big. It wasn't until I got to see him in an incubator that I saw how small he was and I was really shocked. I always remember my GP coming down and saying, "Well, would you like to come down and *see your baby now?" I don't think I wanted to because I was afraid he might die or something. And he said that was a possibility. They give forty eight hours. If they survive that forty eight hours then they've got a chance. I sat there for a few hours sort of thinking, because I didn't really want to see him in case I got attached to him and then he'd be gone. The doctor said, "Well I believe it would be in your best interests if you did see him even if he did die." So I went. When I saw him in the incubator I was pretty shocked because I thought he was sure to die - something that little doesn't survive. They said that because he was a male too, his chances of survival were less. The forty eight hours came and went and then they gave him ten days and he seemed to be coping quite well. Then he got an infection. They were actually preparing him to come out of the incubator and they rang us up to say that he had got an infection. There were quite a few premature babies at the time when Shaun was there and he was the only one that got the infection. That apparently caused Shaun to have a stroke. So he had a stroke and he had to have some blood transfusions as well. He actually went through quite a lot.*

I remember a few years later when he was about two the specialist talking about the events that we had been through and asking us what things we felt would have helped us to cope. I said, "Well, maybe either someone who had been through the experience who would come and talk to you or a social worker that could explain what was happening." The nurses I found were very good but they didn't really tell you anything and then having to go on those horrible milk machines. I remember being up there with the children and them going, "Oh, mum, that looks terrible. Gee mum you look like the cows do." And I said, "I know, I feel like one." And my husband is going, "Do you think the children need to see it?" and I said, "Well I think it's ok." I mean, I had to take them to the hospital anyway. And they went, "We're not going to watch this mum. It looks so gross." So you know they got to see and watch things. And I remember years later my oldest daughter saying to me, "Do all women have to go though those indignities?" And I said, "Yes. I'm afraid they do. We do." She goes, "It's embarrassing."

At the beginning when Shaun was first born there was a lot of stress in going back and forwards to the hospital. I had to learn quickly how to drive because up until that stage I didn't know how to drive. We also needed to move after Shaun was born. We put in an application to change houses because we had a two storeyed unit. Our application came through and we moved out to this other suburb so I had to learn how to drive to get in to the hospital. It was a crash course in driving. It was hard because we had lived in town and there hadn't been a need for me to drive, we just walked everywhere. Consequently now that we live out in the suburb we drive everywhere. Even to the shops. But I guess I was lucky because of the friends I had and the support. Shaun was in hospital for four months. He was born in the beginning of October and he didn't come home until the end of January. So I had to travel quite a bit and we moved out to the new place just before Christmas. That was quite a challenge.

There were so many things changing - lots of things happening in our lives, personally as well. When Shaun came along the older two were coming up to teenagers and that was really difficult. It was hard to cope with Shaun, particularly after he came home, and with their needs as well. Actually the first two years of having Shaun at home was quite difficult because the older girl was going through her adolescent problems.

It was really hard for us as parents because at the beginning there wasn't any social worker to come and help and we didn't have anyone to talk to about what was happening. There were so many things that were going on and the marriage before Shaun was born wasn't very good. When Shaun came along, I guess we had to sort of rethink things but not having anyone to talk to was really difficult. I'd say for the first four years of Shaun's life when I look back now, I don't know how we coped.

When Shaun came home I had a Public Health Nurse. She was wonderful and I guess if she hadn't kept a watch over us .... She used to call quite regularly 'cause Shaun also being a premature baby had a hernia, and I remember this day when he was really screaming and I was thinking, gosh something's really wrong, and she turned up. He was rushed to hospital and everything else. And the Public Health Nurse was the one that actually suggested that we could perhaps have a counsellor to help us. But at the time there didn't seem anyone that was suitable. We did have someone come but - well - we didn't know we could go and find someone else. So a lot of things that needed talking about then didn't happen until later on and that was when I personally went out to find help myself to cope with things. Then I got involved in community work. But having Shaun has been quite a challenge to say the least.

We didn't feel the information from the doctors was adequate. I think they tried to explain it when I think back. For the time that Shaun was in the incubator the eye specialist was coming in and he was explaining what was happening - how the retina detaches because of the rapid growth of the blood cells. He said that when they come out of the incubator the growth usually slows down but in Shaun's case it hadn't. They had just continued the detachment. He sort of said it can cause some visual impairment. He didn't say a lot. He just said that he hoped that there wouldn't be too much damage but they were not sure yet. After six weeks I went back and that was when he found that Shaun's retinas had detached. And he just said to me, "Shaun is totally blind." Then I had a meeting with the specialist at the hospital, the paediatrician. There were two doctors that were on Shaun's case and when I think back to then, I think we didn't know what sort of questions to ask and a lot of the times that the meetings were arranged, they were arranged during my husband's working hours. We weren't assertive enough to know that he could have got some hours off work to go. It wasn't until two years later that my husband realised that he could have done that because when he eventually told the bosses that we have a son that is disabled, they were really supportive and they did say to him, "Well any time that you need to have time off work just ask." But that was so many years down the track. It was amazing when I think back now. Young parents today are more assertive.

So the paediatricians said that Shaun was blind and that he may have some other complications because of the oxygen. They didn't know whether he would sustain much brain damage, but there was never anyone who showed us a diagram of the brain. And they didn't say that epilepsy could be part of that as well. Or the hemiplegia. I didn't know Shaun even had hemiplegia until the RNZFB Early Childhood Social Worker told me because it was in the report. For the two years that I was visiting the Child Development Unit, nobody had ever said to me, "Your son has a weak right side." We hadn't seen the reports and we didn't realise that we could ask. So I went back and said to them, "How come you didn't tell us that Shaun had this impediment of the right side?" And he said, "Oh, I thought you understood what cerebral palsy was." And of course we said, no, and then I remembered the day he said and we had asked what it meant and he had just carried on talking and so it sort of got washed over.

It was really interesting because I remember the first thing to accept and digest was that Shaun was totally blind, because that's what the eye specialist had said. Then when I went to visit the paediatricians they said there may be some brain damage but they didn't know what. All that I could think of was the first thing that I was told, and that was "totally blind." So I guess that the only thing that we really focused on was the blindness until we got further down the track to see how the development stages were going.

The epilepsy started later. When I look back now, Shaun must have been having some petit mal ones, but we just thought it was all part of the blindness. I remember that he had one big one at Homai College when he was there to give us a six weeks break. Then Shaun came home and one hot day he'd come back from the CCS playgroup. He was in the front seat of the car and he was really, really hot and the driver when she came up said, "I think there is something wrong with your son." I thought, gosh, he doesn't look well and so I rushed him into the doctor and that's when we found out it was a seizure. And it was like, something else to cope with. A lot of the things didn't sink in because the focus was on the blindness, because the blindness affects everything. So we worked with that.

When I found out about the cerebral palsy I felt guilty, simply because we had been really working hard on Shaun walking and we were always trying to work out why it was that he couldn't balance properly. Mind you he got to be walking but we had to really push him. Nobody was saying to us that he can't balance properly to do that, and the whole bit, and really to sit down and explain it. I remember feeling really angry. I went back and said I was angry because I felt guilty about the way we were pushing him to walk and other things and then the social worker said one day, "Well, maybe in some ways it was really good because it got him further ahead. Maybe you wouldn't have pushed so hard then. He's moving now and he's actually able to get up and walk." She was saying we were doing our best and so it made us feel a bit better.

Initially we didn't have much family support at all due in part that my family lived in Auckland. I remember a comment once by a Pakeha parent saying she envied us Maori people because we have extended families and I said, for myself, it was non-existent. However, in the latter years my sisters have been of great support since they moved into the area. My mother never came to see Shaun until he was three years old. I remember talking to her when she finally came down for Christmas with my sisters. I remember saying to her that I was really hurt that she didn't come and support me particularly in the months that Shaun was in hospital. When I look back I don't know how I really coped with the daily visits to the hospital, having to look after him and three children, because if it wasn't for several friends I wouldn't have even got up to the hospital. My mother said that she didn't know what to do and didn't know whether she could cope with someone that had a disability. She didn't know how to be. My mum was always very quiet and the only time I heard her talk very much was when she was with her own family and they would speak in Maori. But years later it came out. I was with my mum and several of my sisters and we got to talk about our beliefs. It was really interesting because that was when she got to speak about when Shaun was born. She actually believed that it was a curse of sorts. I asked her what curse she would have thought and she spoke in Maori because she was more or less saying well, you know, way back something had happened in the family, but she didn't go into the whakapapa, the details. She felt that the curse had come from there. I didn't realise that she still believed that and she said that day that sometimes she couldn't help but think that way. And I remember talking to a cousin later and he was saying that's what he felt at the *time. That's why my mum didn't come to help. She's dead now, but it was interesting to hear that at that time. She felt responsible. And I remember as a young child there were a lot of accidents that actually happened to me and I often used to hear her talk that way and I didn't take much notice, until that day. When I look back over my life we had some horrific times and things were often put down to the curse. It was really quite fascinating in a way. I remember meeting up with some of the Ngati Kapo group and some of the older adults talked about when they lost their vision and how several of them were cast out because it was felt that a curse had happened. One woman had spoken about when she was actually a student at the school for blind children when it was at Parnell, and she had got stung by a bee. Her family never visited her while she was there because they believed it was a curse. It seemed strange to hear but it made me look at my own belief system. So even though I was hurt that my mother hadn't supported me and my family, I felt aroha for her because she was honest about how she felt. Before she died she spent some time with Shaun and I will always remember him having fun with her. It was wonderful to see.*

There weren't really many services for the preschoolers back then. The CCS were really good and then of course the RNZFB preschool adviser. She and the RNZFB social worker were really supportive. From her I learnt that we had rights to see Shaun's files. We hadn't realised that we were allowed to. I got support from these people because I was always home. There was also support from the CCS Playgroup, and of course there were other mothers there that you could talk to. Shaun was the only blind child they had ever had, but that was okay. So I was supported in that way and I could still talk to the other women.

I remember feeling quite sad because the relationship between my husband and I was also suffering, but he was hanging in there. I felt sorry for him because there was no support for him. There was always a lot of support for myself because I went out and looked for it anyway. I asked some of the other wives, what happens for the men? Because my husband didn't like to talk, he just got on with things. So a lot of the emotional things we didn't actually talk about, we just dealt with what was on the surface. The deeper stuff, like the guilt and shame we didn't address. I think that didn't come round till about 10 years later, when I had learnt about communication and started to talk to him about it. Being young parents too, we still hadn't mastered the art of communication. And the marriage was up and down a lot.

I also felt for our children. That was a hard time for them too. It wasn't until they got older and I had gone and found out for myself about communication skills and become involved in community work and counselling for Parentline, that I learnt to use those skills with the children. But that was quite a few years down the track. I remember going to a seminar we had at the Sensory Resource Centre about siblings and what comes up for them. I read a list of things that come up for brothers and sisters and I thought, we've never sat down and discussed a lot of the things with the children. We've just gone on and it's not until now the children are adults and learnt to be a little bit more assertive that we talk about those sort of things. I often thought about conferences or workshops for brothers and sisters and wished that I had actually been able to send my own children to them, to give them an opportunity to talk about how they felt about having a brother like Shaun. I've only learnt about it as I've gotten older. The children talk about their own guilts now. It was hard giving the attention and with our older son he had his thing as well. He was at High School and there was a stage when we didn't realise how much school he was missing. One day we got a ring from the school saying, "Mrs P..... and Mr P..... did you realise that your son hasn't been *to school for 6 months?" and you sort of realise, gosh, you haven't been communicating with these children - or somewhere along the line it all breaks down. And somehow it seemed too late to get family therapy or family counselling at that time. So one just battled on the best way they knew how. And one can look in hindsight now or reflect back but a major thing for me was not having any other Maori parents around with a child who was disabled. One day when the social worker came to visit he brought a visually impaired gentleman with him. I thought that was really wonderful but I still couldn't relate to him. I knew what he was saying - that many things can be accomplished - and you have a hope that your child is going to achieve things like that, even with a disability. And I guess TV is a great media for that too. There was a series with a blind man, a blind detective and it was like, if he can accomplish things it gives expectations. But it wasn't until years later that we realised that if you have your sight first, it's very different to not having it at all in the beginning. But we didn't know the difference. When people heard that Shaun was totally blind they compared that too and thought he could learn to do anything.*

Today when I talk to Maori parents and ask them how it is, I'm not really asking how is it with the services, I'm asking how it is for them as Maori parents and a lot of them don't really relate to that because they think we're all parents. I didn't really relate to it either until years later I realised what it was that I felt was missing that day that the social worker brought this gentleman in. If he had brought me someone that was Maori it would have been different. Relating would have been different.

I remember the day that it actually went click. I was at a conference where I had to get up and speak to the teachers and that's when it actually came out. I remember saying to my sisters, "I'm going to talk about this - about being Maori." I notice that some of the parents sometimes when they start to talk about different issues that may come up for us as Maoris, they have to really think about it. I know as parents many of us had to face the same things but there always seemed to be subtle things. For example, I know in dealing with the paediatricians they seemed to treat us differently. With one of them I always just felt that when he went to explain things he didn't think that we would really understand. And I don't think it had to do with just being the parent. I always felt that there was the underlying thing of being Maori. He would always say "Do you think you would understand?" and my husband and I would look at each other and ask what he meant. One day when we had come out of the office after this had happened again my husband asked if I thought it had anything to do with us being Maori. I thought so. I mean we didn't want to think that was maybe the reason, but it seemed to be. And the other thing was the assumptions that because we were Maori, we would be very compassionate and loving.

From what I hear from other parents they felt the same. Some professionals don't like to share their knowledge. Recently we tried to get more information about some of Shaun's medical conditions and it was really difficult to get any answers. We came away from the appointment with nothing further - it was just a waste of time. We were made to feel that we were trying to lay blame rather than wanting some clear facts.

I'd have to say a lot of the time I took the decision-making role on even before I even realised that. When I look back now I can see how I just automatically took that on at some stage. Because I guess I felt my husband wasn't coping and so it just became another role to take and having been the oldest child that's quite easy to do. I didn't realise how much responsibility I felt I had to carry to keep me functioning. Last year was really stressful.

There was a change in the family situation in that I'm separated now and I stopped working. My GP and others commented that they were not surprised - I felt I'd missed something. I actually thought my husband coped the best he knew how with the limited support he had emotionally. We both needed it but instead of trying to come together - we did to a point - we went our separate ways which is quite sad. I think now that hospitals or health services provide families with social workers that's been a big improvement. I remember meeting one of them and I said, "Where were you so many years ago when we really needed you?" I feel young parents today are a little bit luckier in the sense that there is more help and there's more information, although when I approach some parents and ask how they are feeling some of them go blank because they haven't really touched it or come to terms with it.

In the few years I have worked in the Special Education Service that has given me an insight into how parents learn to cope with things and come to terms with some of the issues. Also being a service provider gave me insight into professionals and teachers and how difficult the task is for them as well. They want to do the right thing but they are trying to find how they do that too. So I got to appreciate the both sides. I also encountered the difficulties for teachers without the resources and the help that they need as well. There are some wonderful teachers out there.

I think the hardest thing for me to accept was that Shaun was intellectually handicapped. I could accept that he was totally blind and there's always that argument that he could be an individual in his own right and independent. But I think I am only really starting to come to terms with just how difficult it is for him and how frustrating it's been all those years, I guess for myself, and for him, because of having to accept the fact that he is intellectually handicapped and what that entails and the implications of that for him. Part of this was to do with my own image of intellectually handicapped children. I hadn't realised the breadth of degree in disability. And when I realised I thought a long time about that. Some of the areas that we wanted to help Shaun in we couldn't because we were ignorant of the intellectual disability and in a lot of ways that's where I feel we may have let him down. Perhaps if we had looked at the whole picture, but as a parent I only focused on several things. I couldn't focus on the whole thing until later. Now he's a teenager it's going to be difficult to try and do things for him, or with him, because he's developed behaviour problems. The behaviours are also part of the disability.

I believe part of the motivation for becoming involved in SES, in addition to the fact of truly believing in the value of early intervention, was that I needed to find answers and that was the place to start for me. It was really interesting how easy it was to accept once I got the information and was able to digest it. I was able to talk to someone because I had a colleague who was a psychologist and there were questions that they would answer without having to feel that they had to develop an answer for me. So I got a normal, factual and straight-out answer, rather than one that they felt that they had to colour because you were a parent and you didn't understand.

I also became involved with PVI because I was looking for answers to do with Shaun. I was looking a lot for myself personally too, although I wouldn't have recognised that then. When I first became involved I had no idea what it entailed and I really did not sit back and think why was I doing it. It just sounded like a good idea and I wanted to be given the opportunity. Looking back one of the things I did want to see was more Maori parents because as a Maori parent myself I felt isolated. Even if it just meant sitting on the *committee and being a face there - it meant being there. A lot of times that's virtually all I feel I've done. Raising awareness. It's been really good to see more Maori parents coming through now and I hope it may have made something happen. I did it because initially there weren't any Maori parents there. Whatever meetings I ever went to I never saw any Maori parents but I knew there were some with children and I actually got to see them when I came to Homai. So I guess I felt because we were isolated as Maori parents I wanted to meet other parents. When Shaun went to the Special School I got to meet other parents there that have older IHC children and listening to them talking they say they wished they'd had some of the knowledge available now. As Maori parents we were really not encouraged to ask. When I look back I don't think anyone said, except the early childhood social worker and those at Homai, that you had the right to ask. And for me, if I'd had another Maori parent that came up and said, "Look as a Maori parent you have a right to ask," that would have made a big difference to me. We always felt we had suffered by the schooling system ourselves. So of course we didn't trust it anyway. So it's good for parents to have a support group that is willing to go into battle so long as we don't lose focus on keeping in touch as parents. We need also to be keeping the networks going with other parent groups like IHC because we are all aiming for the same things. One of the things I find really interesting is that they're not going to get less. I actually think there are going to be more children who are going to have disabilities and we are going to need more people with the expertise to be able to cope. We've got all these injuries and medical conditions with children now and a lot of times that involves vision. I think PVI is really lucky as a group to be supported by the Foundation and to be funded. I think that's one of the reasons it's been so successful.*

In thinking about support and services to Maori I like the opportunity that we now have with Ngati Kapo. However I believe that regardless of who we are we still need to have the skills to do the job. We all come with different skills and I think for some of our whanau workers there still has to be the skills like communication. Working with parents is different from working with disabled people. The approach needs to be different and that needs to be learnt. How you approach one person is totally different to how you approach another. I guess until you are aware and accept that people are different you can't treat them the same. So I'd like to see whanau workers develop more skills in certain areas - a lot to do with communication and especially listening skills. I like the idea that parents have a consumer choice now, whether they have a Maori or a Pakeha whanau/social worker. The social workers that I have come in contact with have been very good but there were times that if I'd known there was a Maori worker I'd have gone to them for certain things. And then used both rather than just one. I see that as a good thing to have access to both. But I think so long as the workers themselves have good communication skills too many things shouldn't go wrong. And if people don't know the answers, they need to say they don't know.

I found when I was working one of the things that was interesting was relating to the Samoan families down in our area. I remember thinking, oh, I don't know about that culture, because there are families where there is a Maori wife and a Samoan husband. I went to the women who were Maori but they did not know a lot about their husband's culture themselves. And the husbands sort of smile and don't say anything so I actually just say straight out that I don't know about their culture and if they feel that they don't need me there, or if they wanted someone else to come round, I would try to find a Samoan. But a lot of the times they felt it wasn't necessary. I actually found it just easier to come right out as soon as I met them to say that I'm not aware of their culture and that there are things that they may do differently. I ask them to let me know because in ignorance I might say stupid things that *offend them. It sort of breaks the ice and I found sometimes the fathers didn't have very good English and then I would ask if they wanted me to speak a bit slower. I find a lot of families still get in contact with me even though I no longer work for the Special Education Service. In my work I sometimes shared some of my own experiences. That helped a lot, being a parent as well, and it just depended on whatever was happening at that time. A lot of times I wouldn't mention it and then somebody would say, "Oh do you know that Violet's a parent too?" And it gave me access in. There were a lot of times I think I was the only person that parents could talk to, they didn't have anyone else and the counselling skills I learnt came in handy. But I think for Maori families you need to be a little bit more real in approach. It's like the old saying, "Do unto others as you would do unto yourself." I guess that's what I practise, what I try to do.*

We need more O&Ms and counsellors. Maoris tend to shy away from counsellors and therapists. I always advocated that they use them. Definitely we need to have social workers or support persons. Parents need help in finding out about benefits and other things. Often the GP will give them the information but then they are not sure how to go about accessing things, so for the majority of parents that I have spoken to, I've advised them to use a social worker whenever they need them. It is their job to support, so use them.

I actually find now that as the disabled children get older support is very small. If you've got teenagers that have got problems it's even more difficult to get help. I actually found that I had to go out into the community to seek help for Shaun. I've had help finding it from the workers from IHC, RNZFB and CCS. We all got together and we sat down and looked at ways that we could find people in the community to help. We were successful in finding extra funding and also trying to find families to provide support. That was an interesting exercise because there were quite a lot of organisations out there, like Christian organisations, that had lots of families willing to take disabled children. However, Shaun caused a bit of a problem because he is now very intolerant of other children and when a baby cries he is still very intolerant of that noise. He lashes out and once families got to hear that, it was very difficult and he got taken off the list. So for children that have challenging behaviours it is very difficult in the teenage years.

Shaun's not the only one. There are quite a few of his age group in the community that have different disabilities and the only thing to give the parents a break is sending them down to Kimberley. That was open to Shaun as well and I thought, six weeks away there and then Shaun would come back and I'd have to start all over again. It defeats the purpose. So we looked for several people and it's still ongoing. I find that quite frustrating. But it was good that the three services came together, that was an excellent time and really helpful. We would have a monthly meeting all together to see how things were going and they would have the different families. But I still ended up having to find my own help because the list just dwindled down. One of the ideas we came up with was to advertise for senior high school students. The others didn't think it was a good idea and I said that I felt maybe we might start something - I don't know what but if we don't try something ...

It would be good if we had a person in that age group because trying to find friends for Shaun is really hard - it would be lovely if you could go out and buy some. Unless I, or the school, take him out into the community he's really not involved in any extra activities at the moment. That is still up to me to do. I'm finding it quite hard now and I don't think it's going to get easier. As the children become adults I think care becomes quite a big issue.

IHC are now assisting in this area and there are more opportunities for workers to be trained and upskilled. In our area there just haven't been the workers there and those that were skilled have been leaving because they were not being supported themselves.

I believe that service providers need to be looking at the teenage group and how they will support families, particularly ones that have challenging behaviours. There's not enough skilled workers around for that age group for them to be doing things. There are lots of things that I think Shaun should be doing, and could be doing, given the right atmosphere and people. I've watched at home. One of the things I did when I was working full time was to get a swimming pool so that we could become the focus point in our little street, which we have done. I've watched Shaun over the years and he could go out and swim whenever he wanted to do something for himself. As he's gotten older the younger children in the neighbourhood still come for swims and he won't go out when they're there. When the older kids come he goes out, which suggests to me, he knows, he's aware. He goes out there and he sits and listens to them. They are still a bit wary of him so they just play around him. But he still wants to be part of that group. He doesn't want to be part of a younger group. That's been quite a learning thing having my swimming pool. I mean, it's an awkward age anyway for all teenagers and it saddens me to think that there are children his age that can't have their own peers around them. I guess I find that it's difficult between the ages of say fourteen or fifteen, up to about eighteen to twenty, and if they have multiple disabilities, what is there out in the community for them? You need the community more then too. Young children tend to be acceptable but you need to ask for more help for teenagers and it's more difficult to get. So I think that this age group becomes isolated. My daughter who is nineteen actually finds it more difficult now to go out in public with Shaun than the older two. When I asked her why she has a problem with that she said, "I don't know - I just don't want to be seen with him."

I know there are Maori groups in the community that are looking to finance their own members for health services and support, and look to having their own whares for the disabled in the community. I am starting to get involved in one of those groups because I see that as a need also. Getting to know some of the Maori IHC Workers has been quite interesting. They are now talking about their own issues in working, and their needs, and this had caused them to wonder about the children or the adults that they work with. In particular, whether the parents wanted them spoken to in Maori or wanted a karakia - all those sorts of things. For example, they never thought to ask whether they would have a karakia over the kai. Some of the children even knew about sitting on the table and things like that and they were saying when they were made aware themselves they could then talk about it more freely. A lot of the older adults that they were working with already knew because they had been brought up with that. But no one in the homes and the community houses had encouraged that. It's only just starting to happen now. I've really noticed the difference in them since they've begun to do that. Some children are going to Kohunga and speak Maori. For them too, things would be better. So it's quite good because of the new generation coming through, there is more awareness now. And I think so long as that's there we are heading for the same thing - I think we need to work side by side.

My vision for Shaun is that we continue to work towards independence. I finished work because I wanted to give him some time, and myself time, to help him become a little bit more independent, even though he may never be totally independent. Some things we may be able to help him with. The fact that we have to medicate him to keep him calm distresses me but *it's actually helped us to be able to work with him. He's a little bit more acceptable of things and easier to approach now whereas before he always didn't want to do it. He still has his moments but I hope that one day he will be able to leave home and maybe go into a community home and live with other people. For Shaun to be able to go into his community and be safe would be my vision for my son.*

How have I coped? I think it has to do with having survival techniques, a survival code. Anyway, having come from a certain background I think helped me cope with a lot of things because it was a type of background where you just got on with things. And I guess I'm really thankful to the Public Health Nurse who, I later realised, already knew that I was just functioning at a certain level and she could see that there was a need. I remember, one day when she arrived unexpectedly, I must have looked vacant or something and she said to me, "Do you need help?" And I said to her, "What sort of help?" She was quite persistent and I sort of sat there and something was happening with Shaun - and I just said, "Yes, okay then." I guess I'm really thankful that she persevered and she saw that I needed help even though I wasn't aware of that. And on my doctor's recommendation the hospital provided counselling. I couldn't say that the counsellor was the right person but it got the ball rolling. It started me thinking that I needed to have someone to talk to and I actually went out and looked for help and acknowledged that I finally needed to have it. That was the hardest part, actually asking for help.

And I guess if you already have no self esteem, to actually ask for help is harder because then you feel you've failed even more. And to come to terms with all those things. That's what's helped me over the years, just going to counselling and actually accepting the fact that I need help. In turn, because I got to learn to talk about my own feelings, I was able to go back to my family and help them. That took me a few years and I don't have a problem with it now. That's really how I coped. I believe that all people who have some sort of crises in their lives need to be encouraged to have counselling and that families should be given the opportunity to talk about things. And I guess a lot of parents, regardless of how minor the disability might be, don't realise that still can be a crisis.

