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“When You Lack The Word”

Stories From Parents of Children with Visual and Other Disabilities

**A thesis presented in partial fulfilment of the requirements for the
degree of Master of Philosophy in Social Policy and Social Work
at Massey University**

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Abstract

This document, submitted as a Master's thesis, describes a research project carried out during 1994 and 1995. The study arose out of my multiple identity as a parent of two children with a visual disability, as a professional working in the field, and as a researcher. The aim of the study was to find out how parents of children with disabilities cope: what strategies they employ to deal with the situations they face; how they effect the changes they see as necessary for their children and for their families; and what they want from professionals.

Research data was collected through unstructured in-depth interviews with six respondents from a group of parents of children with visual impairment. I had access to this national group through membership of it, and was also known to the respondents as a social worker with the Royal New Zealand Foundation for the Blind, of which all the children involved in the study are members. Data for analysis was also drawn from official documents dealing with disability issues, and from current New Zealand disability literature.

Research methods were consistent with an emancipatory approach which aims to avoid appropriation and to share power. Strategies were employed which would privilege the stories and characterise the parents as co-researchers in a collaborative exploration of the lives of children with disabilities and their parents.

Theory is used in this study to describe and explain what happens in the lives of children with disabilities and their families, and to imaginatively construct what could happen.

My conclusions suggest ways in which professionals can support parents by listening to them, and by offering them respect, competence, and caring. I suggest that professionals should be prepared to take some risks and share some of the consequences of current social attitudes towards disability. I conclude that what parents of children with disabilities want is not so much partnership, but alliances with people who will listen to them and support them in their search for opportunities for their children.

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The writings of British writers Michael Oliver and Jenny Morris have had a formative influence on the development of disability theory, and the current task of New Zealand writers and researchers is to continue to develop critical theory and practice for a New Zealand context. Keith Ballard, Robyn Munford, Anne Opie and others have written extensively in this field, and I acknowledge my debt to them. I also acknowledge with gratitude the work of writers like Martin Sullivan, Peter Beatson and Pauline Boyles who contribute to the debates from the perspective of the disability community, and Colleen Brown, Rod Wills, Elva Sonntag and others who contribute a parent perspective.

I have built on the work of many others. I have listened to and recorded the stories that I was told. My hope is that the telling of these stories will make a difference in the future for some children with disabilities and their parents, and the professionals who work for them.

Alison Kerr

Introduction

Kublai asks Marco, 'When you return to the West, will you repeat to your people the same tales you tell me?'

'I speak and speak,' Marco says, 'but the listener retains only the words he is expecting. The description of the world to which you lend a benevolent ear is one thing; the description that will go the rounds of the groups of stevedores and gondoliers on the street outside my house the day of my return is another; and yet another that which I might dictate late in life, if I were taken prisoner by Genoese pirates and put in irons in the same cell with a writer of adventure stories. It is not the voice that commands the story; it is the ear.'

From 'Invisible Cities' by Italo Calvino, translated from the Italian by William Weaver 1974, cited in *The Chatto Book of Cabbages and Kings*, edited by Francis Spufford, Chatto and Windus, London, 1989.

The research project described in these pages was not chosen by me from a range of possibilities: it is, like all research, in part the product of my own personal and professional experiences and perspectives. It was born of my experiences as a child with congenital cataracts, and as a mother of five children, two of them with cataracts and consequent visual impairment significant enough for them to be registered with the Royal New Zealand Foundation for the Blind. As a social worker, working with children with visual impairment and their families, I was intensely curious about what parents and their children experienced as helpful, and not helpful, and what they thought about it. I wanted to hear the stories that other parents could tell, and I wanted to privilege those stories, to find an appreciative audience for them. I wanted to use my relative power as a researcher to tell them to people who could make a difference in their own professional practice, and in their own and other people's lives.

The project was also the product of a particular historical and geographical context in which there was a perceived need and a corresponding opportunity.

The historical context is one in which small scale qualitative studies can offer an opportunity for people who have often been marginalised to tell their own stories. In 1991 Mark Cahill, writing "with the voice of someone with a disability" wrote: "The stories of our lives are waiting to be told" (Cahill, 1991, p. 1). The time has certainly come. Geographically the context was one in which it seemed both practical and important to privilege the experiences of children with disabilities whose families live in smaller New Zealand towns and cities, because often where families live has the effect of controlling their access, or lack of it, to services for their children.