I think parent support groups also help but there are a lot of issues that I found as a parent I needed the opportunity to be able to talk about - your guilt, your shame, the whole bit - without having to continue to carry it, to be able to say, yes, I felt guilty, and angry and the rest of it. There is a need for someone who can find the thing that you are really asking for within the conversation, someone with the right listening skills. I think a person that has a good listening ear is going to achieve more than any other person.

I guess one of the things people say to you when you first become a parent of a disabled child is that you must be blessed. And I remember thinking way back then, oh yuck, I certainly don't feel blessed in any way. But I have to say that when I reflect back, I think that yes, in many ways I am blessed. I am blessed in a sense that I have learnt a lot about myself, and accepted who I am a little bit more with all the faults and whatever, and that has helped me accept who they are as well. I guess that's what they mean when they say you're blessed. But it's been a hard road. Not that it's going to end just yet though. So for most of the people that I've seen, they've all grown - and that in itself is something. I guess if we don't grow and learn by our mistakes then that's when it's a tragedy. If that's what happens, and there are some families that I've despaired for when I've come in contact with them because you can see that it's seen as tragedy and they have felt that they're not going to cope, it's *sad. And there are some parents I've met who were advised to give up their children and as they've got older they've been able to look back and see that maybe they would have coped. One of the things I really found frustrating as an early parent was the impression that people kept thinking that you weren't going to cope. I don't think that should be the message that you get. So, I guess that in itself, made me battle more.*

FAMILY PROFILE

Adolescent: **Shaun**

Age: 16 years
Sex: Male

Visual condition: Retinopathy of prematurity
Visual impairment diagnosed by doctor at 3-4 weeks
Totally blind
Tactual mode of communication

Other conditions: Mild cerebral palsy
Hemiplegia (right side)
Intellectual impairment

Educational placement: Special School

Parent: **Violet**

Ages: 42 & (47)

Marital/Parental situation: Separated
Shaun lives with his mother and has contact with his father who lives in the same district

Vocations: House executive; (Labourer)

Siblings:	**Carmen**	**Katē**	**Jaymie-Lee**
Ages:	25 years;	23 years;	19 years
Sex:	Female;	Male;	Female

Family

Time in present community: 26 years in community; 16 years in present house

Most important to family: Caring, sharing, truth, love, happiness

Effective support systems: Family & friends, community services, CCS, IHC, RNZFB

'Gift' to other families: "Seek counselling first to help with emotions - most important to be able to move on. Gain as much information about the child's impairment as you can. Find one or two persons who will help support family decisions when faced with professionals."

RICHARD'S FAMILY

Narrated by David

In the beginning we had no idea of where Richard would be now. I didn't ever think he would ride a bike, go skiing, go to Outward Bound, swim, and skateboard. Richard was twenty three when he rode a bike, so things change. I wouldn't have thought Richard would have gone on to move out of our house into a community flat. I wouldn't have thought he'd have ever adapted and yet he flourishes.

There's only the two of us at home now, Rhonda and me, David - we're Derby and Joan. But there was Kirsty and she's twenty three and Richard's twenty four, so it's really been the four of us in our family. Kirsty's now married and Richard's flatting in an IHC Community home. We are still very close as a family and we communicate a lot. We've been close right through. We're good friends. Kirsty was pretty homesick when she left to get married. She didn't want to get out of our home and that's nice.

We have good support from our families. Rhonda's sister lived sporadically in New Zealand. She's now living in Australia and Rhonda I think misses her contact a lot. Her parents are still alive and my mother is still alive and they are all in Wellington so they have contributed a lot to our extended family. My brother's in Wellington too so we are not great upwardly mobile people, but Richard has probably had a lot to do with that. Sometimes things happen that upset us. Like the family wedding that Richard was not invited to. I know it was done for the reason that it was thought it would be nice for Rhonda and I to go and enjoy ourselves. It was one of those difficulties - you can't ask a person why, because that's the way it happened, but that really upset us.

I think we are open to change, we've had to be. Otherwise we would have been stuck. We had to look at a lot of different options, experiment with things. We haven't been able to do all the changes we probably wanted to because Richard's restricted our ability to do anything which might be quite normal for other families. In other words, I couldn't contemplate moving in some situations. Probably because of the family network. A lot of my mates have gone to Auckland or overseas. And again, I had a family business which meant that I couldn't change without a lot of complications. But we're open to changes except the ones we don't have control over.

Our friends we can count on one hand, our good ones. We've kept in contact with the friends that moved away and they range, I guess, in their ability or inability to cope with our situation. We talk a lot amongst ourselves. In fact we would talk more to each other than the average couple, I think. That mightn't have always been the case because I tended to bottle things up a lot, but now we are chatterboxes. We are good at communicating. If we've got problems, and we've generally got problems, we get things off our chest pretty quickly. There is still always an issue each week that we have to deal with. I can't really describe it, but neither one of us has dominated, taken the front. It's just happened. Rhonda didn't work in paid employment. She's only just started to work in the last three or four years so a lot of the real hard graft fell back on her. So I was lucky in that respect - I was lucky.

For our children - you can't always manage these things - but I suppose that we wanted them to be good friends. You never know what's going to happen there. But I guess being balanced people really without chips on their shoulders, or without prejudices that they are either disabled, or they've got a disabled family member, is what we hoped for them. You know, to enjoy life. So while I wanted Kirsty to do well, it didn't worry me if she wasn't capable of doing well provided that she was happy in herself. One of our proudest moments was when Kirsty asked Richard and myself to give her away on her wedding day - a day we will never forget. You probably can't imagine my feelings as Kirsty walked down the aisle with yours truly on one arm and Richard on the other. I'm not quite sure who was the proudest, me or Richard, but I thought he had really made it into the big wide world with *evening tails, black bow tie and the yellow lapel rose. I admit, and he'll admit that he knew without any shadow of doubt it was one of the biggest days in his life and Kirsty's, and one that he was going to enjoy. The beer went down real well too.*

The children had to have their own space. That was pretty important. And we had to have our space too. All the way along we've actually stopped if I've come home from work and we'll sit down and we'll have a couple of drinks and that's been just our time to catch up. It's not that we were alcoholics but it's quite a good way to relax and reflect.

I think we still, even at this time, enjoy doing things together, the family things. As the olds have got older their ability to help us has dropped away and that has its problems. So we don't do as many things with them now as we did when the kids were younger, but in their moment they were wonderful support to us. You do reflect on those families who are not families - who are solos or away from the extended family. I reckon that's not much fun.

Richard is our eldest child. He has deaf-blindness and I first learnt about it four hours after he was born. He was a very difficult birth. He was late and he was difficult. In those days we (husbands) didn't go into the theatre. They had to resuscitate Richard - bring him back - because he was very small. When I saw him he was pretty blue and battered. I went home after the birth and about four hours later, would you believe, I got a ring from Rhonda's father who knew the gynaecologist. He had phoned him and said, "Would your son-in-law come to the hospital as I think his son is blind? Well, there's something wrong with his eyes." So I tried to drive through the traffic and when I got there he'd buggered off and then I was left with Rhonda. She was a mess. He'd pissed off into the night, or the day. There was another girl with Rhonda in the room and she was trying to get her up to speed. So the doctor came and sat at the end of the bed and said that our kid was blind and probably retarded, and something else, and something else, and that'll be two pound four and six thankyou very much. I think he said that he'd get the paediatrician in. We never saw him again.

The ophthalmologist came in and I thought he looked about twelve. He was marvellous. The paediatrician was marvellous too and they both stuck with us until Richard was nineteen. And we stuck with them. When the paediatrician became a professor at the Medical School he still offered to see Richard, which he did. We actually developed a pretty wonderful relationship with most of the medical people except a couple and that may be unusual. It probably is unusual because if you have a bad relationship it can sour you for ages. So we knew Richard had cataracts. We didn't know he was deaf. And he was struggling. He stayed in hospital for about a month I think. After that he went to Karitane, which was like going to Colditz Castle. The thing then was not knowing whether he could hear. And we thought, my God, I hope he can hear. That question wasn't answered for quite a long time.

It was a definite possibility but we didn't like to hear that. We got in with the audiology clinic at the hospital and the sister there was a wonderful gem. The ENT (Ear, Nose and Throat) guy didn't really want to know us because we were being serviced out of Christchurch. Then I got pulled into a meeting with two or three doctors. I don't know where they came from, and they gave me a real grilling about how I was going to cope. I said I didn't need that shit. I didn't need that at all. I was asked how I was going to cope, reminded that I was a very successful sportsman, and told that we had this kid that was virtually a vegetable. That really upset Rhonda. When I got home I thought, what the hell's *that all about? It was unnecessary. So it was obviously evolved that was a problem. We didn't really know about the intellectual bits. But when he came home Richard was a pretty sturdy little guy so he virtually did a fair amount of things.*

Looking back, we should have been together when we were told about Richard. I believe we should have had someone there that could have been our key worker. We were struggling. We had just started asking questions and we didn't quite know what to do. I guess I go back to my old adage that one of our visiting speakers who came out for deaf children said, "Teach the parents first. The kid will survive - look after the parents." I think that is so true. Because we were just after some answers and hoping that certain answers were going to be in the negative. So I think that apart from the medical profession, someone should be attached to the parents who can get things started. I know they have visiting therapists now, but they're visiting therapists, aren't they?

We had to find our own direction and find out about services ourselves. We went to the ophthalmologist and I asked him what would we do, because you start thinking about ten years ahead. And he pulled out this brochure on Homai College and said, "I wouldn't get involved with the blind too quick because they get their hooks into you." But I took the pamphlet and I put it into my pocket and I actually flew up to Homai because I knew there was a parent thing happening. Someone had told me it was on. I can't remember who. But somehow we got involved with the two social workers in Wellington, one of whom was blind. They came up and I think they gave Rhonda a real comforting buzz because she needed it. Then we got involved with the deaf I think, some how. We saw the ENT guy that gave us the bum's rush at the hospital. We went and saw him privately - he was all over us like a rash!

We kept pretty close to the ophthalmologist and the paediatrician. The ophthalmologist didn't quite know what to do. He rang us one day and asked if Richard would be his guinea pig. Rhonda had to go too and the guinea pig was a seminar of all the ophthalmologists from Australia and New Zealand and there was a visiting professor from London University. He only had three patients at the seminar and Richard was one of them. The ophthalmologist got up and told them he didn't know quite what to do. He was dead keen to operate but the current thinking was to wait until children were two and Richard was just a baby of six months. The professor told him to go for it, which he did. So that started a series of surgical operations which I think was critical to Richard. They were just doing the needling and drilling holes. I think that was a key thing in his early life - a key thing. So again we took a gamble. From a very early age I think Richard got to know that a hospital is where you get better and he became a star turn in the eye ward - got into old ladies beds, all over the place. He had good mobility. So that was the vision side.

The auditory one continued to plague us. I think we came up to Homai for a week when Richard was three for an assessment. We found that interesting. It was still pretty traumatic going through that because you are still asking and answering questions. The thing that struck us about that assessment was that when we visited and talked to the psychologist he said that if we didn't send Richard to Homai College our marriage would break up. We said that he was not going to Homai College. We didn't send him. But Rhonda did go up with him for potty training for a short period and that worked. Immediately he came up here he started doing what we wanted him to do. That was quite a good time for Rhonda because she was able to meet some other parents, and that was good.

When Richard was about four and a half he went to the school where there was a unit for deaf children. That was because we decided that the auditory side was probably the thing that we knew the least about. He spent all his time in the corner just flicking. I don't think anyone knew much about it. He had a wonderful teacher but I think he bamboozled her a bit because he had a few other things wrong with him. So we pulled out of that and opted for the deaf-blind programme at Homai.

I think, at one stage we must have been feeling a bit sorry for ourselves and someone put us in touch with a nun who had just come out of a school for the deaf. She was sent to Manchester for two years to train in the hearing, and when she came back she knew everything that was current. When she tried to put it into practice at the school for the deaf she was told, "You can't do that sort of thing round here." They sent her to the South Island in charge of a kindergarten which didn't have deaf kids in it, so she decided to get out. She ended up on our doorstep and became a very close friend. She then became involved in the advisory service and was really helpful to us, but again, she was confident that Richard was going to speak. You sort of put your badge on that - that something's going to happen next week. She thought his oral and vocal noise that he was giving out was an indication that speech would come. We believed that and I suppose the balloon's got to burst at some stage - the realisation that it's not going to happen. So that was an interlude we had. Then we got into a few more surgeries and then Richard went to Homai.

At that stage we were plugged into parent networks. Both for blind and deaf. I found that good because it helped us with the questions and was good support. We knew no other families with children with deaf-blindness at all. We saw our first examples of that when we returned to Homai. So with our marriage still together we came back. We didn't really want to let him go. Things change so quickly that if you make one decision, that can change a whole life because of one kid. We were still on a string because we didn't know how bad his hearing was and whether speech would come. We were right in on the debate on sign language which was a very bitter debate, and yet Homai had started the programme with signing. So we decided to go for the Homai Deaf-Blind programme because he couldn't get it in Wellington.

Richard was about seven when he went to Homai so he didn't have that long at the Deaf Unit in Wellington. It was a very structured programme at Homai. We felt on reflection that it was too structured and that there was too much patterning or something. I think they put all the deaf-blind kids into one hostel which might not necessarily be the best. They might have needed a wee bit of a mix. And I think there was quite a big gap between the school and the hostel. It was more based on the 50's I think. The hostel staff were more like hospital workers and the others were teachers. So I guess that had its frustrations because if you wanted continuity in a programme it sort of had to follow through between both. And we did have difficulty trying to get organised. If you wanted to do something after school hours it was difficult. We had to do some of that from Wellington and it was just being so far away. It was things like getting volunteers to take Richard to things and do things. Because again you find with your extended friends, some of them couldn't cope. I wasn't going to push it with them. We got married pretty young and our friends had young kids and it became difficult for them to take Richard out so we actually came up to Auckland often. We were up here every six weeks I reckon, so we had good contact.

Looking back on his progress, there was still no oral language. Once we got the signing going though that was a real breakthrough because at last we could get some of the things out of him. Then he got into plateaux. Now I don't know if it was the teaching technique but he was very slow at getting to things compared with some of the things he is doing now. I don't know why. There are questions now as to whether he is deaf. Or whether he is autistic. I don't know. Does one disability block out the other - you know, get flooded with information and neither of their things are working? In some situations can one override the other?

So I guess being so far away communication was important to us. Even the littlest communication and just knowing where he was up to, what he was doing, and how he was. All those sorts of things. He wasn't a very healthy kid. He got a lot of ear infections and things like that which didn't help too much. But he coped all right.

Our first parents group was set up in 1983. The value of getting parents together was recognised and we had a weekend with a number of people talking to us. We talked to each other and we had a wonderful time. There was a couple from the Deaf Blind Unit which was excellent. So that was the start of the parents getting together.

When Richard hit puberty he started to have behavioural problems. He was still having sickness problems but often the behaviour would manifest itself before the sickness manifested itself. If he pushed a kid or did something bad it was generally that in a few days time some illness broke out. He started to be a bit aggressive and that caused some concern which I can appreciate. But often we didn't hear about those things and so it was very difficult for us to then plot a pattern.

We weren't sure whether the problem was with his eyes, or whether it was abscesses in his ears, or whether it was an epilepsy thing. So it was difficult. I think we went to the paediatrician and got a report back in which they seemed to think it might be irregular brain waves or something. I was really very concerned because we were just so far away and there were so many questions unanswered. So I appointed a person as Richard's advocate for medical and educational things in the hope that we could actually find a pattern and work out a scheme of things that would work. While advocates are more common today, unfortunately at the time there was an adverse reaction to this. We actually couldn't have done it ourselves. We couldn't have got answers ourselves because we were very stressed and worried, but to have that reaction coming through from professionals wasn't easy to deal with. Once we started to get a patterning done we started to see that there were things happening in his body medically that were affecting him. It wasn't until two years later that we found out that rubella kids cannot handle puberty. We found out when we went to America and a doctor of the deaf-blind said to Rhonda, "Didn't you know that?" and she said, "No." It would have answered a hell of a lot of things. Richard left Homai when he was thirteen. He returned home to Wellington.

I think that the other thing that was coming out medically for Richard was that he had ear and eye infections. We didn't know what they were and that continued when he went to his new school. We employed the teacher aide. He was a guy that was twenty one and had had thirty nine jobs, but he was about seven foot nine and he was as keen as mustard. He could actually physically take hold of Richard and give him a good shake if he needed to. He was enthusiastic and prepared to try things and he turned Richard round. It was just common *sense that worked. Now in the normal course of events you wouldn't have employed him because he worked on a fishing boat, and he was a shearer, and he did silly things, but we went for him and it worked. He and Richard became very close friends and he learnt sign language. He experimented and did things for Richard that we'd never do and they wouldn't do in a regular school.*

Like all good things they come to an end. Having had thirty nine jobs Richard's teacher aide then decided to go on to Special Education and went to Teachers College. I think he got his degree. He became proficient in sign language and he ended up being a part-time social worker for the deaf because he was so good. He also became involved in mime theatre and that sort of thing. He worked with Richard for about eighteen months. There were key people in Richard's life who were teacher aides. Now that may seem funny but we had good ones, and they were young and enthusiastic.

So having enquired for placement back in Wellington and being told there was nothing, the doors opened and Richard started at the Special School.

Richard's behaviour was still patchy and then it was diagnosed that he had developed keratoconus over a number of years. We think that would explain some of the behaviours. I believe it is one of the most painful conditions because it involves the cornea and almost looks like a boil on the eye. Each time the infection goes away it leaves a scar - you get the bathroom window effect. He was starting to lose his sight but it took us a while to know that and he became desperate to get to a hospital. He'd smash a window and cut his hand to go to hospital and so that goes way back to when he was six months old and the realisation that the hospital makes you better. He went in there several times with bad cuts, self inflicted.

Then Richard started attacking Rhonda and me as his eye condition got worse. It was having an impact on Kirsty because we were needing quite a lot of home support just to keep him stable. We had a number of situations where he really got stroppy. It happened one time when we were at a doctor's appointment. We just couldn't control him and I had to actually lie on top of him. I said to Rhonda, "This kid is dying." You could actually almost see him deteriorating in front of you. It was over a number of weeks and the doctor committed him to Porirua as a mental patient. That's about the worst thing that can ever happen. Rhonda had to go in a police patrol car with Richard and I followed behind. Like going out to 'One Flew Over the Cuckoos Nest' thing. I tell you what, that was the worst thing I ever had to do. The worst thing we ever had to do.

We had to stabilise him. Just prior to that we had a new ophthalmic surgeon that we had been referred to as being brilliant. He told us that Richard had keratoconus in both eyes and he was losing his vision. He said, "I've never done it before, but I'm prepared to give it a go to do surgery." He had never done a corneal transplant on a multihandicapped kid. He gave us a twenty percent chance of success and that was what we had to go away and make our decision on. We decided we'd go for it because otherwise we were convinced that he wasn't going to make it. So I think that the diagnosis was given to us before this incident and we decided that he'd got to go in there to Porirua so we could stabilise it. He was in with all sorts of other people in an environment that was male nurse dominated and all that sort of 1940's stuff. They wouldn't listen to things like IEPs and IPPs (Individual Programme Plans), things that we wanted to do.

While Richard was there we drove him each day to school and back. Gradually we got him ready for the surgery and finally he was admitted to hospital. The night before the operation the hospital had rung us at eleven to say they hadn't had any corneal donors. We didn't sleep too much that night. Then they rang at six in the morning and said they had a donor. It was all go. Richard went in for surgery and Rhonda went in to the operation. She had prepped him and she had all the boots and gloves on and everything. Rhonda spoke in detail to all the theatre staff about Richard and then they kept her in the recovery room so that she was right in there with her arms rolled up sort of thing.

When Richard came out of the theatre he actually went into a straight jacket specially made at the hospital. I went in and saw him and he woke up when I was there. If looks could tell you, you'd almost think, "Thank God you've done something about it!" We had to keep him in the straight jacket for quite a number of months and then we took him out of that and put him into splints - a fibreglass half case so that he could get his arms up to feed but he couldn't touch his eyes. Richard was chuffed because I think he knew something had happened. He knew a hell of a lot had happened. Then he became dependent on these things. If he didn't have the splints on he'd be quivering because he regarded them as part of himself. So when we took them away from him he started to hit himself. Then we had to go through a long process with the behaviour modification team to get these things off him. So really I think all that had started to happen some time ago and we didn't pick it. Because the ophthalmologist said that kids with rubella didn't usually get keratoconus. He said he'd never ever heard of it happening before. So the surgery was really revolutionary.

Next Richard had to get used to being able to see. It took him a long time to get used to seeing things that he'd never ever seen before. They did one eye and they left the stitches in for two years because of its delicate nature I suppose. That was a whole psychological change for him to get used to. We took him up skiing which he usually loved and he freaked out. Richard couldn't get used to seeing all these people. Things were brighter and bigger than he had ever seen before.

Gradually Richard's behaviour stabilised and he started to do things. Then the Special School was closed and I think it was closed without much consultation with the parents. It was closed in this great rush to mainstream. Richard was about sixteen or seventeen then. We had had a good environment up there. There was good parent networking and it was a very caring environment. Then they said, "Sorry folks, we're going to put all the girls into a girls' high school and we're going to build a prefab at a boys' high school and the boys can go in there." And they were all mainstreamed. So they actually closed the school and it became idle. Parents didn't really have much say about the closure and as a consequence we ended up with all the boys at the High School sitting in a classroom, not mainstreamed. They couldn't do phys. ed. with the others, there were negotiations with the woodwork teacher to see if they could actually go and do woodwork, and they were allowed in very few other classes. We then had a marketing job on our hands to sell our kids to the rest of the school as well as to the principal who was quite scared that he had these kids. By contrast there is another secondary school in the region that has a special education unit. It was moved from the back to the front of the school and the job description for all teachers includes taking special needs kids, regardless of the disability. The woman that was the special needs teacher there did a fantastic marketing job. She had blow-up photos of the kids and she sold those kids to the rest of the staff. She did it over a period of weeks. So they are two quite distinct contrasts. Richard was there at school till last year, about four years *altogether. He had a lot of support which he needed over that period because he still had to be pretty careful. If he knocked himself the corneal graft could be at risk. Richard enjoyed the high school experience.*

When Richard was about eighteen or nineteen we felt that he was ready to go into a flatting situation even though he was still at school. It gave us a break and it gave him the chance to become more independent. He was still able to come home and do things as well and this is where we're at now. This is Richard's second flat and he's flatting with four in the house and one in a semi-detached sleep-out. The trouble is the combination's not quite right. Richard doesn't speak, Petra who's about twenty five is a very severely disabled Samoan girl who has very bad fits and because she is so disabled it has an influence on what the others can do. Caroline and Russell have Downs Syndrome. Caroline and Russell have limited communication skills but they all communicate in their own way with each other. Richard loves his house.

Labelling doesn't worry me at all. I think we have to get a message across - the more I dilute the message the harder it is for people who are not there to understand what we are talking about. So as far as Rhonda is concerned and I am concerned, Richard is deaf, blind and retarded. If we are talking to someone about a benefit, that's what he is and they understand. It's no use telling them anything else. They think he gets better each year because we have to go back and review his benefit. We've had a lot of battles because people have withdrawn resources without any consultation. They cut Richard's teacher aide time from twenty five hours to ten and they didn't tell us about it. We don't know why it happened. No one told us. We went to the IEP and we agreed that the support base would continue and then all came home for the holidays. When Richard went back to school the teacher told us that he'd only got ten hours and so we couldn't employ Joe Bloggs any more. Two months had almost gone by without us knowing what had been decided previously. We lodged a complaint procedure with the Parent Advocacy Council and they agreed to take up our case. I went along to the hearing and presented my case and we won it. We won it significantly and we got advised in writing that they were so sufficiently convinced by the arguments that they were making twenty five recommendations to the Minister of Education as a result. We felt quite pleased although it didn't result in Richard getting any hours back. But I thought if it makes a difference to some other kids it's worthwhile. Then we get to the Budget and the Parent Advocacy Council is abolished. So while the people in the Parent Advocacy Council had been wonderfully supportive, nothing could be done with the document because it was abolished. We felt really bitter about that.

That's why I feel very cynical about some aspects of the education system and a number of the people that work within that system. I think they are very smug and controlling over how things work or don't work. And that's been proved right because we've ended up with no policy that we should have had fifteen years ago. I guess if I had something I wanted to happen, it would be to see that we actually achieve something as parents to get a policy in place. I don't think professionals realise how quickly parents get up to speed. Their knowledge becomes quite broad even after a relatively short time.

So, I believe that we need to get the true message across. After this year's IHC ad campaign had been organised a guy came to our meeting and said that they had toned it down. I don't agree with that because what they were trying to say was that the pressures that go on in *families are real. This is the message that should have been given to people - that it is tough. Everyone is so sensitive about exploiting kids but I don't see it that way. If there's a message to give people you may as well give it.*

How have we got through our experiences? I guess we have talked a lot about Richard and the kids to friends. And if they weren't friends, we told them anyway. We just had to get it off our chest at times. People were fascinated with some of the stories you were able to tell. You often were a bit boring maybe. But we have only survived on the humour of the situations and we've maintained three or four parents we started off with that we're still mates with. I'm talking about parents that have got visually impaired kids. We're mates so we have these funny sessions where no one else could be invited because we crack up at all the funny things that have happened and people wonder what the hell these funny people are doing. You don't want it to be a crusade. You know, I think the reason I have stuck with this group is that I've got a lot out of it. I've got therapy out of it. The reason we are together is not because we're on an ego trip but because we need and get support from each other. The things that I found real hard were the normal things that you would do with your son that you couldn't do. I would avoid putting myself in those situations. I suppose I ran away from it. But I would get pissed off if I went and watched my nephew play for the first fifteen rugby and think, Richard should be there. You know, I'd get involved in all these petty things - you know what parents are like when their son or daughter doesn't get in the top team and I'd think - I can't bear this. There are more important issues. So I became a wee bit intolerant of those situations that I felt uncomfortable with.

How did we manage? Well it came back to talking a lot - I think talking a lot to other people. Some of the issues that we tackled I think gave us energy. We met a whole new population of people that we would never ever come in touch with. That brings you back to earth. We might have followed a professional path, I don't know what. If I hadn't made a decision to go into family business I might have gone into professional accountancy, or consultancy, or the academic area - but I didn't. I think you just come into a whole new field of people and get a totally different perspective on things. We've found that when friends of ours start relating crises they've had, they're not like ours. I'm not saying we're blasé, because everybody's crisis is a crisis, but it's different.

We've actually got used to some of the crises. We're a bit blasé because we think Richard's on borrowed time. In other words he's had about fifteen lives. We were talking about it the other night. If he got bowled over by a bus tomorrow I think he'd be happy if he was skateboarding down the road. He's had a few close scrapes. He started running away about two years ago. He got picked up on the main motorway running down the middle of it. That's when we went back to America and started talking to people about the conditions that affect CRS (Congenital Rubella Syndrome) children. One of them was called Restless Legs Syndrome, a condition which happens as a side effect of a drug he was on. Someone put me in touch with a neuropsychologist and that's what he had. Those issues have caused us some real concerns.

About three weeks ago the Resource Centre went to the Aquatic Centre at eleven o'clock and came back at one o'clock for lunch. We got a phone call at five o'clock to say that Richard was missing. There were ten that went and there were only nine that came back. We have this sort of emergency plan - you do that, and I'll do that, and he can do that - because the police know us now. Richard was found at the pool waiting! He had been there for four *hours and so I guess the issue we have now is with the care-givers and the quality of the care-giving. On another occasion Rhonda came back to the house with Richard on a Sunday because they had been in Special Olympics and the others had already had their tea at the flat. Rhonda went to the cupboard to make him something and there was no food. This has happened consistently in that house for two years with staff turnover, bad budgeting, and no food. I don't want to give the impression that I've got a chip on my shoulder but we still have to advocate very strongly.*

Richard's benefit was cut by a hundred bucks a fortnight at the beginning of the year and we weren't told. Now it has taken us three months to get an answer and a mistake had been made. Social Welfare wanted to see that Richard's rubella is still a condition. They wanted Richard to visit the Welfare doctor to be checked. Rhonda responded that Richard was already under five doctors - three specialists and two GP's - and we could provide a report from each one. Richard was still required to go to the Welfare's doctor and so Rhonda said that as she worked she would bring Richard down and drop him off at the doctors. She asked if they thought the doctor would be able to understand Richard's signs because Richard can't talk. And they came back that same afternoon and said it didn't matter, he didn't have to go!

I guess our advocacy role doesn't stop. I think you get sick of advocating because I don't think we should have to. I think I've come across too many incompetent people that are either not trained properly, and I think that is half the problem, or not accountable, or not supervised properly.

I think it's ironic that the system's thrown so much teacher aide resource into disabled kids when they're an unqualified resource. Yet they have become key people and what we were promised with IEPs was that they would be the resource indicator for the whole system. But no-one is accountable for that and the same thing flows on to IHC where they do an IPP, no-one's accountable. We've become quite involved with IHC locally which is a huge bureaucracy. We've got a pretty active committee in Wellington. We don't want to get involved in management issues but we do want to have a say in the resource allocation. In other words we don't want the accountant in Palmerston North saying for the kids there's $6.25 a day for the meals - that's what their food budget is. I think the problem in IHC is that they almost went broke and they now employ people on about $10 an hour. And we see the results of that. The staff are not qualified, the turnover is up, the quality is not there and therefore the service delivery is not good. I think I'd like to see a bit of competition in there somehow.

Recently I got involved with three other parents in Wellington who want to set up an Early Intervention Centre. We've had three meetings and I reckon it would be fabulous if we could get the money to set up something in Wellington, because we've got the support in the agencies. We looked at being innovative and having someone to be a case manager, someone to do some advocacy, and volunteer networking. Put that in the model and we've got something pretty powerful. Now the bureaucracy have got the wheeze that we're starting and they are going to try and beat us to the punch. People are feeling that we are going to impinge on their territory or something like that. So there was the new generation of parent who were going to be this next lot of shakers and movers still seeing those obstacles. I have to come back to the mere fact of challenging people if you don't think the course is in the right way. It's only experience that enables a person to do that. Those that can are only the *tip of the iceberg. The other ninety percent, I think, accept what people say. I don't want to get into battles with professionals or teachers or anything, but if that person is incompetent or is not delivering what is needed I should be able to tell them. But we are terrified that if we challenge that person we are going to be cut away. So that's a power thing - there's a real power problem here. It goes across all the areas that we have to interact with. I am at the stage now where if I feel that something is not right I say so because I know as much in some fields as the professionals. That's why I feel that in the great leap forward to total inclusion parents were lead up the garden path a bit. I think there were many good things happening in special centres.*

In the beginning we had no idea of where Richard would be now. I didn't ever think he would ride a bike, go skiing, go to Outward Bound, swim, and skateboard. Richard was twenty three when he rode a bike, so things change. I wouldn't have thought Richard would have gone on to move out of our house into a community flat. I wouldn't have thought he'd have ever adapted and yet he flourishes. That changed almost within months. A lot of people have said to us in the last year that Richard is not intellectually handicapped. The more he's growing, the more he's doing things. I'm starting to believe that now. I think he's got communication blocks and there are a whole lot of complexities which compound each other.

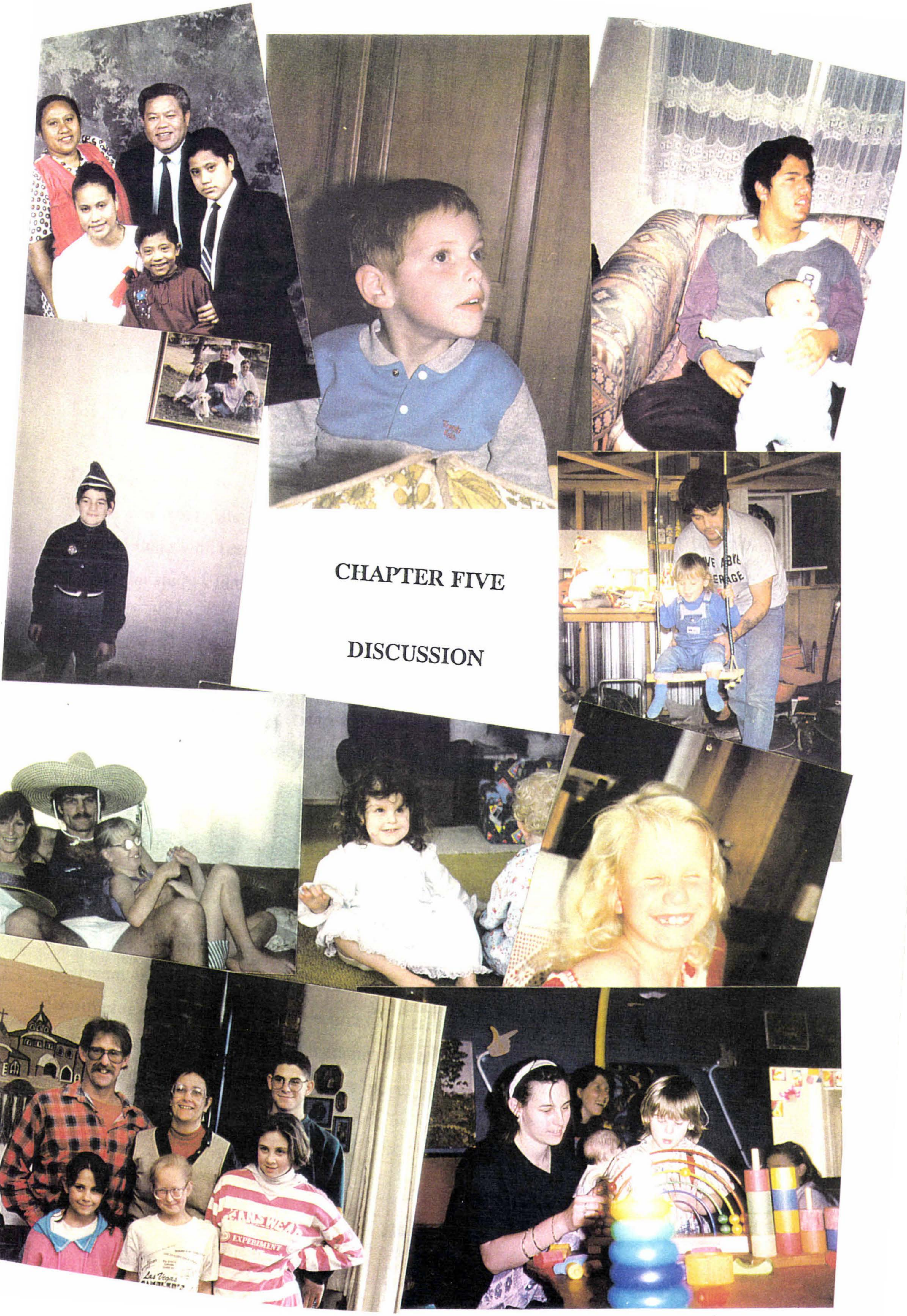
We've come a long way in twenty four years. If you'd said to me twenty years ago that we'd got enough parent knowledge to actually go to the Ministry and say this is what we want and this is it all here, we wouldn't have been able to do that then. We've done it now. We're now into the power play. I didn't think professionals were scared of us. They've got no reason to be scared of us but I think in some ways it's gone backwards. There is a fear by the professionals of the parents. We need to move on. My vision is that we have our own dollars to pay for our children's special education and community needs, top quality service providers, and employment and leisure opportunities. We'd like plenty of friends and the acceptance of choice and viewpoint. I'd be quite happy if together we were able to achieve something that was going to be better. I'd hang my hat up and say, "Yea, that's great - I'll go to the beach."

FAMILY PROFILE

Young Adult:	**Richard**
Age:	24 years
Sex:	Male
Visual condition:	Cataracts, Keratoconus Congenital Rubella Syndrome Condition first diagnosed by doctor at birth Low Vision - changing level of vision Visual/Manual (signing) mode of communication
Other conditions:	Profound hearing loss Possible autism Possible intellectual impairment
Educational placement:	IHC Resource Centre Flatting in community house with 4 other people
Parents:	**Rhonda & David**
Ages:	49 & 49
Marital/Parental situation:	Married
Vocations:	Self employed florist/clerk; Self employed travel & shipping agent
Sibling:	**Kirsty**
Age:	23 years
Sex	Female

Family

Time in present community:	25 years in community; 2 years in present home
Most important to family:	Communication, humour, sharing, and participation
Effective support systems:	Every possible support system
'Gift' to other families:	"Communicate and network with you partner, your family, your friends, your peers and your professional caregivers."



CHAPTER FIVE

DISCUSSION

CHAPTER FIVE

DISCUSSION

> *Our local school was just appalling in attitude. But the principal of the school he attends now said to us, "Well I don't know actually, we've never had anyone with disabilities in our school but I'll talk to the teachers who would be with (him)." And they came back to us in a couple of days and said, "We'd love to try." They were just brilliant.*
>
> *(Research participant)*

5.1 Introduction

This chapter discusses data obtained from focus group exploration and family interviews. Stories and other data obtained from the focus groups have been recorded as participants reported them with no attempt to access files, records or include information from anyone outside the study's families.

Differences were noted in the content of the focus groups and family interviews. From the former there was emphasis on parent-professional relationships with participants indicating the negativity of many experiences. Also, as might be anticipated given the role of participants within PVI, considerable significance was afforded to advocacy. Minimal focus was given to extended family in these early stages of data collection. Conversely, family interviews frequently highlighted the pivotal role of extended family in providing physical and emotional support, and while difficult experiences with professionals were recounted, examples of a more positive nature were also reported.

Overall the stories reflected a search for meaning and purpose. There was discernment of movement through stages of adjustment from the emotional need 'to know why', to a determining of information and resources to find a satisfactory way of moving on. In the search for meaning, hypothesis generating was evident, some of which would probably be considered unrealistic from professionals' points of view. A progression of coping strategies was revealed with power and powerlessness being a feature of all stories.

While the individuality of each family's experiences was apparent, common themes emerged. The like values of families in respect of being together, valuing each other and caring for others was marked. Some themes identified were synchronous with those within the literature while others have been afforded scant attention previously, the latter including differentiation of parental role especially in relation to involvement in parent support and advocacy groups, entry into political advocacy and cultural stereotyping. Other experiences were unique to families within the context of their lives and the specific needs of their child with a disability. Variables included the nature of the nuclear family itself, the nature and severity of the disability, family position of the child, parental and extended family relationships, and cultural context.

Bronfenbrenner's (1977, 1979) ecological model, as adapted by Hornby (1994), was used to provide a framework for this chapter (ref. Appendix 4). It includes four levels: microsystem, mesosystem, exosystem, and macrosystem, and underlines the influence of social environments on families of children with disabilities. Many issues were identified in each ecological band. While issues were interrelated across bands, for organisational purposes discussion of each issue was here confined to one band only. The final section of the chapter explores coping strategies used by parents across the contextual bands.

5.2 The Microsystem: child, parents, siblings

5.2.1 Introduction

The family of a child with a disability constitutes a microsystem, with the child, parents and siblings reciprocally influencing each other (Bronfenbrenner, 1979; Hornby, 1994). Family functioning is likely to depend on variables related to each of its members and might include attributes of the disability itself (Gallagher, Beckman & Cross, 1983; Shapiro, 1983), factors associated with the child in relation to siblings and position in the family, and personalities of all family members. Finally, elements affecting the parents themselves such as those associated with age, personality, financial status, education and health are likely to have a major influence on the family. Of particular significance is the quality of the marital relationship (Mink & Nihara, 1987).

The ten participating families reflected the range of family composition as defined by Robertson (1987), Strully and Strully (1989) and Murray (1991). At the time of the study, eight were two-parent families [Dylan's, p.66; Annie's p.78; Sarah's, p.97; Andre's, p.112; Nuu's, p.144; Toni's, p.150; Hannah's, p. 168; Richard's, p.200][1] and two were one-parent families [Shaun A's, p.128; Shaun B's, p.186], in both instances the sole parent being the mother. Hannah's was a 'reconstructed' family [p.168] where Cloan had become part of the family when she was three, while one of the single-parent families was foster family to Shaun A [p.128]. The fathers of both the one-parent families had left the family home relatively recently.

Disabilities of the ten children ranged in severity. Sarah, Nuulelei (Nuu) and Toni had eye conditions which resulted in low vision (Barraga, 1976; Harley & Lawrence, 1984). Nuu was also diagnosed as having cerebral palsy. Dylan, Annie and Shaun A were blind and used tactual modes of communication (Hodgson, 1985). In addition, Annie was considered to have developmental delay and Shaun, neurological impairment. Hannah and Richard were vision-hearing impaired. Both had profound hearing loss, with autism and intellectual impairment being identified as possibilities in the case of Richard. Andre and Shaun B were blind with multiple special needs. These were reported as cerebral palsy (both children) and hemiplegia and intellectual impairment (Shaun B). Two families had a second child with special needs [Sarah's, pp.96, 100; Toni's, p.156] and in two families the eldest child had died at birth [Researcher's Log]. As Goffman (1963), Nixon (1991) and Voysey (1975) found in their studies, perspectives of parents differed, in part, according to the specific needs of their child.

Many themes were identified within the microsystem - it was second only to the exosystem in the number of issues for families. Over-riding all was the premise that it is the family who will most care about what happens to the child and that inevitably there will be conflict both within and outside in meeting the child's needs. The discussion in this section focuses on broad topic areas which emerged: birth and perinatal experiences; the adjustment process; ongoing issues; parental relationship, roles and responsibilities; and siblings.

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[1] Data is referenced from four sources: directly from families' stories [Georgia, p.104], family interview transcripts where material has not been included in stories [Cloan, Tr.8], Focus Group discussion transcripts [Focus Group 2] and researcher field notes [Researcher's Log].

5.2.2 Birth and perinatal experiences

Dealing with the circumstances surrounding diagnosis was identified by families as one of their most stressful experiences [Cushla, p.67; Georgia, pp.99, 104; Theresa, p.113; David, p.201] with reactions such as those described by Gargiulo (1985) and Hornby (1987) in evidence. Four families, those of Annie [p.78], Andre [p.112], Toni [p.154] and Hannah [p.168], recognised themselves that something was not right with their baby. For Hannah's mother, Gloria, this occurred even before the birth. Illness during pregnancy, gave her cause to suspect that the likelihood of her baby being affected in some way was high and subsequently Hannah's hearing impairment was detected at an early age. Likewise Toni's father noticed her eye abnormality at birth and both Annie's and Andre's parents realised that their babies were not seeing. Parental observations and knowledge were initially discounted by medical professionals [Sue, p.78; Theresa, p.112; Alison, p.154]. For Theresa and Rudi whose son's disabilities were not 'officially' diagnosed until he was ten months old the delay resulted in frustration, anxiety and self-doubt [p.115]. Overall, families stressed the need for accurate diagnosis, a finding commensurate with that of Heller, Rowits and Farber (1992), and the importance of professionals taking cognisance of parents as a source of knowledge regarding their child, an outcome also highlighted by Nixon (1991), [Focus Group 3; Cushla, p.66; Rudi, p.120; Cloan, p.180].

For five families the initial diagnoses were given by medical professionals [Dylan's, p.67; Sarah's, p.99; Nuu's, p.144; Shaun B's, pp.187, 188; Richard's, p.201]. In Feanu's case it was reported that the diagnosis was dealt with competently with appropriate referrals made to support agencies early [p.144]. However, for four families circumstances surrounding finding out about their child's disabilities appeared less favourable. It was reported that the manner in which the information was given was abrupt with little opportunity for parents to ask questions or seek further information [Focus Group 2; Rudi, p.114; Georgia, p.99; Violet, pp.188, 191]. In some cases the mother was not with her partner when told of her child's disability. For David, the news came via his father-in-law who had been contacted by the paediatrician [p.201], while in Georgia's case, the manner in which she came to the realisation that the doctor suspected there was 'something wrong' [p.99] with her baby resulted in perceived loss of confidence and mothering instincts. It was participants' strong recommendation that parents be together when told of the diagnosis of their child and that all medical professionals be skilled in counselling in order to acknowledge parents' emotional and adjustment needs at a time when they were so vulnerable [Focus Group 3; Rudi, p.120; Violet, p.196; David, p.202].

The families of Dylan [p.67], Sarah [pp.100, 103], Andre [pp.113, 114], Hannah [p.169] and Richard [pp.202, 204, 210] faced partial or see-sawing diagnoses in which the nature of the disability was revealed only over time. This clearly added to stress for parents who felt a sense of dread at the unknown and were often required to make major adjustments as each new piece of information was received. For Andre's [p.113] and Dylan's parents [p.67] the emotional impact was profound as prognoses changed. David told of the ambivalence of wanting answers but at the same time being afraid of what those answers might be [pp.201, 202]. Compounding the trauma, was the message given by doctors to some parents that they would not cope, their marriage would not last, and the accompanying advice to place their baby in institutional care [Focus Group 2]. These parents were angered by such judgements.

In addition to coping with the diagnosis, the families of Dylan [p.66], Nuu [p.144], Shaun B. [p.187] and Richard [p.201] were facing the medical fragility of their baby. These parents recalled their shock at the physical appearance of their child, and above all, the possibility of death. Violet highlighted attachment avoidance as an initial means of coping [p.187] and parents quickly became familiar with life and death emergency procedures [p.74]. The risk of mortality remained with parents - even today, as expressed by Richard's father, David [p.208]. Prolonged periods of separation for families ensued as the babies remained in hospital for up to four months [Dylan's, p.66; Shaun B's, p.187]. Most often they were accompanied by their mothers. Bonding with their baby, organising travel to and from the hospital and making arrangements for other members of the family were difficulties which reduced living to one day at a time. For some families such separation would be repeated as their child required further medical and surgical intervention in the years ahead.

Raewyn acknowledged that as foster parent her experiences were different to those of a birth mother. She was aware of Shaun's disabilities before his entry into the family on what was initially to be a short term fostering basis [Shaun A's, pp.127, 129]. While she had a general understanding of the extent of Shaun's physical and neurological impairment Raewyn was not interested in medical diagnoses or prognoses, accepting him 'for himself'. She felt that her background as a Karitane nurse and previous experiences in fostering children had given her some preparation for parenting Shaun.

Medical intervention was an experience common to all families, with multiple medical problems emerging for many of the children. A plethora of medical specialists and frequent hospital appointments featured early in the lives of families who were often required to make decisions regarding medical intervention, the nature of which was at times untried [David, pp. 202, 205]. Medical setbacks, the emergence of latent conditions and anxiety about unknown implications exacerbated parental stress [Georgia, pp.100, 103; Gloria, p.169; Violet, p.192; David, pp.204, 208]. Even as the study was carried out some conditions continued to cause confusion, be misunderstood or the full extent of their impact not fully discerned. In all, families spoke of this time as one of intense vulnerability as they began to deal with not only the physical issues but the complexity of emotion within the family. None had a significant awareness of disability prior to the birth of their child and there was a sense of "having no idea what it really means" [Gloria, p.168].

5.2.3. The adjustment process

Throughout the stories various stages of the adjustment process were alluded to. Parents recalled their feelings of disbelief, frustration and anger, with grief at "not having a normal child" [Georgia, p.105] recognised. Theresa recollected grieving for a perceived loss of enjoyment with her child for both herself and the grandparents. Initially she considered she experienced difficulty accepting her child as she struggled to overcome fear of disability [p.115]. By comparison her observation that her husband found acceptance more readily, likely because of his exposure to people with disabilities as a child [p.116], supported the concept of Goffman (1963) and Voysey (1975) that such previous experiences facilitated adjustment. Collectively families' experiences reflected the continuum of stages of adjustment as identified by Bicknell (1988) and Gargiulo (1985), and salutogenisis, the valuing of difference, described by Antonovsky (1993), Bristor (1984) and Wills (1995).

Following the initial reaction of shock some parents asked 'why me?' (Kubler-Ross, 1969) and sought to find meaning for their child's blindness before moving on. The extended family of one child considered the blindness to be the result of a curse [Violet, p.189], while parents of another sought, unsuccessfully, a reason for punishment [Kevin, p.70]. In the pathway to acceptance some sought to 'find a cure' with alternative medicines such as naturopathy, homeopathy, cranial osteopathy and Bach flowers tried [Rudi, p.117]. Where a child had multiple disabilities there was evidence that one disability could be accepted more readily than another. Intellectual impairment appeared to be the most difficult with which to come to terms [Violet, p.192].

Frustration was expressed at the restrictions families perceived were placed on them by their child [Sue, p.79; Theresa, p.119; Raewyn & Leith, p.136]. Unable to do the same things as other families, resentment built up and stress levels became high, often to be followed by feelings of guilt. Guilt was experienced for a variety of reasons. Trying to teach their child to walk when unaware that he had cerebral palsy [Violet, p.192], not spending more one-to-one time with their child [Rudi, p.118], doing for the child rather than promoting independence because of time restrictions [Gloria, p.171] and reflecting on what might have been had they had more knowledge, more skills, or taken a different course of action [Gloria, p.169] engendered guilt feelings in parents as they faced the reality of their child's disability.

As parents moved toward acceptance they sought out information on the longer term effects of their child's disability and ways of coping. They became upfront with acceptance and did not try to hide the disability [Cushla, pp.70, 71; Theresa, p.116; David, p.207]. Although not the case initially, many parents now considered they understood their child's blindness well [Sue, Richard, p.91]. They were able to focus on the adjustment process for their child and actively help them come to terms with their situations by facilitating strategies relating to effective communication, positive self esteem, self-advocacy skills and acceptance of restrictions [Focus Group 3]. The adjustment process was perceived to be ongoing with stages reoccurring as circumstances and events changed. Time was not considered to erase memories and dates relating trauma experiences were acutely recalled [Cushla & Kevin, pp.66, 67, 74; Focus Group 3].

5.2.4. Ongoing issues

The period following diagnosis into toddlerhood, childhood and, for some, adolescence, brought further issues. Feelings of isolation caused by not knowing others in a similar situation was common. Some felt a strong need to talk with parents of a child with the same condition, conduct which supported Hornby, Murray and Jones' (1987) identification of like-peers as often the persons most appropriate to provide support [Georgia, p.103; David, pp.202, 203]. Gaining adequate information about their child's condition often proved difficult as did the initial linking into support services [Georgia, pp.99, 100, 101; Alison, p.155; Violet, pp.188, 189, 192]. Many conditions were complex [Georgia, pp.99, 103; Gloria, p.169; David, pp.208, 210]. Different perceptions concerning the extent of vision impairment, and new learning required as conditions changed due to improvement, medical intervention, or subsequent deterioration, caused consternation [Alison, pp.159, 161; Kevin, pp.67, 68; Gloria, p.169; David, p.206]. The impact of environment [Toni, p.150, 151] and personal characteristics of the child on visual functioning, were further factors for parents to come to terms with. Above all, the need to ensure the physical safety of their child, particularly in unfamiliar environments, was ever present.

Child development issues were prevalent [Cushla, p.69; Sue, p.79; Theresa, pp.112, 113; Leith, p.127; Raewyn, p.129]. These were largely reflective of Havighurst's (1972) theory of developmental tasks and supported Mitchell's (1985) notion that parents of children with disabilities may be dealing with tasks in addition to other parents. They were also commensurate with Hornby's (1994) observation that development may be slow in some areas with life stages differing from siblings and peers. Six of the ten children were described as experiencing developmental delay in one or more areas [Annie, Andre, Shaun A, Hannah, Shaun B, Richard]. In most cases some degree of delay had been apparent to parents in their child's early months, even though three of these children were first born [Annie, Andre, Richard] and there was no immediate means of comparison with siblings [Sue, p.80; Theresa, pp.112, 113]. There was a sense of needing to provide age appropriate experiences for children with developmental delay. Feelings of grief that their child was not able to independently participate in events, as did younger siblings, was apparent [Theresa, pp.115, 118, 119; Gloria, pp.172, 180, 181]. Parents also experienced unease between the knowledge that their child played happily with children of the same developmental level and an age-appropriate philosophy which encouraged age-appropriate peers and activity for all children [Raewyn, p.133; Gloria, p.172].

Concept development presented particular concern for parents of congenitally blind children, who felt that this important area was misunderstood and when delayed, frequently misdiagnosed as intellectual impairment. They also warned of how competent language could belie limited concept development in a child, or conversely, that when expressive language was slow in developing there was a tendency to underestimate what a child understood (receptive language), [Cushla, p.72; Sue, pp.78, 82, 86, 87; Raewyn, pp.131, 134; Gloria, p.169]. In the early stages some parents underestimated the effort required to teach their child skills, especially those which usually occurred incidentally through visual modelling. For example, Sue did not realise that she would have to teach Annie to walk as she assumed this skill would develop in the same way as for other children [p.79]. Parents tried to develop a sense of understanding of their child's learning needs by putting themselves in their place and although often difficult, persisted in exposing their child to a wide range of experiences. They found that over time their child became more accepting, even at times dispelling their parents' preconceived notion that a particular experience would not be enjoyed [Sue, p.80].