Underpinning this project is a consideration of the way in which people choose, or have chosen for them, identities or subject positions which divide them, both inside themselves and from others, and of the complex power relations in which, as human subjects, we are placed and within which we operate, both as subject to someone else's control and subjecting others to our control. My thinking about discourses of identity has been informed by Dorinne Kondo's *Crafting Selves: Power, Gender and Discourses of Identity in a Japanese Workplace*, in which she describes her experiences as a Japanese American woman working in a Japanese factory - experiences of "identification, fragmentation and self-transformation" which demonstrated for her "the simultaneously creative and distressing effects of the interplay of meaning and power" in the process she describes as 'crafting selves' (Kondo, 1990, p. 24).

I have also drawn extensively on the work of Michel Foucault on the subject of power and on Henry Giroux's theories of resistance in education. The feminist poststructuralist analysis of Jana Sawicki, particularly in terms of identifying and solidifying political goals, has been helpful, as has Norman Fairclough's work on the role of discourse in constituting and constructing selves, and on critical language awareness and emancipatory language practice. The work of contemporary New Zealand writers such as Robyn Munford and Keith Ballard has been useful in terms of locating the project in a specific historical and geographical context. Building on these ideas, I have sought to suggest a way, beginning from the experience of children with disabilities and their parents, to become critically self-reflexive, to challenge the discourses in society which disempower children and their families, women, people with

disabilities, and others, and to claim multiple subject positions in order to create the space for resistance and social change.

My aim is to deconstruct the identities of 'parent' and 'professional' in such a way as to move beyond separatism and hierarchies of oppression towards the possibility of a coalition for the purpose of putting children's and disability issues on the political agenda. Here I am in agreement with Jana Sawicki that building coalitions "rooted in an appreciation of certain commonalities in our struggles combined with a form of consciousness raising that aim(s) to highlight the limits of our individual experiences" (Sawicki, 1991, p. 12) is a viable strategy for building a politics of change. Being able to claim "multiple subject positions and shared and shifting identities" (Lunn, 1992, p. 9), as I have done for myself in this project, allows us to choose our allies and "make claims based on sameness and difference according to our needs at that particular point in time" (ibid, p. 11). The task of putting the issues for children with disabilities on the political agenda could be one where feminist issues (for women as mothers and as carers), disability issues (for women and men with disabilities) and children's issues (for children, their parents and those professionals who are concerned for the wellbeing of children) might meet for a particular purpose for a particular moment in time, in order to effect change.

By making use of writing strategies that attempt to "enact its theoretical message" (Kondo, 1990, p. 304), this account attempts to dramatise the shifting, multiple levels of discourse that are at work in our lives. In this text, for example, the use of the first person voice is strategic, intended to invoke the ways in which my experiences reflect my positioning, as "a way of arguing for the inevitable locatedness and partiality of any understanding and for a voice acknowledging that partiality" (ibid, p. 303). For me, as for Dorinne Kondo, "(w)hat and how I write is no mere academic exercise; for me it matters, and matters deeply" (ibid, p. 302). My emphasis on complexity, power, contradiction, ambiguity and discursive production - that is practices that are "regulated through ideas, language, institutional behaviour, rituals, social relations" (Munford, 1995, p. 28) - is strategic, and designed to show how we forge our lives in the midst of ambivalence and contradiction, using the discursive practices, the language, the metaphors, the narrative traditions, at our disposal. Dorinne Kondo argues that the theory/experience binary is

permeable:

What counts as experience is itself a discursive production underlain by certain theoretical assumptions, and what is conventionally considered "theory" is always already a position in which a positioned subject has "personal" stakes.

(ibid, pp 303-304)

Shifting back and forth then, between methodology, theory, narratives (or "data") and analysis, is meant both to problematise those categories and to point to the fact that the stories must be understood within "complex, multilayered, mobile discourses on ... identities, that throw into relief the complicated ironies of constructing selves within fields of power" (ibid, p. 298). From this perspective then, as Kondo asserts, "'theory' lies in *enactment* and in writing strategies, not simply in the citation and analysis of canonical texts" (ibid, p. 304).