The first five years were considered a difficult time for the majority of families [Focus Group 1]. While the needs of their child with disability for love, shelter, and care were no different to the needs of all children (Smith, 1987; Strully & Strully, 1989), the demand for stimulation and interaction between parents and child was intense. All parents held strong belief in the value of early intervention and did much to ensure that their child got a good start in this respect [Dylan, p.69; Annie, p.82; Andre, pp.116, 117, 121; Shaun A, pp.130, 131; Nuu, p.145; Hannah, pp.169, 170; Shaun B, p.190; Richard, pp.202, 203]. For those whose children developed mannerisms associated with blindness, the desire was that information of such affectations and their means of elimination be provided early [Sue, p.78].

Challenging behaviours were evident in the majority of children, some intermittent at specific stages of development, such as adolescence, while others occurred over a prolonged period. For children in early developmental stages, behaviours such as screaming, often appeared to be an expression of resistance to new experiences, inability to cope with change, and feelings of insecurity. Behavioural challenges frequently increased as the child got older as did their complexity. Richard's dependency on arm splints following eye surgery was such an example [p.206]. Parents sought meaning in their children's behaviours and reported strategies used in dealing with them. These included setting the same parameters and having the same behavioural expectations as for other children, the use of natural consequences, expecting the same parameters from others, and modelling successful approaches used by others [Cushla, pp.71, 72; Sue, p.80; Raewyn, p.131].

Becoming informed about how best to meet their child's needs was important. Parents actively sought to gain more knowledge in their child's early years, with some providing intensive educational input, an approach not without criticism. Both Cushla and Raewyn were reproached for being overly strict, with Raewyn described as more educator than parent [p.71; p.127; p.131]. However, such approaches and perseverance were considered essential if their children's development was to be facilitated. Ideas and resources to plan for the longer term were sought and older children with disabilities visited to gain an understanding of developmental patterns and expectations. Homai was attended for assessment and short term programmes, such as toileting and techniques of daily living, where child and parent learnt together. Proficiency in braille [Cushla, p.69; Sue, p.91] and sign language was achieved by parents whose children used these modes of communication.

Issues regarding sexuality were raised. Blind children were considered to be particularly vulnerable in terms of sexuality development [Focus Groups 2 & 4] and for Annie's parents, puberty and menstruation were matters occupying their thoughts early in Annie's life [p.90]. Uncertainty surrounding the impact of puberty was a concern of younger children's parents, while increased difficulties experienced during adolescence was a feature for families who had reached this stage [Toni's, Hannah's, Shaun B's, Richard's]. Such a position supported the findings of Heller, Rowits and Farber (1992) that the greatest difficulties families experienced were in the adolescent years. Parents believed that specialist input was required to assist them in dealing with these areas of development.

'Ordinariness' was important to families although it could be very elusive. Both the normality of their child with disability and the individuality of all children, each of whom might have special needs in their own way, were recognised. Parents of children with a lesser degree of disability [Sarah, Nuu, Toni] had attempted to convey to them that they were the same as others but "just might need things a little differently to get there" [Alison, p.158]. These children were not made 'special' or singled out by their families who set about teaching strategies to cope. They were urged to take responsibility for those things pertaining to their disability, encouraged to discuss feelings and "make your disability work for you, not against you" [Georgia, p.106]. Above all, parents sought to maintain this sense of normality and provide their families with the acceptance, support and stability which Strully and Strully (1989) identified as the responsibility of all families.

All parents thought about the future of their child. Often uncertain about the extent of their child's capabilities they wondered what would be possible in years to come [Rudi, p.124; David, p.210]. Working towards independence was important [Raewyn, p.134] with some having the expectation that their child would live a 'normal' life and work in paid employment [Daniel, p.163; Georgia, p.108]. Not knowing what the future held and seeing the difficulties other families were tackling with older children, especially in relation to post-school provisions, was daunting. There was dilemma in where to utilise energies - whether they be directed to safeguarding their own family or employed in working towards change in the wider sphere for 'the greater good'. The latter risked a depletion of resources away from the individual family [Focus Group 3; Cloan, p.178] and possibly diminished the ability to live in the here and now [Gloria, p.175]. In either instance there was the realisation that there was no guarantee that what was done in the present would bring benefits in the future. However, finding ways of making life experiences meaningful for their children was the focus of all parents who also urged others to see the potential in their child. While they acknowledged they had made mistakes on occasions, parents believed that they had done the best they could given their circumstances and were open to learning from their various experiences [Sue, p.91; Theresa, p.119; Violet, p.189]. All were willing to use the knowledge they had gained to assist others.

5.2.5. Parental relationships

Generally, parents considered that having a child with special needs placed stresses on the marriage at various time, an occurrence also identified by Shapiro (1983) and Stolarski (1991). Parents of five children reported that their experiences had drawn them closer together [Annie, Sarah, Andre, Hannah (Gloria & Cloan), Richard: Researcher's Log], and in three cases the marital relationship had ended [Raewyn, p.128; Gloria, pp.168, 169; Violet, pp.190, 191]. Parents alluded to statistics which indicated a high incidence of marital breakups (Garth, 1977; Murphy, 1982; Tew, Payne & Lawrence, 1974) where primarily the father had gone, leaving the family manage alone [Focus Groups 1 & 3]. While some parents professed to not always having agreed on the best course of action in respect of their child with vision impairment, there was a strong sense of giving and receiving support from each other, equality of partnership, the right to have their own life and the right to feel supported by others. An acute sense was developed of when their partner was feeling in particular need of support, with leadership within the family likely to change depending on such circumstances [Sue, p.89; David, p.200]. What happened to marriage partnerships appeared to reflect the findings of

Brotherson, Turnbull, Summers and Turnbull (1986) who suggested that having a child with a disability in the family tended to strengthen strong marriages and weaken fragile ones.

Responsibility for decision-making differed. This was primarily undertaken by the mother in three families [Sue, Tr.2; Raewyn, p.129; Violet, p.191], and was the joint responsibility of both parents in five more [Kevin, p.72; Theresa, p.116; Feanu, Tr.6; Gloria, p.171; David, Tr.10]. In Sarah's family all members were encouraged to participate in decision making [Amy, p.95; Georgia, p.106] and for Toni, who was now adolescent, responsibility for decision making was being transferred from her parents [Toni, Alison, Tr.7]. Mothers of two younger children expressed hope that when the time came they would feel able to step aside and allow their children to make their own decisions and choices [Cushla, p.73; Georgia, p.103]. There was an awareness by parents that the implications of their decision were likely to touch many lives.

Effective communication was highly regarded in the parental relationship. This included the ability to identify and articulate problems, express feelings and develop assertion skills [Kevin, p.74; Sue, p.89; Georgia, p.106; Cloan, p.183; David, pp.200, 201, 208]. There was the perception that partners spoke more to each other than the average couple and the need to be openly appreciative and valuing of the partnership was considered significant. Dealing with problems before they were exacerbated assisted in maintaining family stability. In two families where marital breakdown had occurred it appeared the fathers had experienced difficulty in talking about the situation [Gloria, Tr.8; Violet, pp.188, 190], with one that "didn't come around until ten years later" when his wife started talking to him about his son's birth [Violet, p.190]. Featherstone's (1981) perception that sexual relationships might be affected by fatigue, a sense of isolation, and the fear of producing another child with a disability were reflected in the study through Focus Group discussion [Focus Group 2] and Group Graphics [pp.56, 57, 58, 59].

Division of activity between parents was clearly evident. It centred around two key roles: primary caregiver and advocate. As in the studies of Fewell and Vadasy (1986), and Parker (1986), mothers in all ten families were the primary caregivers for the child with disability. Five fathers [Kevin, Tr.1; Richard, Tr.2; Lance, p.102; Daniel, p.165; David, p.200] acknowledged that their partners had been "at the front line" [Lance, p.102], carrying responsibility, working hard in caring for the children, and bearing the brunt of visits to professionals. These fathers considered they were supportive of their partners but some expressed relief that the role was not theirs. For their part, the women perceived less opportunity for fathers to attend appointments due to the structure of the working world and believed some husbands felt "unused" and "left out of it" - potential for marriage breakup [Georgia, p.102]. However, overall, fathers had considerable involvement, with five regularly attending medical appointments and IEP (Individual Education Plan) meetings for their child [Richard, p.88; Kevin, Rudi, Cloan, David: Focus Group 2].

Advocacy, the second area of focus, took much energy in all families and was perceived as a process helpful in working towards empowerment. Discussed more fully in the final section of this chapter, its impact within the parental relationship was evident. Advocacy centred around parents' daily involvement with their own child and in the national sphere. While in three families both partners were significantly involved in advocacy, others expressed that they were satisfied to provide support by acting as a sounding board for the one with a high profile and to maintain the balance within the home by trying "to be an anchor" [Lance, p.102]. However, some felt that given the opportunity, they would choose to be more fully involved in advocacy and there was a sense of being left behind by their partners in skill development and personal growth [Researcher's Log]. Receiving information second-hand was not always appreciated and the expectation that information would be shared was sometimes not met by a partner, who just wanted to tune out and relax after intense involvement.

There were periods of trauma and it was readily acknowledged by parents that at times they had chosen to go down some routes that "had the potential to put off any normal, sane person" [Cloan, p.181]. Experience of fatigue and burnout was common with parents' energy taken up in meeting the needs of their child [Focus Groups 1, 2]. There was often little time for the everyday things and decisions occurred by natural attrition rather than as a result of developing a strategic plan by consensus [Cloan, Tr.8]. For some, the constant demand of being continually aware of what their child was doing was intense [Raewyn, p.136] an experience Gloria described as "like having a small child for a long time" [p.173]. The impact was perhaps captured by Bowman and Virtue's (1993, p.2) statement: "While all mothers experience lack of sleep, lack of income, social isolation and low status, babies eventually grow up."

The ability to 'take a break' and access respite care were important strategies for families [Andre's, Shaun A's, Hannah's, Shaun B's, Richard's: Researcher's Log]. Parents considered that this needed to be more than just a weekend and should result in relaxation and enjoyment for the family, rather than be spent in catching up on maintenance tasks. However, there were frequent difficulties in finding suitably trained persons with the skills to do the job and available at the time when the family might most benefit from their support [Theresa, p.120; Raewyn, p.136; Gloria, p.182; Violet, p.194]. Commensurate with the findings of Lonsdale (1978), and Phillip and Duckworth (1982) parents' situations had impacted considerably on socialising [Rudi & Theresa, p.121; Gloria & Cloan, pp.173, 174]. They blamed themselves for not having time to develop a wider support network, a 'catch 22' situation, where the longer this was not addressed the more it impacted upon their lives. However despite such circumstances those who found mutual support in the parental partnership expressed that there were times when they felt their relationship had been strengthened by having a child with disability and that it had "made us grow up a lot more wisely than maybe otherwise" [Georgia, p.101]. Those who were parenting alone also expressed a sense of personal strength and growth which they believed had arisen, in significant part, out of their experiences with their children [Raewyn, p.137; Violet, p.196].

5.2.6. Participants with vision impairment

Three children with vision impairment participated in interviews, Sarah [p.94], Nuu [p.143] and Toni [p.150]. Sarah described her relationship with her family and what she valued in this context - love, togetherness, working towards a goal, and the opportunity for decision making. Nuu and Toni focused primarily on relationships with peers and experiences at school. These aspects are discussed within the relevant sections of this chapter.

5.2.7. Siblings

Sibling information was collected in two ways. First, eleven siblings expressed their views directly in four family interviews [Jarin, Amy, Kayla, Daniel, pp.95, 96; Leith, Tania, p.127; Katarina, Tafale, p.143; Rebecca, Annemarie, Sarah, p.153]. Second, parents recounted their views of issues which affected siblings. Overall many issues arose reflecting wide-ranging, at times contentious, views. Featherstone's (1981) findings that siblings' concern about the role they would be expected to assume later in life was not reflected in this study. Positive effects on sibling adjustment did however emerge, supporting Furneux's (1988) observation regarding entry into helping professions and the findings of Crnic and Leconte (1986), Ferrari (1984), and Grossman (1972), that siblings were likely to develop positive attitudes towards difference and a maturity beyond their years [Sue, pp.80, 81; Raewyn, pp.136, 137; Gloria, pp.174, 175]. Other issues, such as the impact of parental involvement in advocacy, extended beyond those identified in the literature.

Siblings interviewed ranged in age from seven [Kayla] to seventeen years [Daniel]. Themes which emerged were: valuing the family; understanding the vision impairment; sense of sacrifice; and personal growth and development. Siblings of the first family emphasised the importance of closeness of family, and their valuing of love, sharing and joy of life [pp.95, 96]. Parents who were good listeners, allowed them the opportunity to make their own decisions and gave support if things went wrong, were appreciated. Family members were accustomed to planning and working together towards a goal, and despite differences, they were 'there for each other'. The children perceived they were part of a busy household expressing that they would like to spend more time together just as a family. These siblings highlighted the ordinariness of their lifestyle. Although three of the children living in this household might be considered as having special needs, this aspect of their lives did not feature in what was offered in the interview [Researcher's Log].

Difficulties in understanding the impact of vision impairment were experienced by some siblings, especially where the eye condition was not stable, or where visual functioning abilities changed according to environmental conditions. Taking advantage of the disability by avoiding certain tasks was perceived by one sibling, who felt there was a difference in her brother's behaviours when their parents were absent from the home [Katarina, p.143]. Issues surrounding how to respond when peers asked questions about their sibling with vision impairment also surfaced. While siblings attempted to respond with the knowledge they had, this was not always appreciated by the family member with the vision impairment, who preferred to be asked directly [Rebecca, p.154; Toni p.152].

The siblings of the child with the greatest degree of disability (of the four families) considered that they had made considerable sacrifices in order to support his needs [Leith, pp.127, 128]. These had included geographical relocation, having to make new friends and attend new schools at a time considered difficult, giving much of their time, and going without their mother's support in such things as transportation or accompanying them to events. Feelings of neglect and resentment arose at times. Siblings considered relationships with their peers were affected as they grew beyond them because of additional responsibilities. Absence of their mother due to medical or educational appointments, meetings and advocacy, was also commented on by some siblings [Tania, Tr.5; Rebecca, p.154].

As parents highlighted a range of issues, it was evident that they put much effort into protecting siblings from the pressures of disability. Decisions which impacted upon the family as a whole were frequently spoken of. There was recognition that siblings were possibly "the ones least recognised in the whole thing" [Cloan, Focus Group 2] and relatively powerless in that their opinions were rarely sought. Treating all the children the same was important for parents of children with a lesser degree of disability, and all parents were determined to do their utmost to prevent siblings being disadvantaged or missing out on doing normal family activities [Theresa, p.119]. At the same time there was the realisation that this did occur in some areas [Sue, p.79; Theresa, p.119].

Family position of the child with vision impairment was significant for some parents. Of the ten children, four were the eldest [Dylan, Annie, Andre, Richard], three were middle children [Sarah, Nuu, Toni] and three the youngest [Shaun A, Hannah, Shaun B]. Parents of two eldest children believed this position to be an advantage as the family situation was normal for the siblings arriving subsequently [Cushla, p.68; Theresa, p.118]. "Andre has always been there with his special needs" [Theresa, p.118]. The parents of the third eldest child however, highlighted the disadvantage of having nothing to measure their child's development against. They felt they had been slow to recognise manipulative behaviours or differentiate normal developmental behaviours with those resulting from vision impairment [Sue, p.80]. Violet, whose child was youngest, highlighted the difficulties she experienced in trying to deal with different developmental stages within the family, her older children being teenagers when her baby with multiple disabilities was born [Violet, p.187].

Siblings' early recognition of difference was observed by mothers. The effect of the lack of response to a smile, and the realisation that they needed to interact differently, came between six and twelve months for two siblings [Cushla, p.68; Sue, p.80]. Parents were aware that siblings might need additional skills in order to "bridge that gap" [Kevin, p.68], such as the learning of braille or sign language. Most thought the relationship amongst their children was good, although two children with vision impairment indicated that at times they felt misunderstood by their siblings [Researcher's Log].

Parents of both older and younger siblings were aware of early responsibilities, early decision making and early independence brought upon these children. Generally, a lot was expected and a lot given. Sibling perceptions of coping alone, bearing the brunt of stress and making sacrifices was borne out by parents despite their efforts to avoid such burdens [Focus Group 2]. Parents worked hard to maintain a good rapport between all their children. They did not wish siblings to resent their brother or sister or look back on their childhood with regret [Sue, Focus Group 2; Theresa, p.118]. While not expecting siblings to look after their brother or sister, parents hoped that they would be caring towards one another and perhaps have them to stay occasionally in later years. Younger siblings were being taught self-advocacy skills by their parents at an early age and workshops were identified as a desirable means of assisting siblings in dealing with the many issues with which they grappled. They were also a means of providing peer support.

Both siblings and parents identified positive aspects which had arisen out of sibling experiences. New skills had been generated, positive attitudes developed and personal growth taken place. The practical and emotional support older siblings provided to their parents was valued. Accustomed to early responsibility, these siblings were beginning to take on further responsibilities in wider spheres [Leith, Tania, Raewyn, p.137], such as in working voluntarily with other children with disabilities, teaching Sunday School, providing Alternative Care and planning a teaching career. Parents were acutely aware of their attempts to balance the needs of all their children and to be ready with a listening ear.

5.2.8. Conclusion

In general the study's families described themselves as living hectic lifestyles that, at times, became almost saturated with disability [Gloria & Cloan, Tr.8]. There was an awareness of the need to become more selfish in order to protect the immediate interests of their nuclear family. Parents wanted their children to develop acceptance, self-confidence, high self-esteem, assertion skills, and to reach their full potential. Honesty and respect for self and others were important and siblings were encouraged to become good friends. While parents were aware of some limitations on their families, all had visions for the future with the same aspirations as would be likely in any family. Their experiences however, had given them a different perspective on life. For some, despite difficulties and frustrations, there was a sense of not wanting to change anything. The expression of one parent is perhaps an apt summary of the situation parents found themselves in as they sought to do the best for their families: "Whether you have normal children or children with disabilities, it's the same job description. ...I wasn't born to be a parent, it's something that you learn" [Georgia, p.107].

5.3 The Mesosystem: extended family, neighbours, workmates, friends, peers

5.3.1 Introduction

The mesosystem consists of settings in which the family actively participates. It includes the extended family, friends and the community in which a family lives (Bronfenbrenner, 1979). The extended family has a key role in influencing family functioning. Likewise, peers, neighbours, workmates and friends can have a positive or negative effect on families. While Hornby's (1994) adapted ecological model includes education, health and social workers within the mesosystem, the participants of this study considered that their relationships with such professionals were distinctly different to the previously mentioned groups and did not sit comfortably alongside these. Therefore issues involving the latter group are placed within the exosystem and discussed in the wider context of health, education and social systems.

Of all ecological systems, the least number of issues were identified in the mesosystem. It was noticeable that focus group discussion barely touched on this band even though questions probed its topic areas. Graphic recording highlighted the absence of the extended family and there was a realisation that, for some, it was the inner circle which was missing from the larger support network. Information was more readily available in family interviews with issues depicted in this section arising largely from this source. Both understanding of their children's disabilities and the level of support available to families varied. Compounding difficulties for families was the tendency either to move away from their familiar neighbourhood to access more suitable housing or educational opportunities (four families) or conversely, not to take up opportunities which arose, because support systems were well established in the local environment (three families). While the majority of families drew upon a wide range of coping strategies, they tended to operate in small close-knit units which were likely to be comprised of extended family, friends or peers. Barriers encountered by the nuclear family also impacted on other family members and parents often found themselves in the position of supporting extended family members and friends. Social acceptance was a major issue and parents sought to support their children and find a way forward in environments which were frequently discriminatory.

5.3.2 Extended family

Nine of the ten families had extended family living in New Zealand [Dylan's, p.65; Annie's, p.77; Sarah's, p.93; Andre's, p.111; Shaun A's, p.126; Nuu's, p.142; Hannah's, p.167; Shaun B's, p.185; Richard's, p.199]. The tenth family [Toni's, p.149] had moved to this country six years ago and expressed that the support of their family was greatly missed [p.160].

Although not the experience of all participants, grandparents and other extended family members on the whole were a valuable source of emotional and practical support as found by George (1988); Hornby and Ashworth (1994); Seligman and Darling (1989); Sonnek (1986); and Vadasy, Fewell and Meyer (1986). Good support from their extended families was reported by six parents [Kevin, p.66; Theresa, pp.115 & 121; Raewyn, p.134; Feanu, p.145; Gloria, p.173; David, p.200] with most families considering there was some degree of assistance, if only minimal. Support did not always come from all family members. Sometimes there was contrast in supportiveness between one side of the extended family and the other, or one generation and another [Kevin, p.66]. A further four families were separated by geographical distance from extended families [Kevin, p.66; Theresa, p.113; Raewyn, p.129; Violet, p.189]. However, where there were close emotional bonds and good communication, they felt supported [Raewyn, pp.128, 134, Tr.5]. Practical support, frequently in the form of babysitting, was offered. Particular skills of others, such as the brother and sister who were counsellors [Theresa & Rudi, Tr.4] and the grandmother who made tactile books were welcomed [Cushla, p.69].

Families who received good support found that its level varied over time, given specific circumstances. While grandparents provided a strong positive influence for some families [Kevin, p.66; Theresa, p.115; Violet, p.189; Gloria, pp.173, 182, 183], assistance from this source lessened as grandparents grew older, or in some instances, died [David, Tr.10; Theresa, p.115]. The impact of disability altered life cycle variables (Terkelsen, 1980) and in some families the generational roles had changed with parents supporting both their children and their aged parents, a circumstance which supported the findings of Carter and McGoldrick (1980). Overall, while difficulty in adapting to the changed situation was evident in extended families, especially in the earliest years of the child, for most acceptance had developed over time. This matches the findings of George (1988), and Seligman and Darling (1989).

While some families initially found no, or minimal support, from their extended families, it appeared that friends or professionals filled this gap. Often a key person emerged, sometimes from an unexpected source, as in the cases of Sarah's [p.99] and Shaun B's [pp.188, 196] families. As children grew older there was increasing difficulty in getting help to look after them, especially if the child had multiple disabilities [Theresa, p.123; Raewyn, p.136; Gloria, p.173; Violet, p.194]. Parents perceived two main reasons: the challenging behaviours developed by some children; and delayed development, such as a ten year old's toileting needs, being more difficult to accept in older children. There was the additional complexity of communication with the two children who were vision-hearing impaired [Gloria, p.173; David, Tr.10]. As offers to look after children declined, parents also felt less inclined to ask for assistance for fear of imposing on others. However, there was the desire that assistance would be more freely offered, especially in respect of care-giving [Theresa, p.115].

The impact of cultural differences, such as those outlined by Correa (1987), and Orlansky and Trapp (1987), brought added dimensions to the Maori [Shaun B's, p.185] and Samoan families [Nuu's, p.142]. The belief held by Shaun B's grandmother that his disabilities were the consequence of a curse resulted in her not having contact with the family until Shaun was three years old [Violet, p.189]. Thus, a source of support offered later, was not available to Shaun's family in the early years. It was only much later that Shaun's mother, Violet, understood that the guilt carried because of this conviction was the reason for her mother's absence [p.190]. For Nuu's family there was the struggle with the beliefs of a very supportive extended family whose culture equated 'disability' with 'sickness' [Feanu, p.146, Tr. 6]. Thus while parents were attempting to provide a climate of normalisation which encouraged their son to develop independence, the wider family's beliefs tended towards over-protectiveness, lowered expectations and exceptionality [p.146].

Denial was the initial response of some family members, most often grandparents, as they disclaimed responsibility for the disability. "It wasn't from our side of the family" was a message familiar to some parents [Georgia, p.98; Theresa, p.114, 115; Alison, p.155]. Parents reported that the opportunity to be with their child helped family members progress through the adjustment process [Cushla, p.71; Theresa, p.115; Focus Group 2]. Sometimes grandparents' perception of what might lie ahead exceeded that of parents. Gloria perceived her father, who was a social worker, to be particularly upset [p.168]. She believed this was because initially he alone had some understanding of the implications of his granddaughter's disability. Therefore, Gloria, in addition to dealing with her own and her child's needs, provided primary support for her father and husband [p.168].

Parents indicated that most family members had now accepted their child. However value judgements were projected onto families, particularly surrounding issues of having further children and parenting full-time [Cloan, p.181; Focus Group 2]. The view that at least one parent, preferably the mother, should be at home rather than in paid employment was perceived as "almost like laying a guilt trip" [Cloan, p.181] as well as being in conflict with the right of choice and societal expectations of financial independence. Anxiety of older family members as to what would become of the child if anything happened to the parents was evident, as was the perception that charitable organisations such as the RNZFB or IHC, would provide institutional care, a role not now undertaken by either organisation [Cushla, p.71]. These same family members, however, were swift to take on the role of advocate when the need arose, as in the case of Dylan's great-grandmother and the park steps [p.71]. Such emotional impact on extended families, as they too worked through the adjustment process, supported the findings of Bicknell (1985), Gargiulo (1985), Hornby (1987), Seligman (1979) and Wills (1985).

Physical, social and emotional exclusion occurred across all settings of the mesosystem. While extended families had made considerable adjustment, parents illustrated ways in which their children with disabilities were treated differently. Communication proved difficult, with some giving superficial responses to children while others became over-zealous in their approach to hide underlying anxiety. Disparate treatment might be in relation to the child's siblings, such as exclusion from family occasions like Richard and the wedding [David, p.200], Andre and the birthday [Rudi, Focus Group 4], and Annie and the biscuits [Sue, p.81], or all children of the family might be excluded [Sue, p.81]. Parents, however, identified that they had become particularly sensitised to such issues and that perhaps there was a degree of over-response [Richard, p.81; Focus Group 2].

Overall, for the majority, there was the perception that the extended family was a significant source of support. However there was also a degree of separation from the extended family who remained in the mainstream culture. While there was evidence of genuine attempts to relate purposefully to both the child and it's family, parents in particular, had often moved in their philosophical, and pragmatic perspectives in seeking a collective solidarity within the culture of disability [Focus Group 2].

5.3.3. Neighbours, workmates and friends

Experiences within other mesosystem settings supported Kendrick's (1995) contention that families of children with disabilities typically do not have substantial personal support networks outside of the family to aid them. Neighbours rarely featured in the study. In the few instances where neighbours had been supportive, families had subsequently moved to other locations where similar relationships had not evolved. For those who moved shortly after the birth of their child, loss of local community support was keenly felt [Raewyn, p.137; Violet, p.187]. One family rued the loss of an elderly neighbour who had developed a special relationship with their child and even offered to learn braille [Sue, p.85]. Three families considered their local communities showed interest and had given considerable support to their children [Cushla, p.70; Sue, p.81; Georgia, p.103]. The few who had experienced love and care from neighbours valued such relationships.

Workmates, likewise, were seldom mentioned. Those that were, were described as being supportive of the parent having time off to attend appointments or to provide support to their families in times of trauma [Lance, p.102; Violet, p.188]. Some parents were reluctant to take advantage of such support. In one instance it was two years following the birth that a father informed his employer of his son's difficulties [Violet, p.188]. Four parents who were working with people with special needs acknowledged they were led in such a direction because of experiences with their own children [Raewyn, p.128; Feanu, p.144; Gloria, p.182; Violet, p.192]. Two intentionally entered their particular area of employment because they believed it would assist in gaining information and knowledge about their children [Raewyn, p.139; Violet, p.192].

A third parent, with significant knowledge and expertise gained through her experiences with her daughter, considered she was not accepted as a professional in her own right [Gloria, p.182], with her skills not valued by colleagues in the same way as those with formal academic qualifications. Lack of opportunity for further education and a short concentration span after years of going "to-and-fro" [p.182] with her child were perceived as obstacles to changing the situation. Two of the study's fathers worked together [Rudi, p.121; Cloan, Tr.8]. They valued the mutual support found in having the opportunity to discuss issues, ideas and feelings in the workplace.

Breaking down barriers and building relationships with new people were tasks faced by parents. The level of support available from friends varied. Some received very good support while others, whose friends were unable or unwilling to cope with the family's changed situation, found they faded from their lives [Alison, p.156; David, pp.200, 208; Raewyn, Tr.5; Focus Group 2]. Most often it was a few close friends who provided significant support, some coming from particular contexts such as church [Georgia, pp.99, 103; Raewyn, pp.137, 138]. Such a friend became the major source of support for Georgia and Lance following Sarah's birth [pp.99, 100]. New connections were made with people that, in usual circumstances, would not be likely friends, through contacts with 'disability agencies' and peer support networks [Raewyn, p.138; Alison, p.156; David, pp.204, 208]. To facilitate relationships between their child and friends, some parents, like Rudi, developed particular strategies for breaking down barriers [p.115]. Parents valued the support of friends shown in a number of ways: taking children out, child-care, providing transport to hospital and accompaniment to medical appointments.

Friends looked to parents for a lead, with acceptance and support developing because they observed the family's relationship with their child [Georgia, p.101; Alison, p.156]. Georgia described how friends gave support and acceptance because "they saw that we had never treated her anything different" [Georgia, p.101]. Friends learnt from families' knowledge, with support being reciprocal between parents and friends. Many of the study's families were frequently sought out, as others needed help with crises of their own. It was perceived that competent support would be readily available from people who had developed strategies to deal with problems of seemingly greater magnitude [Georgia, Rudi, Violet, David: Focus Group 2].

With both extended family members and friends, understanding of the child's disability varied. Some parents experienced difficulty in getting acceptance of expectations for, and of, their child. Friends were likely to offer less support for children as they grew older [Raewyn, p.136; Gloria, p.182; Violet, p.194]. Parents of children with severe disability however, were mindful that past practices of hiding children away had engendered negative attitudes and they worked hard towards developing a more accepting environment for their children [Theresa, p.116; Focus Group 2].

5.3.4 Peers and community

The stigma and social devaluation people who live with disabilities risk, was evident in experiences with peers and community. Issues concerning peers arose in two contexts, peers of the children and those of their parents. Attitudes of sighted peers of children with disabilities were considered by some to be more positive than those held by adults [Sue, p.81; Theresa, p.116]. They were attributed to having a better understanding of blindness and being less reticent in developing relationships. The inquiring nature of children and their openness in asking direct questions was thought to facilitate breaking down barriers. While mainstreaming was perceived as good for developing friendships there was also the realisation that social skills did not develop automatically and initiating friendships was especially difficult for blind children [Sue, p.85; Raewyn, Tr.5; Focus Group 3]. It was disquieting to note that teasing had been experienced to a considerable degree by each of the participants with low vision, Sarah [p.103], Nuu [p.143] and Toni [pp.150, 160], especially in the school setting. Education programmes for sighted peers had had some influence in developing more positive attitudes. There were also positive examples of peer support in class settings such as the relationship between Toni and her friend [p.151], and the reciprocal relationship between Annie and her class peer [p.83]. Parents of one child who was considered socially well integrated, observed that his peers did not act as moderators of his, at times, boisterous behaviour, but rather deferred to his blindness - a response they believed too soft [Cushla, p.70].

While some children had many friends, the lack of peers was lamented by parents of children with multiple disabilities [Theresa, p.118; Violet, Tr.9]. Positive interaction with children of family friends who visited from time to time, although valued, was not seen as substitute for their child's personal friends. Interaction was more easily established with those of a similar developmental, rather than chronological, age level for some children [Raewyn, p.133] and adolescence was seen as a particularly difficult time for maintaining peer relationships [Gloria, p.172; Violet, pp.194, 195]. In general parents worked hard to support their child in developing positive peer relationships.

Negative encounters outweighed positive experiences in respect of parents' own peers. Isolation because of discriminatory attitudes and lack of understanding were evident, supporting the findings of Bogdan and Biklen (1977) [Sue, p.82; Cloan, p.180; Violet, p.191; Focus Group 2]. Parents perceived other families had no understanding of what they were going through [Cushla, p.68; Theresa, p.117; Alison, p.156; Violet, pp.192, 193]. While some mothers, in particular, found support from peers in groups such as Playcentre or Plunket, others found the conversation irrelevant to their situation, with peers who shied away when they attempted to share their own experiences. Support for fathers was almost non existent [Richard, p.88; Georgia, p.102; Violet, p.190; Focus Group 2]. The inability of some fathers to talk about their situation and express their feelings, a difficulty also identified by Featherstone (1981) and Lamb (1983), was exacerbated by the lack of natural opportunity.

While some parents felt people were generally well meaning, all had experienced the effects of misperceptions regarding their child. Difficulties arose from both over- and underestimation of their children's capabilities. Overestimation led to inappropriate assumptions and expectations of age appropriate behaviours, while underestimation frequently resulted in significance being attached to the disability rather than the child and over-protectiveness. Leigner's (1994) perception of blindness being feared by society was evident in this study and, where an initial fear of blindness had been overcome, this was often replaced by fear of a child's challenging behaviours when these developed at a later age [Raewyn, pp.136, 137; Violet, p.194; David, pp.104, 105]. Negative or insensitive comments by people in the community appeared to be frequent [Cushla, p.71; Focus Groups, 2 & 3] with both parents and staff experiencing the urge to lash out at the superficial reaction of others [Gloria, p.181]. A more positive experience of community was encountered by Sarah's family, who perceived living in a small town advantageous in developing effective support networks [p.103].

Unwanted advice was received from people who meant well. While being perceived as a special parent, was affirmed by Violet [p.196], others found the notion unacceptable [Georgia, Tr.3; Theresa, p.119]. The expectation that parents would not cope was difficult to deal with [Violet, p.197; David, p.201], as was criticism of those who, in setting parameters and expectations for their child, were accused of being harsh [Cushla, p.71; Leith, p.127]. In general, parents had hardened to such criticisms and believed they had become unaffected by what others thought. Negative attitudes made them more determined to prove their point [Cushla, p.71; Theresa, p.116]. Attitudinal change sometimes took place when contact was frequent and there was opportunity to get to know the child in person. The chance to share experiences with those who have faced similar issues was valued and some parents found adult role models who were blind a good source of assistance as they developed strategies in dealing with the wider community [Sue, p.82; Focus Group 4]. Education of the community was considered of prime importance by parents in the study [Focus Group 4]. The overall impression was of a community largely ignorant of the predicament of persons with disabilities, but with the perception that many within it wished to remain in such ignorance, a challenge which drew these parents to action [Focus Groups 2 & 4].

5.4 The Exosystem: health, education, welfare systems, voluntary agencies, employment, residential contexts, recreation

5.4.1 Introduction

The exosystem consists of social institutions such as the mass media, health, education and welfare systems. Each influences the family indirectly. For example, the portrayal of stereotypic attitudes towards people with disabilities by the mass media, and the availability and quality of education, health and welfare services will have crucial impact on the functioning of the family. The accessibility of recreational facilities suitable for the participation of children with disabilities and employment and residential opportunities in the local community are also important in assisting families to cope (Bronfenbrenner, 1979; Hornby, 1994).

From both focus group exploration and family interviews, more issues were identified within the exosystem than in any other ecological band. Accessing formal systems within the community was a major theme for parents, as it was in the studies of Hornby (1992) and Sonntag (1993). The effort involved and the difficulties experienced in relation to attitudes, access and imbalance of power were evident. Parents' stories showed bewilderment and frustration as they sought to negotiate within and across systems, with no assurance that knowledgeable professionals would make the referrals which would help them. The issue of choice was another major theme. The ability to make informed choices assumes knowledge of the opportunities that exist, coupled with adequate information. Lack of information and limited resources impacted on freedom of choice and were disempowering to parents as they struggled to get the needs of their child met.

Issues relating to education exceeded all others. Education was seen as the means by which parents' hopes for their child might be realised. Its centrality to the cognitive, affective and social development of children was clearly recognised by parents who battled hard against limitations imposed by restricted educational options and attitudes towards disability. Great emphasis was placed on the parent-professional partnership. While group graphics [pp.56, 57, 58 & 59], in particular, reflected considerable negativity surrounding professionals and their disempowerment of parents, it was also acknowledged that "the professional is the one that may make the difference to your child's life" [Gloria, p.179]. The coming into contact with the professional stage [Focus Group 2] marked the entry of a plethora of professionals into the lives of children and their families. While frequently special relationships developed between child and professional, there were also examples of lack of continuity and unrealistic expectations of children in coping with change, due in part, to the turnover of professionals.

Issues relating to health, education, social services and voluntary agencies are discussed within these subsections. A brief account is also given of matters relating to employment, residential opportunities and recreation. The final section of the exosystem focuses on parent-professional relationships across each of these domains. The concept of parents as professionals for their own child is considered, with participants' notions of how parents and professionals might work in a mutually valuing partnership explored. The role of participants within the context of PVI might also have been placed in the exosystem. However, as peer support and advocacy were considered major means of coping these are located in the final section of the chapter, 'Across the bands: parental coping strategies'.

5.4.2 Health services

The medical system is complex and its negotiation by parents of children with disabilities is both daunting and difficult. The multiplicity of avenues to the various services and their covert interrelatedness can act as seemingly insurmountable barriers to access. In addition, medical practitioners are frequently the gatekeepers through which both medical and other services are accessed. The medical professionals whose services were most frequently used by participant families were general practitioners, ophthalmologists and paediatricians, however the issues discussed were relevant to all sectors of the medical profession [Cushla, p.66; Kevin, p.67; Georgia, p.99; Theresa, pp.112-114; Rudi, pp.119, 120; Feanu, p.144; Violet, pp.188, 196; David, p.201; Focus Group 2].

For some, the initial coping with the diagnosis of their child's disability appeared to be closely connected to glorifying or condemning medical personnel. While parents recognised that they were vulnerable and that professionals were not perfect, experiences were recalled with intense feeling and painful clarity. Perinatal experiences and the circumstances surrounding diagnosis were identified as particularly stressful for families and most often necessitated developing relationships with medical professionals while in a state of shock and uncertainty [Cushla, p.67; Georgia, p.99; Theresa, p.113; Violet, pp.187, 189; David, p.201]. Ethics and accountability were issues, in addition to those of this period previously discussed [Gloria, p.176; Focus Groups 2 & 4]. There was a perception of doctors 'playing God', with children kept alive through technological advances and parents then being given life-long responsibility for children with severe multiple disabilities. Participants of the second focus group expressed their belief that extraordinary methods should not be used to keep children alive unless responsibility was also shared by medical professionals and due consideration was given to 'quality of life'. Parents showed willingness to take risks for their child, with decisions needing to be made about medical interventions which had unknown success rates or where procedures were previously untried [David, pp.202, 205]. Overall, parents stressed the need for an accurate and sensitively delivered diagnosis at a time when they were together and timing of medical appointments which enabled both parents to attend. They also suggested a key worker to provide emotional and practical support, and someone who had been through a similar experience to talk to [Georgia, p.103; Raewyn, p.138; Violet, p.187; David, p.202; Focus Group 2, 3]. With a co-ordination role, the key worker might be a counsellor, health nurse, teacher, social worker or parent.

Information was a key issue. Parents expected to be given "good, grounded, solid information" [Georgia, p.104] which was able to be understood as they sought to ease their anxiety and become more knowledgable about their child [Focus Group 3]. Lack of information created barriers for families seeking opportunities for their children. The findings of Heller, Rowits and Farber (1992) that young families were those most likely to experience difficulty accessing information, extended to families of all ages in this study, especially in regard to the disabling condition and its prognosis [Cushla, p.71; Georgia, pp.98, 101, 103, 104; Theresa, pp.114, 116; Alison, p.155; Daniel, p.155, Gloria, p.169; Violet, p.188; David, p.202]. Parents valued those who provided information in a supportive way but more often information-sharing did not meet their expectations. Nurses were described as "being good but they didn't really tell you anything" [Violet, p.187], while it was perceived that some doctors provided information that was inadequate or incorrect, or even deliberately withheld information and knowledge altogether [Sue, p.87; Theresa, p.113; Rudi, pp.113, 114; Violet, p.188]. When information was provided it was often in language which was not understood and some parents believed doctors hid behind medical terminology [Cushla, p.71; Violet, p.188]. Reports could confuse rather than clarify. Difficulty gaining information was exacerbated because parents did not always know what questions to ask [Violet, p.188] and it often took time to establish a working relationship. For Georgia, it was the third appointment before she felt able to discuss her daughter's situation with the paediatrician [p.99]. Children also found difficulty asking questions of doctors [Nuu, p.143]. It would therefore seem important that a lack of questioning not be equated with lack of interest in accessing information.

The timing and extent of information was significant. Parents considered that doctors needed to gauge their ability to take on information at any given time and recognised that information previously given frequently needed to be revisited and expanded upon to provide fuller understanding [Theresa, p.122; Violet, pp.188, 189]. Lack of knowledge by medical professionals of a child's particular condition or its future implications caused anxiety in parents but they were unanimous that "I don't know" [Sue, p.86] was the most appropriate response in such circumstances [Focus Groups 2 & 4]. The practice of sending letters and reports about their child, professional to professional without parents' knowledge was deplored [Sue, p.87]. Across all domains, parents frequently found themselves in a position where they had to find out about services themselves [Cushla, Kevin, pp.73, 74; Georgia, pp.99, 104; Theresa, pp.122, 124; Raewyn, p.135; Daniel, pp.155, 160; Cloan, p.182, Tr.8; Violet, pp.188, 191; David, p.202]. Therefore the notion of a 'one stop information shop' appealed to participants with Visual or Sensory Resource Centres, Homai or the RNZFB being seen as the most appropriate co-ordinators of such a provision [Cushla, p.73; Lance, p.108; Theresa, Rudi, p.122; Focus Group 3]. Packs giving details of services, entitlements, funding sources and support networks would be pivotal to such a scheme.

Attitudes encountered in the medical sphere reflected the imbalance of power between parents and professionals. Issues centred on poor communication skills, and attitudes described as condescending, disinterested and arrogant [Georgia, pp.100; Rudi, p.114; Alison, p.155; Cloan, pp.179, 180; Violet, p.191; David, p.201; Focus Group 2]. Other negative experiences with medical professionals included their manner with children, disregard of parental knowledge and judgement of parents' ability to cope. Dismissal of parent perspectives and concerns led to parents doubting their own confidence and ability. They were disparaging of doctors who judged them as unable to cope and sometimes accompanied this belief with a directive to place their child in an institution [Violet, p.197; David, p.201]. No parent in this study heeded such advice, but going against medical opinion brought extra pressures to an already stressful situation. Parents responded to such barriers in a number of ways. Some, who did not consider the input vital to their child, ceased to attend or make appointments [Rudi, p.114], some worked towards a better relationship with the doctor concerned, and others, where this was deemed impossible, changed professionals [Georgia, p.101; Alison, p.155]. The level of expertise of medical professionals was important to parents as was a willingness to listen to their concerns [Cushla, p.66; Theresa, Rudi, Tr.4; Cloan, p.179; Violet, p.191; Focus Group 3]. Parents' recognised the need to establish themselves as equals to medical professionals in order to develop a workable relationship [Georgia, pp.104, 105; Rudi, pp.114, 120; Focus Group 3].

Blame was an added complexity. Two families who surmised that their child's disability might have been aggravated by medical incompetence could find no satisfactory answers to their inquiries [Kevin, p.67; Gloria, p.169], while a third family, in attempting to gain further information of their son's disabilities in order to understand and move on, were seen by doctors as seeking to apportion blame [Violet, p.191]. These parents had the perception of professionals backing professionals. While some families were referred on to appropriate support services by medical professionals, others were left to deal with the situation themselves [Sue, p.78; Georgia, p.99; Theresa, p.122; Alison, p.160; Violet, p.194; David, p.202].

Professional support needs to be perceived by parents to be of value to their child, otherwise they may see it as a waste of their time. In this respect the role of the Low Vision Clinic appeared to need clarification and higher profile. The parents of Annie, who was blind, saw little point in attending Low Vision Clinic appointments [p.87]. In Sarah's case attendance was completely overlooked by professionals because of the assumption that she would already be attending [p.100]. For Toni and Alison the issue was the relevance of a vision assessment which appeared not to take account of every-day environmental conditions [p.161]. In all, early referral was considered vital in accessing the best opportunities for children and while many experiences frustrated parents, there was recognition of the stress professionals were under due to heavy case loads, inadequate counselling skills and limitations of time [Rudi, p.120; Focus Group 3].

Despite early difficulties, at the time of the study families generally acknowledged positive relationships with their medical professionals [Cushla, p.67; Sue, p.89; Georgia, p.99; Rudi, p.114; Feanu, pp.144, 145; Alison, p.155; David, p.201]. They were quick to commend by name those with whom experiences had been good and such relationships, especially with paediatricians, were often of considerable duration. Cushla and Kevin returned with their children to visit hospital staff on anniversaries and birthdays [p.71], while Violet's gratitude to the public health nurse, who saw her need and assumed the primary role, was most apparent [p.196]. General practitioners were particularly well regarded. The role parents might play in medical intervention was highlighted by Richard's mother, Rhonda, who accompanied him to theatre and provided information and support to the medical team [p.206]. Differences in the public and private sectors were encountered by two families [Rudi, pp.114, 120; David, p.202]. In both cases parents experienced a more satisfactory outcome from the latter. Whatever the sphere, parents valued those medical professionals whose interest was genuine and extended beyond the medical setting to an holistic view.

5.4.3 Education services

Education was a key theme in the study. Families' stories portrayed the extent to which children's lives were shaped by experiences of schools and the education system including both opportunities and disadvantages. Their struggles revolved around accessing a fitting education for their children with issues relating to choice, resourcing and programming prominent.

Education was valued highly in all families [Focus Groups 1, 2, 3 & 4]. Considered as the prime means by which children would reach their full potential, it was the domain in which parents had invested much energy and advocacy, from local to national levels. Parental roles in education were prominent, with parents frequently initiating educational input themselves [Cushla, p.69; Leith, pp.127, 128; Raewyn, pp. 129, 131, 139; Gloria, p.170; David, p.202]. Being appraised of placement options and having the knowledge and ability to make an informed choice were considered important [Sue, p.82; Theresa, p.118; Feanu, Focus Group 1; Alison, Focus Group 1; Cloan, p.177]. Unfortunately this was not the experience of all parents. Parents visited a variety of facilities to assess at firsthand attitude, programme suitability and the capacity to meet their child's needs before making their choice [Theresa, Rudi, p.118; Gloria, Cloan, p.177]. More frequently, although not exclusively, it was the mothers who did the finding out. Parents sought advice on determining the next step in their child's progress and affirmation that what they were doing was right [Sue, p.79]. Co-operation between home and education settings was vital in developing skills and appropriate behaviours in the child [Theresa, Tr.4; David, p.204] with parent as well as child education deemed essential in meeting such an aim [Cushla, pp.72, 73, 74; Sue, pp.79, 90; Raewyn, p.139; Violet, p.190; David, p.202; Focus Group 2]. The provision of educational programmes, workshops and materials for parents were seen by participants as a means of supporting parents in their role as prime educators of their children, reflected in the perspective of Boyd and Dixon (1994).

Given the emphasis placed on education it was important to get "the education system right" [Georgia, p.108]. It was perceived that the current system did not meet children's needs, and that a seamless, multi-level, multi-functional structure would be more likely to result in success for all children [Georgia, p.108]. While 'good' teachers were affirmed it was recognised that much depended upon their good will and expertise as they worked within a framework of inadequate policies, difficult systems and insufficient resourcing [Raewyn, p.139, Tr.5; Alison, pp.164, 165; Cloan, p.180; Violet, p.192; Focus Group 3 & 4].

Parents were strong proponents for a range of placement options which allowed them to exercise choice in the education of their child [Cushla, pp.69, 70, 73; Sue, p.83; Raewyn, p.132; Cloan, p.177; David, p.210; Focus Groups 2 & 3]. However, this ideal was frequently unattainable because all options were not available geographically and some families were involved in making painful decisions which either resulted in moving regions or separation from their child. Educational placement of the study's children was reflective of both the continuum of provision for learners with vision impairment, and parents' attempts to get the changing needs of their child best met throughout their years of formal education. Children were currently fully mainstreamed at the local school [Sarah, pp.102, 105; Nuu, pp.143, 146; Toni, pp.150, 158, 159], partially mainstreamed and also attending a specialist facility [Dylan, p.69; Andre, pp.117, 118; Shaun A, pp.128, 132; Richard, p.206], in a Special School [Shaun B, p.193] or attending campus-based programmes at Homai Vision Education Centre [Andre, pp.117, 118; Annie, pp.84, 86; Hannah, p.169]. The former placements were supported by itinerant teachers from Visual and Sensory Resource Centres. During the study Annie had four different school placements, alternating between her local primary school in one region and Homai Vision Education Centre (Homai VEC) in another. Towards the end of the study her family moved to Auckland. Table 2 shows the extent of past and present placements of children.

There was a strong belief in the value of early intervention with the realisation that such a vital area needed good resourcing. Features of early childhood education experiences were the young age at which most children attended a formal programme [Dylan, Tr.1; Annie, p.82; Andre, p.117; Hannah, p.169; Richard, Tr.10] and the prominent role of voluntary agencies. Facilities administered by CCS [Dylan, p.69; Annie, p.82; Hannah, p.170; Shaun B, pp.189, 190], IHC [Annie, p.82] and the RNZFB [Andre, p.117; Nuu, p.145; Hannah, p.170] provided the earliest formal educational provisions for six of the children. Generally these experiences were reported as positive. Where staff lacked knowledge and expertise in vision impairment there appeared a genuine willingness to learn [Cushla, p.69; Georgia, p.101; Theresa, p.118]. Most families considered they were well supported by the early intervention services of Visual and Sensory Resource Centres, Homai VEC and the RNZFB Early Childhood Adviser [Georgia, p.100; Theresa, pp. 114, 121; Feanu, Focus Group 1; Gloria, p.170; Violet, p.190]. Where they did not feel adequately supported this related to assistance with choice of educational placement and with their efforts as first educators of their child. Difficulties which arose in mainstream settings included staff over-protectiveness, fear of blindness and normal developmental behaviours being attributed to blindness [Raewyn, pp.130, 131]. Parents reported working hard with their children in the early childhood years to facilitate developmental milestones [Cushla, pp.69, 70, 72; Raewyn, pp.129, 130, 131; Violet, p.189]. Given the intensive nature of their efforts and the crucial significance of early childhood education it was considered there might well be a place for teacher aides working alongside parents in the home during the pre-school years [Cushla, p.72].

Table 2 Educational placements: past and current

Child	Past placements	Current placement/s
Dylan		CCS early childhood centre/ Local Playcentre
Annie	IHC pre-school centre CCS early childhood centre Local primary school Homai Vision Education Centre Local primary school	Homai Vision Education Centre
Sarah	Local Kindy & Care	Local primary school
Andre	Homai early childhood centre	Homai VEC/ Catholic primary school
Shaun A	Local pre-school Local kindergarten Mainstream at VRC base school	Special class within Visual Resource Centre/ Partial mainstream at VRC base school
Nuulelei	Homai ECU/Local kindergarten Homai VEC Local primary school	Local intermediate school
Hannah	Child Development Centre CCS kindergarten McKenzie Centre	Homai VEC
Toni	Local kindergarten Local primary school Local intermediate school (refused entry to 2 schools)	High school
Shaun B	CCS early childhood centre Homai VEC	Special School
Richard	Local kindergarten Deaf Unit Homai Deaf-Blind Unit Special school	Special Unit at high school (final placement)

Eight children had been mainstreamed on either a full or partial basis at some time during their formal schooling [Dylan, p.69; Annie, p.83; Sarah, p.102; Andre, p.118; Shaun A, pp.128, 132; Nuu, pp.143, 146; Toni, pp.150, 158; Richard, p.206]. In addition to educational benefits, this was considered positive in terms of children's visibility facilitating acceptance in the community. Parents regarded teachers' willingness and positive attitudes as important as resources and professional expertise [Cushla, p.69; Theresa, p.118]. The school principal was seen as a person with the potential to be a strong motivational force for effecting attitudinal change [Sue, p.83; Georgia, p.108; Focus Group 3].

Mainstreaming experiences varied; some were seen as positive in their commitment to the child and provision of adequate resourcing [Georgia, pp.102, 103], others were disadvantaged by lack of specialist support and lack of understanding by regular teachers [Cushla, Tr.1; Sue, p.83; Raewyn, p.132; Feanu, p.146; Alison, pp.159, 161; Daniel, p.160]. Annie's parents, in making the decision to change placement from the local school to Homai, found it hard to leave [pp.83, 86], but while the local school had made good provision, they felt that basic specialist skills such as braille, O&M (orientation and mobility) and TDL (techniques of daily living) first needed to be established to access what the mainstream offered [Sue, pp.84, 85].

Toni, with low vision, had twice been declined entry into schools [Alison, p.159]. Budgetary implications appeared a strong influence in the decisions. However the creative, positive approach adopted by this student's present school had resulted in the development of an equitable and efficient system for meeting resource needs across the curriculum [Alison, p.163]. Theresa, while indicating that there had been no difficulty in gaining entry into programmes chosen for her son with multiple special needs, perceived there might well have been had they wanted full mainstreaming [p.118]. The parents of other children also drew attention to the importance of putting in the preparation prior to commencement at school to facilitate acceptance [Sue, p.83; Georgia, p.102; David, p.206].