Experience, then, and the specificity of my experiences, as a parent, as a professional and as a researcher, who encounters particular others at a particular moment in time and has a particular stake in those encounters, serves to enact, and to embody theory, and cannot be separated from theory. So my account of the construction of identities is the product of a complex series of negotiated interactions in specific, but shifting contexts where it is impossible to separate the personal from the political. Identity, says Kondo, "is not a fixed "thing", it is negotiated, open, shifting, ambiguous, the result of culturally available meanings and the open-ended, power-laden enactments of these meanings in everyday situations" (ibid, p. 24). The production, or what Kondo calls "crafting" of this text, of my identity, and of the identities of the parents I interviewed, as represented here, are the complex outcomes of power-laden negotiations. The use of the narrative "I" in preference to the impersonal passive voice that has traditionally been favoured in academic writing is one strategy in an approach that aims to challenge the distinction between personal and political, experiential and theoretical.

Another writing strategy which is designed to enact the theoretical and the political is the use of a multi-coloured text, in which the voice of each of the

parents in the research project is represented by a different print colour. This textual device has two primary aims: to privilege and give a physical prominence to what the parents said, and to make each narrative immediately recognisable as belonging to a particular parent. I hope that this helps to contextualise and synthesise narratives which have been necessarily fragmented. My intention is that the parents' stories should be read in relief, raised, as it were, above the surface of the whole text. The point is that the parents' stories need to be listened to and taken seriously, and as Keith Ballard points out, they should also be read in the context of the critical appraisal which forms an essential part of research practice. (Ballard, 1994, p. 299).

I have used some grammatical conventions to make the parents' stories readily accessible to the reader. For example, while we do not indicate punctuation when we speak, I have used the conventional signs to indicate the sense and flow of the stories, and where a new idea or topic is introduced, I have started a new paragraph. I have, however, not used inverted commas to indicate direct speech within the stories, because I found that when I did that, there was some confusion in my mind about whether that was what the person actually said, or whether it was the parent's recollection, sometimes many years later, of what had been said. So by leaving out the speech marks I have attributed responsibility for the reporting of the remark to the parent who is reporting it. I have used three dots, thus ... , to indicate a pause; and three dots within square brackets, thus [...], to indicate that some words that were spoken have been omitted. When words appear within square brackets the intention is explanatory: I have indicated a person referred to by profession instead of by name, or inserted some words that contribute to a clearer understanding of the text. Where my own voice appears in a parent's story, I have represented it in black print and in italics to distinguish it from my editorial voice.

The parents' words are their own, the stories commanded by a particular 'ear', at a particular time and place. I have felt constrained by the process of analysis and the organisation of the narratives according to themes and patterns identified by the parents. I was so aware of the interconnectedness of those themes and patterns that I found the task of dissecting the narratives and choosing parts to represent the whole both difficult and disquieting.

I have used the convention of people first, disability second, though I am aware of the view that favours acknowledging disability as an integral part of and inseparable from the person. Four of the parents chose to use their own names in their stories: Violet, Frank, Doreen and Mary appear in the text as themselves, as do their children, Shaun, Bruce, Chelsea and Justin. Other family members' names have been changed to protect their privacy. The other two parents preferred to use pseudonyms for themselves and their family members. I have generally omitted any identifying information such as the names of schools, hospitals and other institutions, except for national service providers IHC, CCS and RNZFB, which would be identifiable even without names, by their uniqueness in their respective fields of service provision. Likewise I have left 'Homai' where parents have referred to Homai Vision Education Centre, because it is the unique national service provider in its field.

My intention then, is to set what the parents have to say in the context of some useful ideas about identity, power, discourse and language in particular, and to locate this discussion in the context of the present political climate and current policy debates in order to explore the experiences of a group of children with disabilities and their families, at this point in time, in New Zealand.

I want to suggest ways, arising out of the parents' answers to the research questions, in which policy and practice might be shaped to foster a coalition between parents, professionals, people with disabilities and others, such as politicians and policy makers, which might work to promote the interests of children with disabilities. My hope for change in this area lies in the possibility of finding strategies which might encourage such alliances in the context of a coalition politics in which "our allies are best chosen on the basis of their political commitments not their identities" (Lunn, 1992, p. 9). As Michelle Lunn points out, this perspective creates real opportunities for non-disabled people to work alongside people with disabilities towards shared goals. This position involves "an awareness of how parochial it is to present the loss of hope or progress as a universally available mode of adjustment to the ugliness of our times" and "an open commitment to certain political principles and values" (Soper, 1991, p. 120). To take this position, as I do, "is to recognize certain objective structures of oppression, by reference to which we discriminate

between practices, dispute the wisdom of various emancipatory strategies, and, indeed, engage in more than theory" (ibid, p. 123).

In Chapter One I discuss research design, contextualising myself as researcher and the parents as research participants. I consider the story-telling tradition and the status of stories as research. I go on to discuss the ethical issues that arise in the practice of research, and consider ways of doing research that are consistent with an emancipatory approach. I set out the research questions and explain the research process, covering data collection and analysis and discussing the issues of control that arose out of the collaborative approach I chose.

Chapter Two begins by defining the particular perspective on disability that drives this research agenda, and goes on to introduce theories about power, in terms of relating to others and in terms of the way our identities are shaped. I go on to discuss ideas about people as subjects, and about resistance as a strategy for change, and then to consider ways of multiplying the sources of resistance in a 'politics of difference'. Ideas about discourse and structures of oppression in our society such as professional dominance and managerialism, along with theories of language, power and discourse technologies, are presented in the context of the respondents' own views, and the current New Zealand situation. Theories of schooling and ideas about the contribution of narrative to the struggle for change conclude this discussion of the politics of power.

Chapter Three begins with some ideas about families as the context in which children with disabilities live their lives and shape their identities. Parents' own stories about the experiences and achievements of their families are presented, organized according to themes identified by the parents as important. Parents talk about the effects of labelling, of their children and themselves, and of not being listened to. They discuss the need for assertiveness, the expectations placed on them as mothers and fathers, and the effects of their child's disability on the whole family. Hopes and dreams, and the way their private lives are often played out in public, are important themes for the parents, as is the time they spend waiting; for services, equipment or accommodation. The particular situation of parents who are also

professionals is considered, and parents talk about how they often have to support others inside and outside the family, and to plan minutely for a manageable lifestyle. Accessing care and support in the community is a major theme for parents in the context of the current government policy of deinstitutionalisation, and 'community care', and this chapter concludes on an anxious note.

In Chapter Four I consider the issues families face in dealing with medical systems and medical people, in the context of the current health reforms in New Zealand. I use the metaphor of a maze to introduce this chapter, because the medical system is not an easy system for parents of children with disabilities to negotiate or to exit, or even, for that matter, to enter: there are many avenues which lead nowhere, walls which confront at almost every turn, and often it is impossible to see beyond walls which seem insurmountable. The chapter begins with a discussion of the market model which informs the current health reforms, and goes on to consider the parents' experiences of medical intervention in their children's lives. I have organized the stories around themes that parents identified: the hospital was an important site of medical care for families, and they also talked about how they tried to find ways of managing the medical system outside the hospital. Information, lack of it and difficulties in getting it, are discussed, as is the language of medicine. The parents consider the attitudes they encounter in the medical world, and the problems they have experienced in getting the right medication for their children. They discuss their own experiences in the light of the current importance of 'medical' assessments in accessing support. The chapter concludes with a discussion of the power imbalance between parents and medical professionals.

In Chapter Five I consider the current educational climate in New Zealand; the legal right that all children have to attend their local school, and the practical implications of a lack of resources to realize that right. Education is an important topic for all the parents, and they identify themes relating to the educational choices, or lack of choices, that exist for their children. They talk about the extra efforts their children often have to make to survive in the system, and the frequent lack of acknowledgment of those efforts and achievements. The social exclusion of children who are 'different' is

considered, and parents talk about the impact of inadequate or inappropriate resourcing on the education their children receive. Teacher training is discussed, and the parents consider other structural factors, such as poverty and parental educational achievement, which impact on their children's learning.

Chapter Six considers the role played by professionals in the lives of children with disabilities and their families, and shows how relations of power often work to disempower the families. This chapter also highlights strategies of resistance and points toward the construction of a framework for professional practice that demands a sharing of resources and information in order to redress injustice and imbalances of power. This section discusses partnership between parents and professionals from a parental perspective. Here parents discuss the information they have received from professionals, the interest shown in them and their children, the support given to them by professionals, and their expectations of professional competence.