Difficulties experienced in the regular classroom were reported by both children and parents [Sue, p.84; Raewyn, p.132; Feanu, p.146; Toni, p.151; Alison, pp.158, 159; Focus Group 3]. Class teachers' lack of knowledge about vision impairment, the nature of the specific eye condition of their student, and its implications for their educational programme was of concern.

Stereotypic perceptions were usually manifested in terms of imposing limitations, but there were also instances of overestimating capabilities and intolerance through ignorance.

Variance between a child's language and cognitive development similarly led to incorrect assumptions being made [Raewyn, p.134]. The compounding effects of several disabilities were understood even less, especially in relation to the specificity of learning and teaching approaches required [Raewyn, p.132; Gloria, p.169]. Parameters, expectations and consequences which were not the same as those for sighted peers were reported, with consequent confusion, and sometimes challenging behaviours [Raewyn, pp.131, 132].

Transition from one school to another, or even class to class, frequently involved adjustment from an environment where teachers had become familiar with children's needs, to these being again unrecognised and unmet [Theresa, p.117; Toni, p.152]. Sensitivity on the part of the teacher in eliciting information from the child, and support for the child's efforts at self-advocacy were both needed to ease the situation [Cushla, p.73; Toni, pp.151, 152].

Comment about the difference that a particular teacher or teacher aide might make to children's ability to access the opportunities which schools offered frequently arose. Teacher aides were considered key people in the lives of the children [Sue, pp.84, 86; Georgia, p.102; Raewyn, p.132; David, pp.204, 205, 209]. At times, with seemingly unlikely backgrounds for such a role, they provided excellent support in both integrated and specialist settings. Many were highly skilled in carrying out roles it was felt had developed in ways never intended. The functions of teacher aides of children in the study were wide ranging and included assistance with self-care, making resource materials, brailling and carrying out teaching programmes. Two mothers were themselves employed as teacher aides, Feanu in an Intermediate School [p.144] and Raewyn in a Visual Resource Centre [p.128]. Sue was employed one day a week as teacher aide for Annie during part of the study [p.84]. However, parents saw a risk in teacher aides taking over teaching functions in that the child no longer perceived the class teacher as their own [Raewyn, p.132]. Many different teacher aides came and went in children's lives.

Educational placements where there were both sighted and vision-impaired peers, plus ready access to specialist teachers, were considered advantageous [Sue, p.85; Feanu, p.146; Raewyn, p.133]. One parent advocated for a number of children with vision impairment to attend a designated primary school in order to rationalise resources and provide such an opportunity [Sue, p.85], while the parents of a second child enrolled him at a particular high school for similar reasons [Feanu, p.146]. Here Visual Resource Room staff provided specialist support and it was the parents' perception that the school environment would be more accepting than the current milieu where their child was the only student with vision impairment. The third parent was grappling with issues in relation to the future direction of her son's programme [Raewyn, pp.33, 34]. Her preference was for him to remain at primary level and continue to attend the class within the Visual Resource Centre where he would benefit from continuity, specialist knowledge of teachers, and specialist resources. High school could come at a later stage. Whatever the setting, schooling needs to be structured to give students opportunities to affirm their own identities and experiences.

Training and ongoing professional development was considered essential for all educators [Kevin, p.74; Raewyn, p.132; Feanu, p.146; Alison, p.159; Gloria, Tr.8; Violet, p.195]. There was strong advocacy for the inclusion of a compulsory special education component in pre-service teacher training, inservice training for regular and specialist teachers, and specialist training for those working in vision education [Focus Group 3]. Parents of children with multiple disabilities supported the notion that in schools where there were attached units, all teachers should be required to undertake training in order to meet the needs of these students [David, p.206; Focus Group 3].

Specialist educational support to the children and young people with vision impairment came from three major sources, Homai Vision Education Centre (previously Homai College) [Annie, p.83; Andre, p.118; Hannah, p.169; Richard, p.203], Visual Resource Centres [Dylan, Tr.1; Annie, p.84; Shaun A, p.132; Nuu, pp.143, 146; Toni, p.161, Richard, Tr.10] and Sensory Resource Centres [Sarah, p.100; Shaun B, p.190]. Input had also been provided to some children by the Special Education Service.

Parents strongly believed in the necessity for specialist facilities such as Homai Vision Education Centre (Homai VEC) as part of the education continuum [Sue, pp.86, 87; Cloan, p.176; Focus Groups 2 & 3]. Six children had attended on-campus programmes at Homai [Annie, p.83; Andre, p.118; Nuu, p.145; Hannah, p.169; Shaun B, Tr.9; Richard, p.203] and all families had accessed at least one of Homai's national services. Four of the children attending campus-based programmes were from regions outside of Auckland. The families of these children described the anguish and guilt that went with the decision to send their child away to school [Annie, pp.83, 85; Hannah, p.169; Shaun B, Tr.9; Richard, p.203]. Resentment was strong at a system which put parents in the position of having to make such a decision at all. Coming to terms with separation and the impact on the marital relationship brought much stress. Families also had to contend with the criticism of others. One was accused of wanting to institutionalise their child, and a second was charged by others, including their own children, with sending their child to Homai because they wanted to get rid of her [Researcher's Log], a decision finally arrived at after a loan application to provide for their child's needs at home was declined [p.170].

In addition to the emotional pressures on families there were practical issues for those trying to manage at a distance. The importance of good communication between school and home was emphasised as was the need to attend to any problems early. Because children were involved in two services, school and residential, effective cohesion was considered significant [Cloan, p.170; David, p.204], as was the importance of having positive peer role models in both settings [David, p.203]. The understanding and support provided by residential staff was particularly valued by one family, who had successfully modelled strategies used by staff with their child [Sue, pp.80, 90]. The high staff turnover was of concern, with such constant change considered detrimental to the wellbeing of the children. This situation was perceived to be due, in part, to low renumeration and the low value society placed on those in caring roles [Gloria, p.170]. For families whose child later returned home to education in their local community there were significant issues in the transition and in establishing a support network, particularly for older children [Violet, pp.195, Tr.9; David, p.204].

Parents were generally affirming of the services offered by Homai VEC. It was seen as a facility where teachers were caring, had expertise in the education of learners with vision impairment and understood the impact of deaf-blindness [Sue, Tr.2, pp.84, 85, 87; Rudi, pp.119, 121; Gloria, p.170]. Programmes were considered to cater well for children's needs with two exceptions. The first involved the inappropriate copying by a child with low vision of children who used tactual learning methods [Feanu, p.146]. The second situation surrounded the decision to close the specialist unit for children who were deaf-blind and integrate these children with other learners in the campus-based programmes [Gloria, Tr.8; Focus Group 3, Researcher's Log].

For those who accessed services less frequently, Homai was seen as a place to get information: plan for the longer term, see older children to get an idea of developmental patterns and expectations, seek advice and resources, and to access programmes which would assist parents in moving on to the next step with their child [Raewyn, p.130]. The Assessment Service was considered particularly valuable, with most families having used this service on more than one occasion [Cushla, Tr.1; Georgia, p.106]. The complementary nature of clinical and functional assessments were seen as a unique strength and parents valued the reinforcement received for the work they were doing with their child. The positive experiences of these families were marred by the reduction of funding available for parents to accompany their child for assessment. A father who had attended previous assessments felt strongly that the effect had been to cut out fathers, the parent who often had the least opportunity to attend medical and educational appointments [Richard, p.89]. Another family saw benefits in the service extending to provide functional assessments across a wider range of ecological environments [Alison, p.161]. The optimum would be for children to be assessed in their everyday environments but where this was not possible the simulation of conditions similar to such environments could provide a more realistic indication of a child's visual functioning.

Eight children had received educational support services from Visual and Sensory Resource Centres [Dylan, p.69; Annie, pp.83, 84; Sarah, pp.100, 105; Shaun A, p.132; Nuu, pp.143, 146; Toni, p.161; Shaun B, 190; Richard, Tr.10]. Most parents considered their children were well supported by the teachers of these centres who had high levels of expertise. Teachers were knowledgeable, understood the children's needs, listened to parents' concerns and were readily available to discuss issues. Inservice courses held were beneficial to both regular class teachers and parents. The programme developed by one Visual Resource Centre in which a class of learners with vision impairment received specialist teaching was considered an excellent way of meeting learner's needs with the benefits of both mainstreaming and specialist education available [Raewyn, p.132]. Concerns identified focused primarily on the level of support available and working effectively in partnership with professionals. The latter included difficulties in developing shared expectations for children, attitudes of ownership from professionals, and lack of support for parental decision-making in respect of their children [Focus Groups 2 & 3, Researcher's Log].

The Special Education Service (SES) featured primarily in regard to the allocation of teacher aide hours. An issue of general concern to participants was that while SES had such resourcing responsibilities to children with vision impairment, it was not perceived to have specialist expertise in this domain of education [Raewyn, p.139; Alison, p.162; Focus Group 3]. While in some geographical areas SES and vision education professionals had developed a cohesive team approach to support children with vision impairment, this was not the situation in all instances [Focus Group 3]. Violet's story highlighted the impact of her experiences as a mother on her role as an early intervention teacher within SES and how her multiple positions allowed her entry into the lives of families with whom she worked [pp.192].

Competence in the specialist curriculum gave children with vision impairment a tool for accessing the National Curriculum and, indeed, life experience itself. Issues about the specialist curriculum were intense, particularly in relation to orientation and mobility (O&M) and techniques of daily living (TDL), with the perception that education needs were not being met in these areas [Cushla, pp.69, 70, 74; Sue, p.84; Raewyn, pp.134, 135; Kevin, p.139; Violet, p.194; Focus Group 3]. Access to the specialist curriculum from mainstream contexts was considered problematic on two counts - the availability of specialist teachers, and how these essential areas of learning might best be fitted into the regular school programme. O&M and TDL programmes needed to be functional and ongoing, with those who implemented them trained in working with children. Parents wished to be taught TDL skills themselves in order to adequately support their child in learning such skills in the natural environment, the home. Sex education was deemed important, with children considered particularly vulnerable in this respect [Sue, p.90; Focus Group 4]. Specialist input was requested by parents in dealing with aspects such as sexuality, puberty, relationships and AIDS. Many parents felt a weariness in the fight for specialist curriculum input for their children. It was costly of time and energy and successful outcomes were few.

In both regular and specialist education settings, the Individual Education Plan (IEP) was seen to be the prime means of accountability for children's education [Focus Group 2 & 3]. The IEP meeting attended by parents, professionals, and sometimes children, was the vehicle for developing the plan. A typical IEP might include identification of the child's special needs, an evaluation of progress and current levels of achievement, identification of programme and resource needs, and programme goals for the coming period. In five families both parents regularly attended IEP meetings [Cushla, Tr.1; Richard, p.89; Rudi, p.117; Cloan, Tr.8; David, pp.205, 207, 209], one adolescent attended with her mother [Toni, p.151], and in three families it was the mother who was most likely to attend [Lance, p.101; Raewyn, p.134; Violet, p.191, Tr.9].

Overall, there was a need for equitable, accessible education services throughout the country. Even in large cities adequate services were not guaranteed. Differences in service delivery were evident with no apparent commonality in philosophy, systems, methods of prioritising, or expertise [Cushla, Tr.1; Sue, p.87; Daniel, p.160; Alison, p.161]. Educational professionals were urged to set aside their differences and work more cohesively in order to enhance the effectiveness of services to children [Alison, p.161]. There was an ever-present uncertainty surrounding education that parents found unsettling - not only uncertainty about programmes and opportunities for the future but also about existing services. Parents told how teacher aide hours were cut without warning [David, p.207], a Special School closed with minimal consultation [David, p.206], and a classroom of the Visual Resource Centre was needed by the base school [Raewyn, p.132]. Always there was an underlying sense of unease that something was "going to happen to Homai tomorrow" [Rudi, p.124]. Seamless, lifelong education was considered essential. Many students required extended education in recognition of their different time-frame for learning. The notion of ongoing education appeared to be inequitable with a cut-off point of twenty one for learners with special needs, while other adult students were encouraged to attend community colleges and enter tertiary education. The outer limits of children's capabilities were most often unknown [Rudi, p.124; Raewyn, p.133] and the question arose as to whether societal expectations of some return influenced such policies [Cloan, p.173]. The matter parents saw as most urgent was getting a comprehensive national special education policy in place, a development it was believed would go a considerable way to address such issues [Kevin, p.74; Sue, p.88; Raewyn, p.139; Cloan, p.178, Tr.8; David, p.207, Focus Groups 3 & 4].

5.4.4 Social services and voluntary agencies

Social services were primarily provided to families by the Social Welfare Service and voluntary agencies. Of the seven families who told of experiences with the Social Welfare Service, two found the assistance positive and helpful [Sue, p.88; Feanu, p.144], while five families found the interaction to be frustrating and of minimal use [Cushla, p.73; Georgia, p.101; Raewyn, p.138; Gloria, p.170; Cloan, p.182; David, p.209]. Nuulelei and Annie's families reported positive interactions and prompt responses in respect of financial allowances, Alternative Care and information of suspensory loans following referral by medical professionals. Such experiences were not shared by others.

A major frustration for families who received the Handicapped Child Allowance was the necessity to validate their child's disability each year. The process involved visiting medical specialists, form filling and explanations that their children would "never get rid of their blindness, or cerebral palsy, or intellectual impairment" [Cloan, Focus Group 2]. Towards the end of the study there was notification that this system was to change, however parents had felt particularly demeaned by such a process.

The social welfare system was described as a minefield [Cloan, p.182; David, pp.207, 209]. Some found no support at all, with loan applications declined [Gloria, p.170], or funding assured and then rejected as in the case of Dylan and the braille books [p.73]. One family reported that they were accused of defrauding when they attempted to access support for their daughter [Georgia, p.101]. Inconsistencies in what could be funded, as well as inequities in systems were apparent. The foster family, for example, appeared to be ineligible to receive Alternative Care or Disability Allowances. During the study, in the ninth year of their child being a family member, they discovered that the Accident Rehabilitation and Compensation Insurance Corporation (ACC) had the ability to provide equivalent funding. No information had been provided; they found out by chance [Raewyn, pp.135, 136]. Finding out what resources were available was a major source of frustration for most families with the implications supporting the findings of Philip and Duckworth (1982) that while most countries have financial benefits available, many families do not receive their entitlements.

Collectively families had involvement with three main voluntary agencies. All children were registered with, and received services from, the Royal New Zealand Foundation for the Blind (RNZFB), four were members of CCS (previously Crippled Children's Society) [Andre, pp.114, 121; Shaun A, p.127; Nuu, pp.144, 145; Shaun B, pp.189, 190], and three children were registered with the New Zealand Society for the Intellectually Handicapped (IHC) [Andre, pp.118, 121; Shaun B, p.194; Richard, p.200]. As previously discussed, the voluntary agencies played a significant role in early intervention programmes, with children who were vision impaired able to attend the early childhood facilities of CCS and IHC even though not necessarily registered members. Mothers, in particular, valued the opportunity such centres offered for developing informal support networks with other parents. One family received home help through IHC [Theresa, p.118].

The RNZFB was the first point of contact for most parents following the diagnosis of their child's disability. In addition to the RNZFB's education services accessed through Homai VEC, the agency provided O&M, TDL and recreation services, financial and resource assistance, and social worker/whanau worker support. Its Child and Family Social Workers emerged as having a prominent and effective role [Cushla, pp.69, 73; Georgia, pp.100, 106; Richard, pp.88, 89; Alison, p.160; Gloria, p.182; Violet, p.190]. Frequently they had been the initial connection with the agency and families welcomed their input. Perceived as being highly skilled, they were people in whom families had developed trust and confidence with some parents now regarding their social worker "as a very close family friend" [Richard, p.88]. The role of the Child and Family Social Worker was multi-faceted and included provision of information, appraising parents of their rights, counselling, advocacy, facilitating access to other services and conducting parent education workshops. The advent of Whanau Workers, who provide support primarily to Maori families, was seen as a positive and necessary direction. Violet welcomed having the choice of Maori and Pakeha social workers [p.193], an option not available until Shaun's adolescent years. Parents stressed the need for a competent counsellor or social worker to be available from the time of the birth, or diagnosis, of their child [Theresa, p.120; Violet, p.187; David, p.202]. Overall parents saw voluntary agencies as vital to their children's wellbeing and held definite expectations of their role in the future.

5.4.5 Residence, recreation and employment

Few issues arose within residential, recreation and employment spheres. Matters relating to residential placement at Homai VEC have been discussed previously. Concerns regarding future accommodation options were expressed by parents of five children [Sue, p.90; Theresa, p.123; Cloan, pp.170, 175, 176; Violet, pp.195, 196; David, pp.207, 208, 209]. These focused on uncertainty surrounding the level of independence likely to be attained by their children, and the perception that the needs of some children would best be met in an interdependent living situation. Trusts were seen as a means of providing for children's futures. One family planned to develop a family trust [Rudi, pp.123, 134] and a second was involved in the provision of a trust house for young adults with vision-hearing impairment [Gloria, p.170]. Community housing provided by IHC was an option considered, with recent developments initiated by Maori iwi promising choice for Maori families [Violet, p.195].

Richard, at age twenty four, was flatting in a community group home, an experience which reportedly he enjoyed immensely [David, p.207]. For his parents however, his living situation brought the realisation that their responsibilities, although changed, remained. Quality of caregivers, safety, ongoing education and accountability were all issues requiring constant advocacy. The vision of many parents was to reach the developmental milestone of returning to a two-people household when the children had reached adulthood (Havighurst, 1972), [Sue, p.90; Georgia, p.108; Theresa, p.123; Daniel, p.165; Focus Group 3] for which adequate residential provision would seem essential.

Limited opportunities for socialisation and recreation were highlighted by the parents of four children with multiple disabilities [Raewyn, p.133; Theresa, p.118; Gloria, p.172; Violet, p.195]. Peer interaction was limited despite parents' efforts to foster relationships by inviting peers to the home or organising an environment conducive to interaction, such as Violet's use of her swimming pool [p.195]. Parents were saddened by their children's isolation. Involvement in age appropriate activities proved difficult for some families and the demand on parents' time meant that recreational activities were often neglected, once again giving rise to feelings of guilt. Organised recreational opportunities for children were valued but frequently participation was not extended to children with multiple special needs.

Due, in part, to the ages of the children, employment was rarely considered. The notion of workshop activities as the only option, both in pre-vocational education and as a means of post-school employment, was rejected [Gloria, p.172; Cloan, p.173]. 'Work', in the traditional sense, was not considered appropriate for some, while the parents of others believed their children would take their place in the workforce alongside their fully sighted peers [Georgia, p.108; Alison, Daniel, p.163]. The implications of unemployment statistics did not, however, go unnoticed. There was despondence at the high unemployment rate of persons with disabilities and even higher rate if these persons were women, Maori, or Pacific Islander [Focus Group 3].

5.4.6 Parent-professional relationships

A major theme for parents, and one which elicited strong affective responses, was the relationship with professionals involved in their lives. While participants recounted positive experiences with professionals, negative encounters impacted greatly. There was disillusionment with attempts to establish partnerships with professionals whose role and actions frequently highlighted how such relationships were disempowering to families. What parents asked of professionals mirrored the responses obtained by Seligman (Murray & Shaw, 1994), however parents went further, claiming for themselves the role of professional, in relation to their children, and, in the recent climate of greater accountability, were asking more questions and demanding answers [Cushla, Kevin, Tr.1; Sue, pp.87, 88; Georgia, p.107; Theresa, p.120; Alison, p.158; Gloria, Cloan, pp.179, 180; David, p.210; Focus Group 3].

Much of the language used to describe people with disabilities focuses on the individual's impairment and takes no account of the disabling effects of society (Wills, 1994). Professionals may create barriers by using language which labels both children and parents. However, the value of labelling in certain circumstances was recognised, as categorising of disability was considered valid for accessing appropriate resources and allowances under present systems [Georgia, p.106; David, p.207]. For some families who had experienced initial difficulty in getting the needs of their child met, a diagnostic label brought them under an agency umbrella [Georgia, p.106]. Others considered a label, such as 'deaf-blind', the only means of accurately portraying to the community the needs of a child with this disability, in terms which would be understood, even though giving the message straight was sometimes in conflict with political correctness [David, p.207; Cloan, Focus Group 3].

However in general, parents did not like labelling and believed a needs-based system more appropriate. Labelling frequently resulted in stereotyping, misperception and devaluation [Focus Group 3] and there was a danger that labelling would determine the type and level of service available to a child rather than individual need [Cushla, p.68; Sue, pp.86, 87]. Brown's (1994) view that, in their struggle to gain equality in the parent-professional relationship, parents risk being labelled as radical, or trouble makers, was also experienced [Cushla, p.71; Alison, pp.159, 162]. However, it was perceived as vital that parents continue to convey to professionals the individual needs of each child and its family [Focus Groups 3 & 4].

Disempowerment of parents by professionals and the need for parental expertise to be validated were prominent themes in the study. Parents experienced difficulty in getting their observations and cognisance of their child accepted and acted upon. Discounting parental knowledge appeared widespread with the attainment of expertise validated only through the hierarchy of formal learning and 'authenticated' if held by professionals [Cushla, p.66; Sue, p.78; Theresa, pp.112, 113; Rudi, p.120; Raewyn, 136; Daniel, p.154; Cloan, pp.179, 180, David, p.202]. Parents listened and took the advice of professionals because of their status and position, and early on tended to disregard their own perspectives because of inexperience [Cushla, Tr.1; Sue, p.87; Georgia, p.104; Gloria, p.179]. Initial encounters left some parents with feelings of intimidation and worthlessness, exacerbated by professionals' projections that they would not cope or were too emotionally involved with their children to make decisions [Sue, p.89; Georgia, p.104; Violet, p.197; David, pp.201, 202; Focus Group 3].

Parents' initial expectations that professionals know and understand, have all the answers and are always right [Focus Group 2] were, over time, replaced with a degree of mistrust. They no longer automatically accepted the word of professionals and thought through issues for themselves. However, superficiality in the parent-professional partnership was reflected in parents' perceptions that they were not listened to, were patronised and their knowledge not valued, "even though the professional lacked the knowledge of the parent" [Cloan, Focus Group 2]. Parents were also inhibited in challenging professionals for fear this might disadvantage their child [Cloan, p.179; David, p.209; Focus Group 3]. Keeping on-side with professionals was paramount and parents considered they strove hard to develop a workable relationship. Such issues, together with the constant need to change professionals' attitudes reflected the experience of Brown (1994) and Wills' (1994) whose perspective that real partnership was difficult when relationships were based on inequality in terms of information, financial and material resources, was also evident in this study. However, over time parents became selective, remaining only with professionals they felt comfortable with and learnt to prioritise what professionals asked of them in respect of their child [Georgia, p.105]. Parents developed and kept their own vision for their child in preference to those imposed by professionals and their restrictive practices.

As parents developed knowledge and expertise they increasingly saw themselves as their own child's professional [Cushla, p.70; Sue, p.87; Georgia, p.108; Theresa, p.120; David, p.210; Focus Group

3]. They had the ability to perceive their child in an holistic way, in contrast to professionals whose input was mostly restricted to professional practice environments. Parents expended much energy in developing their expertise which, as with Wills (1994), was frequently born out of sheer frustration and necessity. Parents had a strong belief that the prime responsibility for their child was theirs, not that of the state or support systems and considered themselves realistic about where they were going [Sue, p.89; Georgia, p.105; Daniel, p.164]. Although not their initial expectation, parents felt that they had, over time, become professionals in the education, health and welfare systems, often knowing more about policy and practice than some who were making decisions for their children [Georgia, p.109]. This did not mean that parents did not value the knowledge and expertise of professionals. Knowing systems were in place as a back-up was described as a great relief [Sue, p.89; Focus Group 3] and the assistance of someone with the appropriate skills to advocate on families' behalf was also appreciated [Sue, p.89; Lance, p.107]. Examples of positive relationships, good networking between professionals, and effective services were part of the experiences of all families who acknowledged that their situation was exacerbated by the expectations which they themselves placed on professionals.

Establishing relationships that are collaborative and reflect genuine sharing of power was the desire of parents [Cloan, Focus Group 3]. Professionals who were highly regarded by families were frequently mentioned by name, reflecting the degree of intimacy, trust and confidence which was indeed possible. Such professionals had offered services in a way which was helpful and which showed a genuine interest in the child and family.

Participants' stories identified the qualities they most desired in professionals together with strategies of partnership and practice that would enable a sharing of information and resources, decision-making and control. Professional competence and accountability were considered essential [Theresa, Rudi, Tr.4; Cloan, p.180; David, Tr.10]. Competence encompassed experience, in addition to knowledge, skills and qualifications. Knowledge of the impact of blindness was deemed a pre-requisite to working effectively with a child who was blind [Sue, Richard, p.87]. Parents wanted professionals who knew what they were talking about to inform and support them. Facilitation skills and the ability to synthesise approaches and services were held in high regard, as were positive and enabling attitudes [Raewyn, Tr.8; Alison, pp.161, 162; Violet, p.194; David, p.202]. Compassion, empathy, good listening skills, open and honest communication, and the understanding that they were in a relationship with people who might be under great stress were what parents wanted from all professionals and service providers [Kevin, p.74; Cloan, p.180; Focus Group 4]. Such qualities were deemed equally relevant to a doctor, receptionist, or director of services. Parents looked for acceptance and mutual understanding [Cushla, Kevin, p.74; Georgia, p.104]. Counselling skills as part of professionals' basic training were considered a priority [Kevin, p.74; Sue, Tr.2; Georgia, Tr.3; Cloan, Tr.8, p.180; David, p.210; Focus Group 2, 3, & 4].

Parents desired the parent-professional partnership to be one of respect and equality set within the context of a team where professionals also valued the roles of allied professionals [Cushla, Kevin, p.74; Sue, p.87; Alison, pp.161, 162; David, Tr.10; Focus Groups 2, 3 & 4], similar attributes to those identified by Gargiulo (1985), Murphy (1982) and Murray (1991). Such a relationship might exist if there was ongoing critical evaluation of professional practice with professional knowledge and parents' practice knowledge applied together.

5.5 The Macrosystem: culture, ethnicity, religion, the economy, politics and the law

5.5.1 Introduction

The macrosystem refers to the attitudes, beliefs and ideologies of a society's social institutions. Cultural values and ethnic beliefs have major effects on families and religious convictions may also have a part in determining how families function. The economic situation defines the nature of health, education and welfare services and the level of support available to families. Political policies, inherently linked to the economy, are operative in determining how resources are distributed. The political system is also responsible for legislation concerning the rights of children with disabilities and legal rulings may influence health, education and welfare systems (Bronfenbrenner, 1979; Hornby, 1994).