The parents consider the impact on their lives of time spent obtaining professional services, and the time taken, as well as the timing, of appointments for their children. They also discuss the effort involved in managing the services for their children, and the difficulties they experience in terms of attitudes, access and the imbalance of power between themselves and the professionals they encounter. This chapter concludes with a discussion on ways in which this power imbalance can be addressed, given the current context of market-driven health and education reform.

Chapter Seven considers the way in which language, discourse and the daily 'technologies of power' function to 'construct' (Kondo,1990) the lives of children with disabilities and their families. By analysing three different texts relating to the subject of family support, I show how the texts can be read in a critical way which engages the reader in a 'conscientised' (Freire,1972) struggle over their meanings and interpretations. Some suggestions follow for the building of a framework as a way of working alongside people that is collaborative and respectful and emphasises a 'real' sharing of power. The Conclusion offers reflections on the research process and suggestions for possible directions for further research, and some implications for practice.

The Parents

Sarah is the mother of two children, Emily aged 5, and David, aged 2 years and 9 months at the time of the interview. The family lives in a small New Zealand town, where Sarah's partner Mark pursues a professional career. Neither Sarah's family nor Mark's live nearby. About a year before the interview David had contracted meningitis, which caused severe visual impairment and a right sided partial paralysis at that time. Sarah's story is one of the family's battle for information, services and resources at a time of extreme emotional and physical upheaval and strain.

Mary works part-time as a legal secretary and cares for her three children, while studying part-time towards a diploma in working with people with disabilities. Justin, Mary's elder son who is eighteen, has cerebral palsy and a severe visual impairment as a result of birth trauma. Justin has experienced both segregated and integrated living and educational settings, and at the time of the interview was in the process of trying to move in to a purpose-built shared flat. This process has been protracted and traumatic, and Mary's story illustrates the extent to which her life continues to be defined by what is happening for her son.

Theresa and her husband John live with their daughters Carol aged ten, who has a significant visual impairment, and Holly aged eight, in a town of a couple of thousand people, in which after around fourteen years Theresa can still be described as 'an import'. They are happy in the community and comfortably off, having planned and worked hard for what they have. They want their children to do the best that they can do, and to be happy. Theresa is on the local school Board of Trustees and her story tells of the vigilance and energy needed to make the policy of inclusion work for her child.

Doreen and her husband live in a small, quite isolated town with their two daughters, Christy and Chelsea. In a town of high unemployment, Doreen and her husband own their own business. Christy is at school and Doreen has just enrolled Chelsea, who has severe disabilities, to start at her local school at the beginning of 1996. Doreen invited her cousin to take part in the research interview, and their story tells of the pleasures, and the pressures, of patiently and graciously managing the interactions with the numerous professional helpers in Chelsea's life.

Frank is a widower with a daughter who has left home to train as a teacher, and a son, Bruce, who was seventeen at the time of the interview and had been waiting, for several years, for a place in an IHC family home. Frank is a retired civil servant whose wife, a former teacher, died two years ago. He tells a story which highlights how much personal effort has to be put in by the family to achieve and maintain appropriate educational options for a child with disabilities, often against a background of community prejudice and ignorance, and inadequate funding.

Violet is a Maori woman who cares for her youngest son Shaun, who was sixteen at the time of the interview, at home. Shaun, who has severe disabilities, attends the local special school during the day, and his father and other members of the family assist Violet in caring for him at other times. Violet is an Early Intervention Teacher who worked, until recently, with the Special Education Service. She wanted to share her feelings of grief and sadness, and her learning experiences, especially with her own people, the tangata whenua. She tells of a growing awareness of the importance to her of her whanau and of tikanga Maori. Violet's story is one of spiritual strength and personal growth in the face of painful circumstances, difficult decisions and a high cost to the family.

Chapter One

Research Design and Methodology

'How can you write if you don't understand the world?' George accused her.

'How can I understand the world if I don't write?' was her defence.

'The only way to grow in wisdom is to ask questions,' George told her.

'Writing is also a way of asking questions,' said Griet.

'Don't stories always ask other questions?'