5.5.2 Society and the culture of disability

The deficit view of disability appears to be deeply embedded in the culture of western society. Such a model determines a fixed identity and becomes the means by which all other aspects of a person's life is defined. Exclusionary practices limit the lives and choices of people who are not only seen to be different, but defined in terms of problems and inadequacies. Participants showed acute awareness of the impact of societal values, with recent shifts in New Zealand economic policy, to which resourcing was linked, considered particularly disadvantageous. They viewed the attitudes and mores of society as influencing the status of people with disabilities more than any other factor and thought that the seeing of the disability and not the person would be their children's greatest handicap [Georgia, p.108; Alison, p.163]. As Georgia claimed, "the only thing that's going to stop [Sarah] from reaching her potential is an outside influence ...by the policy makers not acknowledging that children with low vision are just as important as people with no abnormalities. Society will let Sarah down, not herself" [p.108]. Such perception imitates the views of Bogdan and Biklen (1977), and Sullivan and Gill (1975) who suggested that society was likely to cast a person with a disability into a socially inferior status merely because of the disability. Although legislation might be passed to safeguard the rights of all, participants pointed out that you could not legislate people's minds [Cloan, p.171] and the materialistic nature of society made attitudinal change difficult. Therefore educating society about people with disabilities in the hope that it would then demand that more be done was considered one of parents' major functions [Georgia, Tr.3; Alison, p.159; Gloria, p.176; Cloan, p.180; David, pp.207, 208; Focus Groups 3 & 4].

Sound philosophy coupled with action was seen as the means of working towards change. Consideration of specific issues invariably led to wider philosophical debate with the realisation that nothing could be seen in isolation. Participants wanted philosophy tempered by a good measure of reality [Cloan, p.176]. However, striving for the ideal at times appeared in conflict with meeting the needs of children in the here and now, a dilemma which remained unresolved [Cloan, Gloria, pp.176, 178; Focus Groups 3 & 4]. It was recognised that while it might take radical action to effect change, the constant shifts within society made the task more difficult [Gloria, p.176]. Rigid philosophical stances which endeavoured to uphold rights and seek the valuing of people with disabilities were ultimately not perceived as helpful. For example, it was considered inclusion had been interpreted by some as an imperative rather than a right with an element of choice, and had devalued relationships among peers with disabilities [Gloria, Cloan, p.177]. Likewise one parent's understanding of normalisation led to feelings of guilt because her child "maybe isn't doing a lot of normal things" [Gloria, p.172]. Such philosophies were not unsupported by parents, who had battled hard and long for their children's right to inclusion in society. Rather they had a continuum perspective which they believed best served the interests of their children [Focus Groups 1, 2, 3 & 4]. While such a position was neither acceptable to some other advocacy groups, nor fully aligned with current trends and policy direction, parents expressed disappointment that while they could see the view of others, others could not see theirs.

5.5.3 Culture and ethnicity

Correa (1987), and Orlansky and Trapp (1987), considered it essential that cultural dimensions be understood if family-professional relationships were to be effective. Of the study's participant families one identified as Maori [Shaun B's, p.185], six New Zealand Pakeha [Annie's, p.77; Sarah's, p.93; Shaun A's, p.126; Toni's, p.149; Hannah's, 167; Richard's, 199], one Maori/NZ Pakeha [Dylan's, p.65], one Dutch/NZ Pakeha [Andre's, p.111] and one Samoan [Nuu's, p.142]. While the study largely reflects the dominant culture in which families lived, New Zealand Pakeha, this section focuses on cultural dimensions of Maori, Samoan and Dutch participants' families.

Rudi and Theresa highlighted the significance of maintaining close links with extended family in Holland [pp.115, 124]. Their distance had an economic impact and Theresa told of how they worked hard so that they might afford to visit with their children [p.124]. Kevin, who was Maori/Pakeha was just beginning to explore his Maori roots. He had a strong desire for his children to have knowledge of, and place in, this part of their cultural heritage [p.66]. Violet's and Feanu's families both had strong connections with their cultural communities and emphasised the importance of reflecting their heritage.

Violet was the Maori Whanau representative on PVI, having undertaken this role because of her experience of isolation from other Maori parents of children with disabilities [pp.191, 192, 193]. She expressed a strong need to identify with people of her own culture and had made links with Ngati Kapo, the Maori self-advocacy group for those who are vision impaired, for support in tikanga Maori [p.190, 193]. The impact of cultural beliefs was evident in Violet's story of her mother believing a curse on the family had resulted in Shaun's disability [p.189]. Violet considered her family's Maori ethnicity influenced professionals' attitudes which she experienced as condescending and demeaning [p.191]. She also felt disadvantaged by professionals and others who stereotyped Maori as having caring families with much support available [pp.189, 191]. This was not the case for Violet and such an assumption perhaps denied her needed support. She welcomed the introduction of RNZFB Maori Whanau Workers (Family Social Workers), as this offered her a choice of professionals [p.193]. However while having professionals of the same culture was valued immensely, Violet emphasised the necessity of competency in working with families of children with disabilities as a pre-requisite for any professional fulfilling such a role [p.193]. The initiatives by Maori iwi and service providers in responding to the cultural needs of persons with disabilities were looked to as a possible means of assistance for Shaun as a young adult [p.195]. In telling how her experiences impacted upon her own work with families, genuineness and an emphasis on practicality, were considered important [p.194].

The centrality of their Samoan culture was reflected in the home of Nuulelei's family [Researcher's Log]. Portraits of ancestors and extended family were prominent and the language spoken was Samoan. Feanu told of cultural beliefs which regarded vision impairment as sickness and influenced the extended family's perception of Nuu. Difficulty was experienced trying to persuade others to treat him the same as his siblings in a way which would promote independence [p.146]. Like Violet, Feanu noted discriminatory attitudes in some service providers which she attributed to her family's ethnicity. She perceived that especially in relation to social welfare support, Pacific Island people were not treated the same as others [p.147]. In addition, the complexity of accessing services and welfare entitlements with much form filling and the mandatory visiting of medical specialists, was a deterrent to people whose cultural beliefs made them reluctant to come forward in the first place, for fear of being blamed for their child's disability [p.147]. In all, Feanu considered Pacific Island people lacked understanding of systems and processes, and had only a limited knowledge of services available.

5.5.4 Religion

The importance of giving regard to the religious convictions of families in developing trust is emphasised by Erin, Rudin and Njorge (1991). Religious beliefs evoked two distinct positions. They were seen either as a strong source of support, or regarded as particularly unhelpful. Three families stressed the importance of Christianity in their lives, both as a source of strength and as a basis for the values of their families [Lance, Georgia, p.97; Raewyn, p.128; Leith, p.137; Feanu, p.144]. Each family was part of a church community which offered practical, emotional and spiritual support. Both church and faith were central to their lives and formed a solid foundation for coping.

Conversely two families reported experiences which they considered unhelpful with people who were 'religious' [Cushla, p.70; Rudi, p.121]. Such instances involved attitudes about disabilities which included ascribing parents as having been chosen by God, and wanting to effect a cure through prayer over belongings of the child. Cushla described the effect her son's disability had on her grandmother's religious views and how the grandmother was close to breaking down when there was no change in his blindness [p.70]. Families felt able to allow others to do what best assisted them, while making their own views clear, although they were neither helped by these perspectives, nor shared such views.

5.5.5 The economy

The implications of living in a capitalist society with its inherent ideologies and limitations for financing quality services were evident to parents [Alison, Tr.7; Daniel, pp.164, 165; Cloan, pp.170, 171, 180; David, Tr.10; Focus Groups 1, 2, 3 & 4]. It was considered that funding should be provided as of right to meet health, education and welfare needs of children with disabilities [Focus Groups 1, 2, 3 & 4]. However, there was a belief that New Zealand lagged behind other OECD countries in the allocation of funding to special education [Cloan, p.180]. The concept of user-pays, at least in part, was supported by one parent who suggested that alternative funding might be sourced from insurances or through employer assistance [Daniel, p.164].

In most families there was evidence of additional financial costs to parents [Alison, pp.158, 162, 165; Focus Groups 2 & 3], a finding of Lonsdale (1978) and Murphy (1982). Such costs might include visual aids, environmental adaptations and medical appointments. Accessing costly services and resources proved difficult for parents, some of whom experienced being passed from department to department and from agency to agency as the responsibility for funding was disclaimed [Raewyn, p.139]. Ensuring adequate financial resources to provide for their child's future was problematic [Theresa, p.121; Rudi, pp.123, 124; Gloria, p.176]. Some parents who expressed an inability to rely on the government to make adequate provision were actively involved in negotiating funding sources themselves, while others placed their confidence in voluntary agencies and consumer groups to advocate for future provision on their behalf [Kevin, p.74; Sue, pp.89, 91; Lance, p.107; Alison, p.162].

5.5.6 Politics and the law

While parents were adamant in claiming responsibility for their child, they nevertheless wanted sound policy to support them in their role [Focus Groups 2 & 3]. Views surrounding policy were many and varied. The new health and disability policies held hope for some [Raewyn, p.135; Alison, pp.162, 163] while the scepticism of others arose out of previous experiences [Georgia, p.105; Rudi, p.124; Gloria, Tr.8; Cloan, pp.180, 182; David, p.207; Focus Groups 2, 3 & 4]. Policy makers and service providers were deemed to have failed in their responsibility to place adequate resources in the community. They were seen to be hiding behind Acts [Raewyn, p.139] where there were difficult decisions to be made or costly financial implications.

Parents generally felt disillusioned with policy makers whom they considered had no concept of children's needs, talked in riddles, worked in theory and paper and had all care and no responsibility [Georgia, p.105; Raewyn, p.139, Focus Group 3]. The need to regain focus on children was captured by Georgia when she stated, "Policy makers have got no eyes. They aren't actually seeing what they're dealing with. Yet they hold the lives of those kids' in their hands" [p.105].

Another point of view was that policy makers understood the problems but had no ability to be effective given the economic constraints [Sue, p.88]. Rather, they were committed to policy and had different public and private faces. On rare occasions parents felt they caught a glimpse of understanding individuals [Cloan, p.180]. Whatever the stance, parents saw policy makers as agents of the Minister and believed they should assist parents in pleading a case to this, the highest authority.

Changes occurring, with systems being dismantled and safeguards removed, caused considerable concern [Daniel, p.163, Focus Groups 3 & 4]. Danger was seen in emulating what had occurred in other countries, where policies and systems had been dismantled and moneys had not been put into the new systems. Parents made a strong plea that they be listened to when policy was developed but had little faith that adequate policies would be devised [Focus Groups 3 & 4]. They advocated the need for parents to be protagonists in this respect, as they believed only those directly involved (such as persons with disability and parents) might have an effect on policy makers. The approach needed to be many faceted with consumers having the ultimate authority to say what they specifically needed [Cloan, Tr.9; Focus Groups 3 & 4].

The urgent need for a comprehensive special education policy was emphasised throughout all the focus groups attended. Parents who had invested considerable time and energy in SEPIT (Special Education Policy Implementation Team) proposals were disappointed and frustrated at the lack of outcome [Alison, p.164; Focus Groups 1, 2, 3 & 4]. The value of a special education policy was seen to lie in its ability to set over-arching guidelines, with strategies for each area developed within such a framework [Sue, p.88]. To that end, parents strongly advocated the establishment of a national body which would administer all specialist educational services to learners with vision impairment and reflect the parent-professional partnership of the 'Tomorrow's Schools' (1988) model [Kevin, p.74; Sue, p.88; Raewyn, p.139; Cloan, p.178; Focus Groups 3 & 4]. Parents believed such a body could realise their desire for an equitable, cohesive education service for their children.

Specific policy areas were identified as currently deficient. Anomalies existed in eligibility for support services such as Alternative Care, Disability Allowances, and Home Help [Raewyn, p.135, Focus Group 2]. Inadequacy of education services, equity issues and the restrictiveness of some systems designed to support people with multiple disabilities all required attention. The dearth of educational and appropriate residential opportunities for young adults with disabilities were further areas for policy development [Violet, pp.194, 195; David, pp.208, 209]. Ongoing advocacy and political lobbying was seen as the means of effecting change with health and education the prime areas of focus [Rudi, pp.121, 123; Alison, pp.158, 162; Daniel, p.159; Cloan, pp.176, 179; David, p.209; Focus Groups 3 & 4].

While legal decisions may impact upon policy, there was the realisation that changes in the law do not necessarily make things better [Focus Group 3]. Parents recognised there was danger in believing that they merely needed to press their rights and problems would be solved. As Wills (1995) observed, rights alone do not meet children's needs and the law is a blunt tool with which to shape and mould societal attitudes. Effecting attitudinal change and getting adequate resourcing were seen as essential if human rights issues were to be addressed [Cloan, p.171; Focus Group 3]. In this respect the loss of the Parent Advocacy Council evoked much disappointment, as it was considered a pivotal body through which parent issues had been addressed [David, p.207]. In the end it was parents who battled for their children to establish fairer and more equitable provisions. Their role as active participants in the policy-making process was considered a prime way forward by linking their personal lived experiences to the political arena, a model of practice which might benefit all.

5.6 Across the bands: parental coping strategies

5.6.1 Introduction

Parents described a range of coping roles and strategies in their efforts to realise their hopes and dreams for their families. A progression of coping skills was identified in which early strategies, linked to initial stages of the adjustment process, were complemented or replaced by more functional approaches. One father told of his movement from heavy reliance on drinking, smoking, and expression of anger, to being able to talk through issues and significantly contribute to community programmes for people with disabilities. Individual partners had different ways of coping and at times compromises had been necessary. Some parents were clear sighted in defining discrete coping skills while others were familiar with blind panic, following instinct, or just muddling through. Sheer determination was a strategy common to many, especially in relation to the negotiation of systems, as was the honest acknowledgement that "sometimes we haven't coped" [Theresa, p.120]. In this section coping strategies parents identified are discussed according to the emotions, beliefs and inner resources of individuals; skills, strategies and activities; communication and the parental relationship; support from family, friends, peers and professionals; self-advocacy; and PVI as a system of support and advocacy.

5.6.2 Emotions, beliefs and inner resources of individuals

Shock, annoyance, anger, yelling, crying, withdrawal, avoidance and denial were responses experienced initially by parents as they realised their situation [Kevin, p.67; Cushla, p.74; Georgia, pp.99, 101, 105; Theresa, pp.113, 120; Rudi, p.120; Violet, pp.186, 187; David, p.201, Tr.10]. Stubbornness developed as they sought to get the needs of their child met [Cushla, p.71; Kevin, p.74; Georgia, Alison, Cloan, Focus Group 2]. As parents came to an acceptance of their changed circumstances they adopted a position of hope and began looking ahead to the future. Inner strengths such as determination, belief in self, ambition, drive and vision were drawn upon, as well as the pragmatic view that they just had to cope [Cushla, p.74; Kevin, p.75; Georgia, p.105;

Theresa, Tr.4; Rudi, pp.121, 122; Gloria, pp.181, 182]. Parents believed that they were strong people in their own right and some found strength in their Christian faith [Georgia, & Lance, p.97; Feanu, p.144; Raewyn, p.128]. Acknowledging painful memories and dealing with emotions was considered important, as was accepting what had happened and moving on [Cushla, p.74]. Parents became aware that they could make a difference in their child's life. With information came the realisation of rights and entitlements, and confidence in their own knowledge and expertise as parents [Cushla, pp.69, 70; Sue, pp.87, 88, 89; Georgia, p.105; Raewyn, pp.137, 138; Alison, p.159; Cloan, Tr.8; Violet, p.190; David, p.210]. Single-mindedness and belief in a set of principles helped parents focus on their task. Some even claimed to enjoy the struggle but warned that "if you think you know everything and stop questioning and searching, you've lost" [Georgia, Tr.3].

5.6.3 Skills, strategies and activities

Specific skills and strategies were developed as parents became proactive. Dual purposes for such action were identified: to help the parent to keep functioning [Violet, p.191; Focus Group 2] and to benefit the child and family [Focus Groups 2 & 3]. Thus, focus on wider issues became a means of coping with private life [Focus Group 2 & 4]. Good organisation skills were considered an advantage as was the ability to prioritise and plan ahead [Sue, Tr.2; Georgia, p.106; Rudi, p.121; Raewyn, p.136; Gloria, pp.181, 182]. Effective communication, assertion and counselling skills were developed in order to assist themselves, siblings, and other parents [Cushla, p.73; Kevin, p.74; Georgia, p.101]. Such skills helped in dealing with the parent-professional relationship and negotiating systems. Tackling issues and the 'busyness of doing' gave energy and the impetus to continue [David, p.208].

Visioning and goal setting were important strategies [Georgia, p.105; Rudi, p.122; Raewyn, p.130; Focus Groups 1 & 2]. Some valued seeing 'the big picture', having a clear, specific overall vision of what they wanted and how they would work towards its attainment. Others identified specific shorter term goals which contributed to a more general end result. The opportunity to see older children with vision impairment or other disabilities helped parents to dispel unfounded assumptions and realise what might be possible for their child [Sue, Tr.2; Raewyn, p.130; Focus Group 2], while some parents had gained helpful information from adults who were blind [Cushla, p.72; Sue, p.82]. Humour was considered a valuable strategy both for disarming others and for their own wellbeing [Cushla, p.70; Rudi, Tr.4; David, p.208]. Joke sharing amongst parents served as a means of peer support and a way of relieving tension. Learning braille [Cushla, p.69; Sue, p.91; Raewyn, Researcher's Log], involvement in community work [Violet, p.188], and obtaining employment that would help in developing further knowledge of their child [Raewyn, p.139; Violet p.188] were other approaches taken by parents. Activities used as means of coping included music, reading, sleeping, going to town for the day and watching television.

5.6.4 Communication and the parental relationship

Good communication, especially between parental partners, was considered significant to coping. The majority of parents reported that they talked a lot to each other, took time to discuss issues and regarded each other as a major source of support [Kevin, pp.74, Sue, p.89; Theresa, Rudi, 120; Georgia, Lance, pp.97, 98; David, p.200]. Companionship, having their own space and taking time to be together was valued, if not always possible to achieve [Georgia, p.97; Rudi, p.121; David, p.201]. Expression of emotion such as anger, grief, or frustration within the relationship was considered healthy. Problems were dealt with early with some parents examining their own approaches and the environment first, while others adapted as they went [Cushla & Kevin, p.72; Sue, p.89; Alison, p.158; Gloria & Cloan, pp.174, 175; Violet, p.196]. Most parents believed their experiences had drawn them closer together and an acute awareness of each other's needs had developed [David, Tr.10; Sue, p.89]. Perseverance in working things through and drawing on the complementary nature of partnerships assisted in achieving goals [Kevin, p.72; Cushla, p.74; Gloria & Cloan, p.183]. There was an awareness that working as a team helped maintain focus and recognition that being there for your spouse was a means of coping for yourself [Cushla, Tr.1].

5.6.5 Support from family, friends, peers and professionals

Support from family, friends, peers and professionals was sometimes offered, sometimes sought. Talking things through with family and friends was valued by parents, as was the practical support these people gave [Cushla, pp.67, 68; Kevin, pp.70, 71; Georgia, pp.99, 101; Theresa & Rudi, pp.115; Raewyn, p.137; Feanu, p.145; Gloria, p.173; Violet, p.190; David, pp.200, 208]. Parents usually had a small close circle of friends and family, and most learnt to ask for support when it was needed, although they did not find this easy. Emotional support was significant in helping parents cope, even if those who offered it were not in a position to give practical help because of separation by distance or lack of skill [Kevin, p.66; Theresa & Rudi, p.115; Raewyn, p.134]. The support of their older children was also of considerable help [Raewyn, p.137; Gloria, p.174].

The support of others that understood because they had similar experiences helped parents realise that they were not alone in their situation [Kevin, p.73; Georgia, p.106; Rudi, p.121; Raewyn, p.138; Alison, p.157; David, pp.203, 204]. Listening to other parents who did not profess to know all the answers and often did not know what the future held brought a sense of solidarity [Georgia, p.106]. Parents helped each other by finding common ground, providing emotional support, and sharing information and strategies. There was the uniqueness in belonging to the culture [Georgia, p.109] and richness in finding the meeting points [Georgia, Tr.3]. These parents endorsed the notion of Hornby, Murray and Jones (1987) that another parent of a child with disability is often the most appropriate person to provide support and from these sources found renewal and inspiration.

Support from competent professionals within an equitable, positive relationship was significant in coping [Rudi, p.121; Raewyn, p.137; Alison, p.155; Gloria, pp.170, 182; Violet, p.196; David, p.202; Focus Groups 2 & 3]. In order to get the best assistance parents suggested taking time to find out what particular professionals did and how, and to "use those people you feel comfortable with for support" [Georgia, p.106]. Being proactive in seeking out services was deemed essential [Cushla & Kevin, p.73; Georgia, p.101; Theresa, p.122; Alison, p.160; David, p.202; Focus Group 2 & 3]. Professionals and services reported as providing the most support to families were: counsellors; RNZFB Child and Family Social Workers; Early Childhood services of the voluntary agencies, RNZFB, CCS and IHC; Visual and Sensory Resource Centres; Homai VEC; respite care support (Alternative Care, Homai VEC), and organised sport and recreation opportunities (RNZFB, Rotary) [Focus Groups 2 & 3].

5.6.6 Self-advocacy

The need for advocacy arises out of a general world view from which people with disabilities are usually excluded. It can mean becoming involved in committees, making submissions, lobbying and campaigning in an effort to claim an ordinary lifestyle, gain resources, access services, provide input to policy or bring about social change. The role of advocate was of prime importance to the parents of all the children. It was carried out at two levels, first, from an individual, informal basis as advocates for their own child, and second, collectively as members elected to PVI. Parents considered they were their child's best advocate and saw their efforts as the most likely means of getting needs met [Cushla & Kevin, p.73; Sue, pp.87, 88; Georgia, p.106; Theresa, p.117; Raewyn, pp.135, 137; Feanu, Tr.6; Daniel & Alison, p.159; Gloria & Cloan, p.176; David, p.209; Focus Groups 1, 2, 3 & 4]. Parents had no expectation prior to the birth of their child that they would become 'professional advocates' and reported that they were initially tentative in the role [Georgia, p.109; Theresa, p.122; Raewyn, p.137; Gloria, p.179; Violet, p.188]. While some acknowledged that they might well have advocated for children without disabilities in the same way, circumstances had required them to be involved much earlier [Cushla, p.73; Theresa & Rudi, Tr.4]. Despite initial misgivings surrounding their new role, parents supported Kendrick's (1996) view that the risks of not undertaking advocacy were too great and they would not be able to live with themselves if issues which disadvantaged their child were neglected.

The sources of motivation to begin advocating were different. Theresa, whose child was unable to speak for himself, realised that if she did not speak for him, nobody else would [p.122]. Advocacy for Alison began the day her five year old was declined entry to school [p.158]. In general, advocacy skills developed as a result of difficult experiences. Parents learnt to identify those holding power who could provide assistance and there was the gradual realisation that parents too had power [Georgia, p.105; Alison, p.159]. Taking responsibility to be well informed, to learn how systems worked and to prioritise what was important, equipped parents to work towards their goals. Some felt strongly that parents of children with disabilities needed make a stand and that parents could not expect a lot without putting in effort themselves [Georgia, p.106]. However, it was also recognised that some parents were so weighed down by their situation that they needed others to speak for them [Lance, p.107, Georgia, p.108]. This, then, together with seeing the wider needs as a result of experiences with their own child, lead parents to align themselves to other like-minded advocates through PVI.

5.6.7 PVI as a system of support and advocacy

Because all participants were drawn from the PVI national committee, it was not surprising that this was considered a prime means of support by them [Focus Groups 1, 2 & 4]. The organisation encompassed the purposes attached to action groups by Gitterman and Shulman

(1986), Hatch and Hinton (1986), and Murray (1991): providing practical and emotional support, enskilling each other in assertion and negotiating skills and influencing each other about their expectations of professionals. Parents were both recipients and providers of assistance. Most were involved early at the local level of PVI with introduction coming from other parents, RNZFB Child and Family Social Workers, and teachers [Kevin, p.73; Richard, p.89; Georgia, p.106; Alison, p.162; Focus Group 1 & 3]. The over-riding motivation for participation was to assist their own child through gaining knowledge, and skills, thereby lessening the worry about their child's future. [Kevin, pp.73, 74, 75; Sue, pp.89, 90, 91; Rudi, p.124, Focus Group 3].

Further reasons for joining PVI included feelings of isolation, previous involvement in supporting other parents, affinity with PVI's aims and objectives, concern at diminishing services, the desire to learn more, and the belief that PVI had the ability to make changes significant to the lives of children [Kevin, p.74; Sue, pp.89, 90, 91; Georgia, p.106; Rudi, p.122; Raewyn, p.138; Feanu, Tr.6; Cloan, Tr.8; Violet, p.192; Focus Group 3]. Initial entry to the national committee came almost by default for some, when no others would take on the responsibility. Violet, who attended a small hui for parents, was motivated when no one else came forward by the need to have more Maori parents involved [Tr.9]. Likewise, Feanu was influenced by the need for Pacific Island people to be represented and to establish support networks [Tr.6].

Introduction for some was difficult with little realisation of what they were becoming involved in [Sue, p.89; Violet, p.192]. Initially the terminology and political issues were incomprehensible to new members who kept up involvement "to get a level on it" [Kevin, p.74]. Knowledge grew gradually. PVI was a place where parents could ask questions and challenge things without appearing to be weak [Sue, p.89]. It was instrumental in both personal growth and in developing the skills of advocacy. While thinking was broadened from local to national level [Georgia, p.107], supporting parents in regional matters was seen as important as political advocacy in the wider sphere [Kevin, Tr.1; Rudi, P.121]. The PVI experience provided the training and confidence to work with professionals and the stimulus to extend activity to other forums, such as the Board of Trustees of children's schools [Georgia, p.107].

While the concerns of parents and needs of their children were diverse, there was discernment that they were all "going in the same direction" [Georgia, Tr.3]. PVI was seen as a vehicle for getting like-minded people of drive and vision to action [Rudi, Focus Group 4]. It was a means of intentional planning and goal setting in which advocacy might be shared and personal and systemic safeguards forged (Kendrick, 1996). While even informed, assertive parents experienced feelings of powerlessness, collectively they developed skills in persuasion, consensus building and persistence in respect of long and difficult challenges.

Parents saw the purpose of PVI as striving for fair treatment of all children with vision impairment. While readily acknowledging they joined PVI for the benefit of their own child, this rapidly extended to considering the needs of all children as an awareness of wider issues and their implications was gained [Kevin, p.74; Sue, pp.89, 90; Georgia, p.107; Rudi, pp.121, 125; Alison, p.162; Cloan, Tr.8; Violet, pp.192, 193; David, Focus Group 4]. Political advocacy was directed primarily to education with some attention to the health arena. Policies to bring about adequate and equitable service delivery, resource allocation and improved education opportunities were the thrusts with accountability from policy makers, service providers and professionals demanded [Focus Group 3]. Developing a vision accompanied by action, was a key strategy [Kevin p.74]. Collective advocacy involving creative, effective alliances by active parents' groups was considered one of the few ways likely to effect change. Advocacy was ongoing, costly of time and energy [Rudi, Tr.4; Gloria & Cloan, p.176] and frequently undertaken with the realisation that future change would likely be too late to benefit their own child during schooling years [Raewyn, p.139]. A vision of fair treatment and social changes, the reduction of stigma and a strong belief that they "could make a difference" [Georgia, Tr.3; Focus Groups 2, 3 & 4] were the bases for parent advocacy and this process was considered to be born out of moral and ethical issues [Cloan, Tr.8].

5.7 Conclusion

This chapter has explored issues and strategies for coping within an ecological perspective. The beliefs, feelings and experiences of individuals and families have been examined with the influence of societal institutions, cultural values and norms, social relationships and social networks emphasised to gain a fuller understanding. Prejudicial attitudes within society remained apparent. Nixon's (1991) observation that the shock of learning that a child has a disability might be explained as much in terms of the negative societal meaning of impairment as of the incapacity the impairment might cause for the child, was evident in the study. Families' stories reflected struggle and frustration, particularly against the restrictive nature of the very systems whose purpose it was to serve their needs. While issues within the micro- and exosystems predominated, matters relating to education superseded all others. Central to the discussion was the nature and quality of the parent-professional partnership, with educators the professionals whom parents most expected to support them in realising their vision for their child. While 'good' professionals were affirmed, strong messages were delivered on the valuing of parental expertise. Clare's (1981) perception that parents and professionals had moved towards partnership was not seen to go far enough by participants who considered that such a relationship needed to reflect equality, with action based on parent as well as professional knowledge and skills. Both informal and formal networking was used as a means of support. As might have been anticipated support networks were found primarily in the family. However, they also occurred through relationships in the wider sphere with friends, peers, professionals, service providers and organisations. Relationships with other parents of children with vision impairment were of particular significance. Advocacy was deemed to be the prime process by which to bring about change to systems which remained unchallenged by the great majority of parents.

While participants' active involvement in PVI may mean that certain stances differ from those of parents who are not thus involved, their task on the committee is to represent those parents and their views may, in fact, reflect the forefront of parents' thinking. As a group, their styles of coping and their familiarity with issues may act as useful models to other parents of children with vision impairment.

CHAPTER SIX

CONCLUSION AND IMPLICATIONS

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> *It's not necessarily knowledge I'm looking for, but it's just the acceptance and mutual understanding that we're here to work together - not (professionals) to make all the decisions, not me to just make the decisions. It's a mutual understanding of what needs to be done.*
>
> *(Research participant)*

6.1 Conclusion

The aim of the study was to reveal hidden aspects of disability by exploring the lived experiences of families, in order to help others understand the impact of disability on parents and their children. The stories families told were complex, containing their own specific truths, rooted in time, place and social relationships. Families' accounts helped them to make sense out of what might, at times, have seemed perplexing experiences. Their search for meaning and purpose led them to positions as "professionals of their own child".

Stories challenge readers to learn and to reflect. The prime significance of the study was to be its usefulness in empowering both participants and other families of children with disabilities. There is also, however, much to inform those on whom they depend for education and other services, and for those who have little understanding of the impact of disability. By reflecting and acting upon what families have said, professional practice may be improved, further appropriate policy and services developed, and community awareness enhanced. In this final chapter implications for families, professionals, service providers and policy makers are identified from the study's findings. Limitations in the study are described and areas for further research indicated.

6.2 Implications for families

Families hoped that what was learnt from their stories might be useful to those with disabilities, their families and whanau, in making a positive difference to the overall quality of their lives. In seeking to make life meaningful for their children they had identified attitudes, practices and structures which might assist others.

While parents often struggled with their situations, they strove to maintain a sense of 'normalcy' for their families. They saw their responsibilities as those outlined by Strully and Strully (1989) for all families - to provide their children with a sense of support, stability, acceptance and caring in order to develop self-confidence, self-identity and promote learning and social interaction. Parents did not see themselves or their children as special and were guided by ordinary values and motives. The challenges to such achievements which arose in each ecological system were apparent. Parents had developed effective approaches to working towards their goals however and recommended these strategies to other families. Parents would:

1. Believe that they can make a difference in their child's life. They should be proactive and open to learning from experiences.
2. Develop and keep their own vision for their child.
3. Become well informed, gaining as much information as they can about their child and the services available.
4. Draw on their personal qualities, skills and interests, learning to prioritise, set goals, and plan ahead.
5. Develop effective communication and assertion skills, which will help them to access resources and expertise, and to communicate ideas, concerns and needs directly.
6. Network and seek support from family, friends, peers, professionals, understanding that they are not expected to cope alone.
7. Seek out parents with similar experiences, and adults with disability who are positive role models, through the use of support systems and self-advocacy groups like PVI.
8. Ask for help when they need it and be involved in decision-making.
9. Share experiences and knowledge to assist others, telling their life stories to help educate society about people with disabilities.
10. As their own child's professional, contribute knowledge and expertise in collaborative relationships with other professionals.

The impact of disability on siblings was recognised. While parents tried to protect siblings from pressures which arose, early responsibilities, early decision making and early independence were frequently unavoidable. The powerlessness of being a child whose opinion might rarely be sought was acknowledged, with parents acutely aware that decisions made in respect of their child with disability affected the whole family. However positive aspects also arose out of siblings' experiences in the form of new skills, positive attitudes, personal growth and the ability to shoulder responsibility in the wider community. It is recommended that workshops be held for siblings and Peer Support Programmes be established to support their needs.

6.3 Implications for professionals and service providers

Another aim of the study was to provide others, such as professionals, service providers, policy makers and those in advocacy groups with the ideas, experiences and emotions of the participant families as a basis for critical analysis and change (Lather, 1986). Disempowerment of parents by professionals emerged as a major theme in the study. This, together with the uncertainty parents felt surrounding the future directions of policy and service provision, led to parents becoming involved in advocacy and political lobbying. Parents sought a collaborative relationship with professionals in which the knowledge and expertise they brought was validated and acted upon, seeing themselves as professionals in relation to their own children. Parents also acknowledged the potential of professionals to empower when they could depend on their competence and genuine regard for their child and themselves. Parents felt supported when professionals provided encouragement and affirmation, empowered them through information and training, and facilitated access to appropriate services.

The nature of the parent-professional partnership was central to the lives of families. While stories revealed positive experiences with professionals, they also reflected frustration and disillusionment. Attitudes, as well as skills, were crucial to the calibre of the relationship. Parents recommended that basic counselling skills be part of the training of all professionals working with families of children with disabilities. While professional counsellors were available in the community, teachers, physiotherapists, social workers and nurses were among those identified as needing to use counselling skills. These professionals need training in such skills, in order to support families in meeting the additional demands they experience. Parents recommended the following for professionals who worked with them:

1. To develop competence in interpersonal communication skills, including effective listening and basic counselling skills, and to show empathy and compassion.
2. To develop specific knowledge and skills in working with families, using practices which take account of the different lifestyles of families and facilitating participation by all family members.
3. To be sensitive to the complexity of the adjustment process, aware of the wide range of feelings parents, siblings and extended family members were likely to experience and of what was involved in the parenting of all children in a family.
4. To be competent and accountable in the specialist area of expertise, providing well grounded, accurate and understandable information.
5. To communicate openly and honestly, having courage to say when they did not know answers to questions.
6. To recognise parents' knowledge and expertise, developing collaborative relationships in which parents were treated with equality and respect.
7. To co-operate with relevant professionals in the same and allied fields.
8. To be informed about the rights of children and their families, and be assertive in advocating for them with colleagues and service providers, in order to access a wide range of services and opportunities.
9. To become informed about sources of financial assistance, such as allowances and grants from government agencies and voluntary agencies.
10. To be aware of the implications of disability for different cultural and ethnic groups and informed as to networks to access culturally appropriate services and programmes.

Difficulties in accessing support services, especially in the early stages following diagnosis, were common to most of the study's families. Assistance which should have been available through professional referral often came about by chance and, when services were in place, they frequently did not meet the needs of children and families to the level expected. Therefore much advocacy was focused on professional practice and service development. Advocacy alone, however, was not sufficient if it did not lead to the development of alternative practices and improved services.

The following recommendations should be considered as a basis for future action:

1. That service delivery be equitable and cohesive, based on the premise that provisions are to meet the needs of families rather than families needing to fit a system.

2. That a continuum of educational placement options be available which supports parental choice.

3. That parents be supported at the time of diagnosis of their child's disability by being informed of the diagnosis together, being linked to another parent who has had a similar experience, having a counsellor available and being assigned a key worker to access and co-ordinate services for the child and family.

4. That early referral be made to medical, educational, social welfare and any other services needed by families.

5. That the notion of a 'one stop information shop', where packs providing information on entitlements, services, sources of funding, and support and advocacy networks, be explored.

6. That education programmes be multi-faceted with future developments including:
   - validation of parents in their role as first educators of their child with assistance available for early intervention in the home;
   - appropriate education programmes for parents, including the provision of resource and informational materials, instruction in specialist skills such as orientation and mobility, and techniques of daily living and sexuality education;
   - peer support programmes for children and adolescents, both vision impaired and fully sighted;
   - workshops and support programmes for siblings;
   - public awareness and education programmes;
   - empowering those in positions of influence, such as school principals to become agents for attitudinal change;

7. That orientation and mobility, and techniques of daily living programmes be functional and ongoing, with those providing instruction trained in child development and skills and techniques in working with children.

8. That urgent attention be given to the development of post-school education and residential opportunities. Such developments should adopt a philosophy of life-long education in line with parents' visions and expectations.

9. That specialist programmes for children who are deaf-blind be further developed and implemented by educators trained in this very specific area.

10. That training providers address the following needs:
    - a compulsory special education unit of learning in pre-service teacher training;
    - ongoing professional development and inservice training for all practising professionals;
    - the inclusion of counselling skills in the basic training of all professionals who work with families;
    - specialist courses for professional counsellors working with people with disabilities and their families.

6.4 Implications for policy

Parents recognised that appropriate policy was required to underpin their efforts and those of professionals. The delay in developing a comprehensive policy for special education was seen to be particularly disadvantageous. It was considered that many of the present inefficiencies and inequities in services would be resolved if policies were effective in setting clear guidelines. Three recommendations emerged in policy:

1. That additional financial resources be allocated to meet the health, education and welfare needs of families of children with disabilities.
2. That a comprehensive special education policy be developed and implemented.
3. That a national body responsible for the administration of educational services to all students with vision impairment be established.

6.5 Limitations of the study and implications for further research

The purpose of study was to explore the perspectives of families, in this case, a specific group of families active in PVI. These participants were articulate, strong in advocacy, experienced in working collectively, and had offered themselves as support to others. There is no claim that the families were representative of all families of children with vision impairment and in this respect there is a strong likelihood that these parents were more focused on political activity than others might have been. Information arising from the stories is not directly generalisable because of the small number and specific nature of the participants, but it has the potential to provide insights to others by offering understanding, interpretation, application and evaluation.

In choosing a sample elected annually by democratic process, there was risk of not retaining participants. By the conclusion of the study three of the participant families were no longer represented on the PVI national committee. However, they and their families continued as participants in the study to its completion. There is the need to recognise that families' stories reflect an on-going journey and a perspective set in time and place. Participants will move on in their personal and family lives, and as changes occur in economic conditions, policy, and societal attitude.

Limitations of time impacted upon developing relationships with families not previously known. While the focus groups were a valuable fore-runner to family interviews and much information was shared, the development of deeper relationships occurred over time. Upon returning to families to check details of their stories or obtain photographs during the final stages of the study, the researcher was often engaged in conversations which provided further insight into families' experiences. Such information was unable to be included in the stories due to the time frame for the study.

While every effort was made to ensure respect and sensitivity to those of a different culture to the researcher, there was an awareness that for Maori and Pacific Island participants, their culture is one of collectivity rather than the individuality on which the methodology of the study was largely based. Thus, while Violet represented Maori whanau, and Feanu, fanau Samoa on PVI, their stories reflected their personal view and that of their individual families. While such views might also be held by others, there is no claim that these are representative of their cultural communities.

The study was intentionally broad based. There had been no such study undertaken previously in New Zealand and both participants and researcher discerned that it was first necessary to depict the 'large picture'. While a multiplicity of issues were identified, it was not the scope of the study to explore each in depth. However, implications for future research lie within the study.

Themes such as parents as professionals, the impact of self-advocacy groups on professional practice and service delivery, equity in education services, and means of effecting attitudinal change might well lead to more focused studies. Questions arose about the effectiveness of training programmes, especially in relation to developing competent communication skills, basic counselling skills and enabling attitudes in professionals.

There remains much to be explored with siblings, given the intensity of feeling surrounding their contribution to the study. The views of Maori, as tangata whenua, and Pacific Island communities might also be explored further to ascertain how policy and practice might be informed better to meet the needs of their whanau.

Families shared those things in their lives that they find support them in their efforts to live their chosen lifestyle, in order to inform systems and practices, so that families in the future will not have to struggle so hard to obtain what they need. Their stories have a powerful potential for enlightenment. As a research approach, they provided an opportunity for the voices of people with disabilities and their families to be heard and a means of dealing with disempowerment, adding to the growing body of literature which seeks directly to reflect experience. Taken into a public arena, families' stories extend into the political sphere where they can be heard by those who make policy and implement practice. Readers will make interpretations in the light of their own experiences and perspectives. If they take cognisance of the voices and recognise in them something of their own experience, then they may act to create working partnerships.

This study is a tribute to the resourcefulness, tenacity and determination of parents and their children, who work hard to realise their vision for the future. Parents were articulate in describing how the vision they had created might be given life. They emphasised strategies of parents supporting each other, collaborative relationships with professionals and advocacy for policies and services which would bring about equitable, non prejudicial education, health and welfare practices. By such means they move towards a position of equality with the power to make choices which will enhance their lives.

The participants of the study have also illuminated the wider structural, social and cultural settings of which they are a part, and by making their personal stories available, have made a unique contribution to understanding the impact of disability on the lives of families. The insights gifted into their experiences, feelings, frustrations and aspirations have the potential to educate society towards critical analysis, acceptance, empowerment and justice.

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APPENDIX 1

RESEARCH QUESTIONS

1. What issues are there for families of children with disabilities?

    - surrounding the child, the parents, the siblings, the extended family?
    - what stages of family development have been the most difficult?
    - what do families perceive to be the effect of the attitudes of others - extended family members, the community, professionals, policy makers?

2. How do families organise themselves to provide support for their family and how have they negotiated issues in working towards a satisfactory solution?

    - what coping strategies and approaches are used?
    - in what ways have problems and issues been negotiated?
    - what support networks and service systems have been available?
    - which of these networks and support systems have been of value?
    - what needs of the family are not being met?

3. What strengths do families draw on to meet their needs and goals?

4. What is needed now and in the future to provide adequate support to families to fulfil their role in relation to developmental tasks and the expectations of themselves and their community?

    - from whom is such support wanted?
    - what implications are there for future policy and practices?

APPENDIX 2

FAMILY DATA SHEET

1. Name of your family ....

2. Number of children you have ....

3. Age and sex of each child ....
....
....
....
....

4. Your age ....

5. Your partners age (if applicable) ....

6. How long have you lived in your present home and community? ....

7. How would you describe the occupations of yourself and your partner?
....
....
....

8. What are the most important things to you and your family?
....
....
....

In relation to your child with vision impairment:

9. What level of vision does your child have?
....
....

10. What is the name of your child's eye condition? (if known)
....
....

11. What was the cause of your child's eye condition? (if known)
....
....

12. When did your child first become visually impaired and how did you learn about it?

....

....

....

13. Has your child's vision changed much since they first became vision impaired?

....

....

14. Do you expect your child's vision to change much as they get older and is this something you think much about?

....

....

15. Does your child have any other significant impairments or disabilities?

....

....

....

16. What early childhood centre/ school/ post school centre does your child attend?

....

....

17. How do you feel about your child's school (or early childhood, post school) situation?

....

....

....

....

18. What support systems (both informal and formal) have you used in the past?

....

....

....

19. Which of these systems has been the most useful?

....

....

Which has been least useful?

....

....

20. If you were asked to give advice, what do you consider is the one most important thing which you would choose to share, from your experiences, with another family who has a child with vision impairment?

....

....

....

APPENDIX 3

INTERVIEW TOPIC AREAS

A. Family Background

1. Could you tell me about who is in your family and something of your family lifestyle?
2. What are the most important things you have wanted to teach your children as they have been growing up?
3. What things are of most importance to your family?

B. (Name's) special needs

1. Could you tell me about ......'s vision impairment and when and how you learned about it?
2. Has ......'s vision changed over the years?
3. What do you consider have been the major implications and issues for ...... in relation to her visual impairment?
4. How well do you think that ......'s vision impairment is understood by the family and by those outside it?
5. Were there any particular problems for your family surrounding ......'s vision impairment and if there were how did you deal with them?
6. Who makes the decisions in your family about ......?
7. Who is most concerned with people's feelings in your family?
8. Who is most concerned with getting things done and solving problems in your family?
9. Could you tell me about ......'s schooling experiences and how you were involved?
10. Could you share something about ......'s current situation?
11. What is ......'s social situation?
12. What are the most important things ......'s needs and is she getting what she needs?
13. What do you think is the best way to ensure that ...... gets what she needs in education and other areas of life?

C. Issues

1. What do you think have been the issues for the other children in the family?
2. What have been the major issues for you as parents?
3. What are the most important things you need as a parent of a child who is vision impaired?
4. Have there been issues surrounding the extended family?
5. What stages of family development have been the most difficult?
6. What do you think has been the effect of the attitudes of others:
    - of: the extended family; the community; professionals; policy makers

D. Family self-support, the negotiation of issues and self-advocacy

1. What coping strategies and approaches has your family used to deal with issues and problems which have arisen?
2. What support networks and service systems (eg. family, neighbours, friends, peers, church, education, health, welfare, social) have been available to you?
3. Which of these networks, systems and services have been of value?
4. How have you negotiated these systems?
5. What do you think of the people who provide services to ...... and your family (e.g. doctors & medical professionals; educators; O&M; social workers, counsellors, therapists; people who do parent training; lawyers; advocates)
6. What needs of your family have not been/ or are not being met?
7. What strengths has your family drawn on to meet its needs and achieve its goals?
8. What motivated you to become a member of PVI?
9. What do you consider PVI's main function?

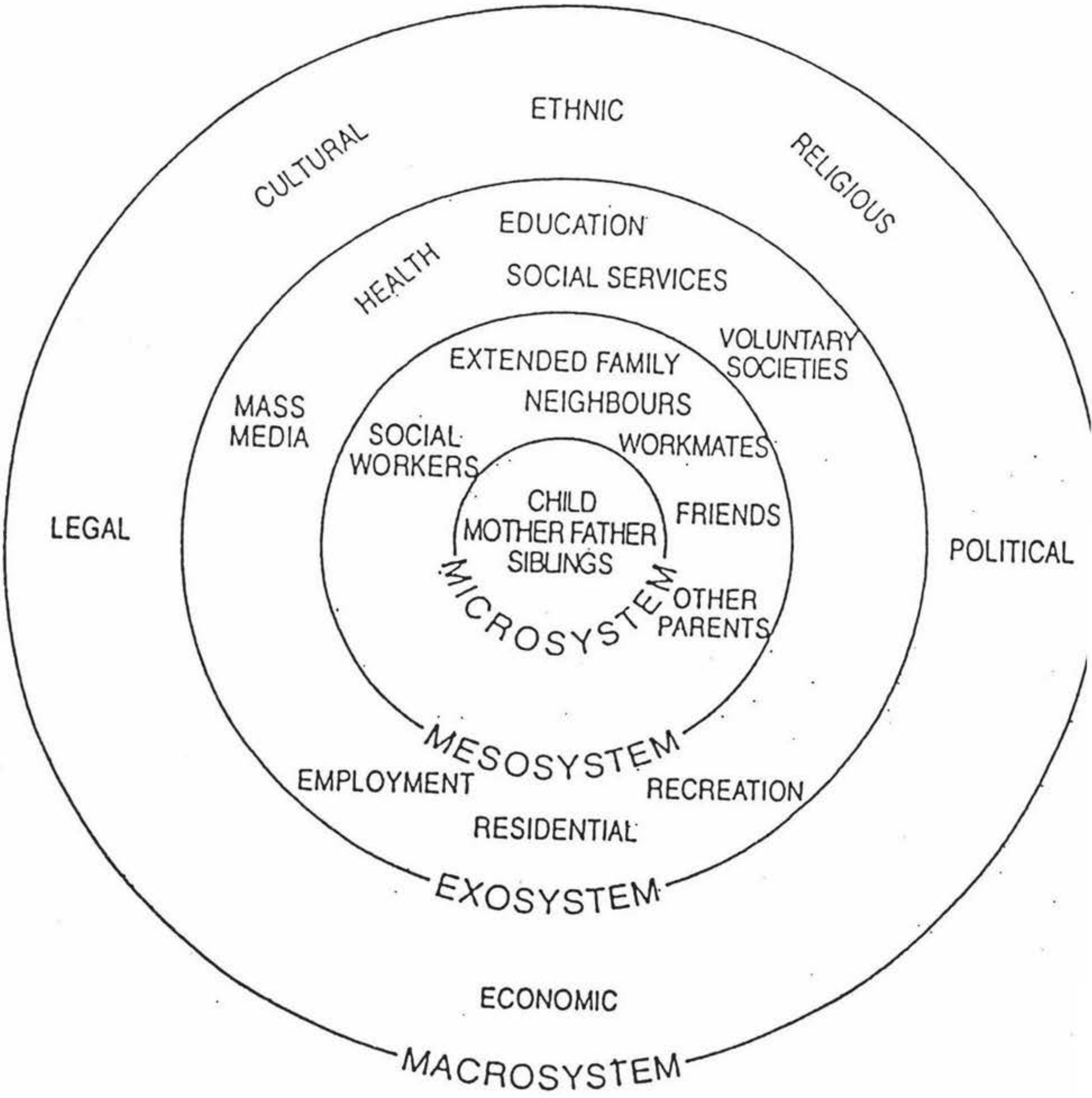
E. Meeting Family Needs

1. What is your vision for your family?
2. What is needed now and in the future to provide adequate support for your family to fulfil its tasks and expectations?
3. Who do you want such support from?
4. What implications are there for future policy and practices?

Do you have any questions or are there any other things you would like to add?

APPENDIX 4

ECOLOGICAL MODEL FOR THE FUNCTIONING OF FAMILIES



Source: Hornby (1994), <u>Counselling in child disability: skills for working with parents</u>, p.27

GLOSSARY

ACC	Accident Rehabilitation and Compensation Insurance Corporation
Alternative Care	Twenty eight days respite care per year (Health Service)
Astigmatism	Refractive error in which the rays of light do not come to a point focus on the retina
Autism	Characterised by a withdrawn state, a lack of social responsiveness or interest in others, communicative and linguistic impairments, and a failure to develop normal attachments
CAD	Coaching Athletes with Disabilities
Cataracts	An opacity of the crystalline lens of the eye
CCS	Crippled Children's Society
CCTV	Closed Circuit Television
CDU	Child Development Unit
Cerebral Palsy	Physical impairment resulting from injury to the motor centres of the brain
Congenital	Present at birth
Coloboma	A fissure of some ocular tissues; e.g. iris, retina, which usually develops in the embryonic stage
Cortical Vision Impairment (CVI)	Visual impairment resulting from damage to the visual cortex of the brain
CRS	Congenital Rubella Syndrome A condition which may give rise to cataracts, heart disease, deafness and mental retardation
CAT Scan	Computerised Axial Tomography Scan Technique for examining soft tissue of the brain using X-ray beam and computer analysis

Deaf-Blindness	Dual sensory loss, the effects of which are greater than the sum of deafness and blindness
Disability Allowance	An allowance for persons with a disability to assist with regular expenses that are a result of the disabling condition (Income Support Service)
DPB	Domestic Purposes Benefit (Income Support Service)
ECG	Electrocardiogram A record of the activity of the heart
EEG	Electroencephalogram A record of the changes in electrical potential of the brain
ENT	Doctor who specialises in conditions of the ear, nose and throat
Glaucoma	Condition of the eye caused by increasing intraocular pressure and resulting in optic atrophy
GP	Medical doctor who is a general practitioner
Handicapped Child Allowance	An allowance to assist with the home care of a child with a serious physical or mental disability (Income Support Service)
Hemiplegia	Paralysis of one side of the body
Homai Vision Education Centre	Previously Homai College; also referred to as Homai
IEP	Individual Education Plan or Programme
IHC (NZSIHC)	New Zealand Society for the Intellectually Handicapped
IPP	Individual Programme Plan
Keratoconus	Degenerative condition of the cornea which becomes cone shaped with irregular astigmatism
Kohanga (Kohanga Reo)	Language nest Early Childhood educational facility grounded in Te Reo Maori and Tikanga Maori

Lebers Amaurosis	Complete loss of vision with no evidence of any pathological condition in the eye itself
Light Perception (LP)	Ability to distinguish only light from dark
Myopia	Nearsightedness
Ngati Kapo	Self Advocacy organisation of Maori persons who are visually impaired
Nystagmus	A rhythmic, involuntary movement of the eyes
NZISS	New Zealand Income Support Service
Ocular-Dental-Digital Syndrome	Syndrome in which the vision, teeth, hair, fingers, hearing and bone structure are affected
O&M	1. Orientation and mobility 2. Teacher of orientation and mobility
Ophthalmologist	Medical doctor who specialises in the conditions of the eye
Optic Atrophy	Destruction of the function of a part, or all of, the nerve fibres comprising the optic nerve
Paediatrician	Medical doctor who specialises in conditions in children
PVI	Parents of the Vision Impaired Organisation
RHA	Regional Health Authority
ROP	Retinopathy of Prematurity; previously known as Retrolental Fibroplasia; eye condition characterised by an overgrowth of immature blood vessels from the retina into the vitreous behind the lens; caused in the premature newborn by a high concentration of oxygen
RNZFB	Royal New Zealand Foundation for the Blind; Also referred to as the Blind Foundation, the Foundation, the Foundation for the Blind
SEPIT	Special Education Planning and Implementation Team
SES	Special Education Service

SPECC	Special Education Consumer Coalition
SRC	Sensory Resource Centre
TDL	Techniques of Daily Living
VRC	Visual Resource Centre
Whanau	Family, extended family (Maori)