What happened to Gretel after she and Hansel climbed on the goose's back? When they got home to their father? When they grew up?

Marita van der Vyver, *Entertaining Angels* p. 175

The Research Design

The dual subject positioning or 'identity' of the researcher in this project as both a 'professional' and a 'parent' suggested participant observation as one obvious method, and life history as another. Participant observation, based on the principles of symbolic interactionism, and necessitating a subjective, involved, 'insider' perspective on the part of the researcher, involves some participation, some observation, and a frequent and flexible movement along the continuum between the two. Denzin defines this method as one involving a range of data collection techniques, including in-depth interviewing and document analysis, as well as direct participation and observation, and 'introspection'. It is, he says, "deliberately unstructured in its research design so as to maximise the discovery and verification of theoretical propositions" (Denzin, 1970, p. 186).

It is, again according to Denzin, a central assumption of this method, that the researcher shares "as intimately as possible" in the life and activities of those studied, including their "symbolic world" (Denzin, 1970, p. 187). Denzin's description assumes that this means learning a new language, etiquette, eating habits, and work patterns, and involves a "continual attempt by the field worker to carve out a role for himself". He does suggest as a general principle, though, that the observer

should not try to present himself as something he is not and he should

use to advantage all the personal characteristics he possesses to enhance his observational role. Depending on the investigation, this may include drawing on such diverse past experiences as law violations, experiences as a mental patient, association with drug users, and so on.

(Denzin, 1970, pp 188-9)

While this serves to illustrate in several ways how the thinking about and the doing of research has evolved since it was written, it was nevertheless interesting and useful to me as a researcher, both as reassurance and as warning. It served to reassure me that the world I intended to study, that of children with visual impairment and their parents, is also the world that I inhabit. There was no need for me to learn a new language, or to dredge up experiences or associations from the past in order to share in the symbolic world of the research participants. I already know the language - it is the language of disability, the language of exclusion or inclusion, the language of medicalisation, the language of professional mystification, the language of failure, success, tears and joy. This was confirmed during the course of the research by Violet, who said to me:

And when I listen to some of the different other parents ... yeah, because you have to be so tactful and diplomatic at times, I just ... I get ... you get sick of it don't you? And so, how much do you push, and how much do you go and look like you're intruding, and ... you know?

This collaborative use of "don't you?" and "you know?" implies an assumption of shared knowledge, shared experience, a shared "symbolic world", as does Mary's comment:

... you think about school IEPs [Individual Education Plans] for one, where you and I both know this Alison ...

At the same time, in an environment of increasing awareness of the ethical issue of who will benefit from this type of intrusion into the lives of children and families, it serves as a reminder that the research design needs to be transparent and clearly articulated. As Rees suggests:

Even if credibility and trust have been achieved at one point in time, that is unlikely to be a permanent feature of working relationships [...] The maintenance of trust, an awareness of exercising power in different contexts and a sensitivity to the use of language are features of all exchanges concerned with empowerment .

(Rees, 1991 p. 87)

Thinking about these issues, and about misunderstandings and confusion that have arisen during the course of the research project, I have become increasingly aware of the differences between myself and the participants, and their differences from each other. What brought us together was our shared experience and our membership of the same group. What has kept me here, 'carving out a role for myself' as a researcher, is an increasing awareness of, respect for and determination to represent our differences - the identities we have chosen for ourselves or had chosen for us. There are some obvious differences: for example, one member of the group is a father, all the rest are mothers; three members of the group parent alone, three with partners; three are Maori, three Pakeha; most of the children involved have other disabilities in addition to their visual impairment. Other differences, economic and class differences for example, relate equally strongly to the ideas about discourse and language practice which are at the heart of this study, and are also powerful in the shaping of identity for parents and children.

Mindful of my own changing, or multiplying, approach to the research design, I drew again upon Denzin:

Central assumptions of the life history are that human conduct is to be studied and understood from the perspective of the persons involved. All data that reflect upon this perspective will be employed. Clearly this is a case for taking the role of the acting other and actively sharing in his experiences and perspectives, and these notions of course lie at the heart of participant observation, which is one life history many times expanded ...

(Denzin, 1970, p. 220)

One of the participants in this study was very clear about the limitations of this

approach:

Nobody - **nobody** - understands what it's like to have a child with a disability - other than the parent of a child with a disability, and what really gets up my nose is when you go somewhere and people say, I understand. If they're not a parent of a child with a disability, no matter what the disability is, I just keep it quietly to myself, but I say, you wouldn't understand a thing. They might be able to - I don't know - have a bit of empathy with you, but they don't actually understand what it's like. In the course that I'm doing at the moment, the tutor has worked in a psychopaedic hospital for seven years, she's worked for the IHC so she's had a lot of dealings with people with disabilities, but she still says to us, to [name] and I who are the parents, I don't understand what it's like. And if people acknowledge that, that's great. because **nobody** understands what it's like to have a child with any sort of disability other than other parents.

If actively sharing in the experiences and perspectives of research participants is never really possible, the researcher needs constantly to be on guard against pretending, or seeming to claim that it is; that is, against appropriation in the form of assumptions about shared perspectives. One way of doing this is to privilege the actual words of the people in the research, the stories they have to tell.

Stories to tell

Focusing on the creation of coherence in the production of life stories, Charlotte Linde describes how such life stories are created, negotiated and exchanged. She characterises the life story as

a temporally discontinuous unit told over many occasions and altered to fit the specific occasions of speaking, as well as specific addressees, and to reflect changes in the speaker's long-term situation, values, understanding and (consequently) discursive practices.

(Linde, 1993, p. 51)

In considering how a selection from "a lifetime's worth of talk" might be made

Linde suggests that

A cross section of a life story, taken at a single moment in time, contains a large enough number of narratives and their relations to permit us to study the creation of coherence. Because this method of sampling a cross section of a speaker's life story generates a manageable amount of data, it also permits us to consider a number of speakers and to compare the ways in which they handle equivalent problems in constructing similar types of narratives and in creating coherence for similarly problematic chains of events.

(ibid, p. 52)

In the course of reflecting on the research process, Frank made the following remark which seemed to be about the creation of a coherent account of what his family and other families had experienced:

Well, when you live through it, it's sort of not quite as hair-raising possibly, and when you read what other people have been involved in, you think, well, they are in the same boat as we are, and they may not be as badly off as we are, or they may be worse off than we are, but you still have got a darn good idea just where they are and what they've been facing up to ...

The narrative tradition, the tradition of story-telling, is one in which

the style is more akin to ethnography, with the investigator seeking to record the culture as it is lived and spoken. Yet there is a crucial difference. Unlike ethnography and observation, story-telling is not a covert method of data-collection. The narrator knows she is providing information: the story marks out the territory in which intrusion is tolerated.

(Graham, 1984, p. 107)

Stories are part of the way people make sense of their world. Telling a story can provide the teller with the means of "weaving personal experiences into their social fabric" (ibid, p. 119). Stories, it is suggested by Graham, can also

be a means by which people can describe and deal with the power of professionals when "the dominant vocabulary robs them of an adequate way of communicating their experiences" (ibid). If people are invited to 'tell it like it is' their stories can guard against the opportunities for misrepresentation and exploitation that exist in social research:

In researcher-structured interviews, the respondent becomes a repository of data, while interpretation and analysis remains the prerogative of the investigator. In stories, data and interpretation are fused, the story-line providing the interpretative framework through which the data are constructed.

(ibid, p. 120)

Keith Ballard goes further. He claims that the stories he has recently edited and published in *Disability, Family, Whanau and Society* (1994) are

as important, relevant, valid, reliable, meaningful and generalisable as any other writing that is referred to as research. Also, these stories go beyond simply being a research account of disability. They provide a critical analysis of current issues undertaken by people who have experience of disability in New Zealand. This analysis indicates directions for change in policy and practice.

(Ballard, 1994, p. 22)

Researchers, Ballard says,

should engage with research participants as equals in a process of critical reflection and mutual problem solving. In this way we may hope to understand our different realities as they exist at a particular time. We can act on those understandings in order to improve policy and practice. That will lead to new circumstances that, once again, will need interpretation, reflection and action.

The goal of sharing ideas in this way is not that of prediction and control, but that of understanding. This understanding will be relative to culture, experience, time and place.

Ballard's view of "research" as a concept which "implies an important way of knowing" (ibid, p. 305) is shared by Michael White, who views his practice of family therapy as "ongoing private research" and suggests that those who practise therapy, along with those who seek therapy, are the "primary or basic researchers, and that those people who collect data in a more formal way are the secondary or supportive researchers" (White, 1995, p. 46). He suggests that:

we can render transparent many of the taken-for-granted practices of the culture of psychotherapy that are reproductive of problematic aspects of the dominant culture. In part, we can achieve this through critical accounts of the history of these ideas and practices, and by a review of the real effects of these ideas and practices on persons' lives. We can deconstruct these ideas and practices by stepping into alternative sites of cultures - we can take up vantage points, perhaps at the margins of culture, from which we might review these dominant and taken-for-granted ideas and practices. We can explore the alternative modes of life and of thought that are associated with these alternative sites of culture. We can solicit critical feedback from persons of other races, cultures and classes. We can openly acknowledge the political dilemmas that we face in our day-to-day work. And we can stretch culture by stretching language - we can extend the limits of the known through the imaginative use of metaphor, through the renewal of metaphor.

(ibid, p. 46)

Research Methods

My goal was to conduct a small-scale, manageable, cost-effective, yet rigorous research project which could be used to generate effective alliances of parents with professionals, and parents with parents. The research was designed to incorporate a qualitative, critical, interpretative methodology in a search for meaning and pattern rather than "prediction and control" (Ballard, 1994, p. 304). The strategy of multiple triangulation, that is triangulation of theory, methodology and data was used to build interpretations and to acknowledge a

social world which is “shifting, conflictual, emergent and constructed” (Denzin, 1989, p. 139). Strategies for triangulation included participation in and observation of group discussions, in-depth unstructured interviewing, document analysis of relevant public documents from the fields of health and education particularly, and other relevant written reports and communications.

I sought by these means to develop a rigorous research practice, using Opie’s interpretation of ‘rigour’ to refer to

the breadth of knowledge about the field brought by the researcher, to the reflexive use of that knowledge, to the modes of interrogation of the data, and to the representational practices embedded in the writing.

(Opie, 1995, p. 39)

In my search for a research method or methods that would be appropriate and effective for this particular project, I was influenced by a variety of ideas. Michael White’s use of the narrative metaphor and his ideas about “stretching language” are consistent with my own commitment to a critical language awareness and practice. His promotion of a vantage point at the margins of culture suggests a congruence with Anne Opie’s emphasis on the limitations of research and knowledge, and her assertion that : “Taking up a strategic position ‘at the edge of the frame’ has fundamental implications for the practice of social research” (Opie, 1992, p. 58). She suggests that the use of qualitative research methods can lead to

an empowerment of participants on a personal and broadly therapeutic plane. Deconstructive textual practice can importantly assist in political empowerment, through the incorporation in published research of participants’ multiple and very different voices, so that the way that ideology can smooth over differences is disrupted and questioned; and through the encouragement, as a result of participation in the research, of individual and collective challenging of the system.

(ibid, p. 64)

Michael Oliver, in his work towards the development of an “emancipatory research paradigm”, suggests that:

researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose. The task for emancipatory research is not, as is sometimes implied, to help the researched to understand themselves better, but to develop its own understanding of the lived experiences of those very subjects. This is, of course, a dialectical process in which research can play a significant part.

... such research can challenge the social relations of research production, it can be about the self-understanding of researchers as well as researched and it need not be separated from wider processes of education and politics.

(Oliver, 1992, pp 111-112)

I was looking for a way of doing research that would enable me as a researcher to work alongside parents and professionals in the role of support person, facilitator, advocate and resource person on issues that they, the research participants, identified as important. I envisaged an approach that would be collaborative, with the aim of working together on issues that arise for children with disabilities and their families in much the same way as the researchers in the Otago Family Network set out in their project report (Ballard, Bray, Watson, Burrows and MacArthur, 1992). It would need to be exploratory, especially in the early stages, seeking to identify themes and patterns arising in the course of the interviews, and active, seeking to apply what was being learnt. The action research process is one in which participation and observation in the field is combined with reflection among participants, and used in the service of participants, to achieve their goals.

The assumptions of action research have contributed significantly to this project, particularly in terms of researcher identification with the experiences and goals of the participants, and emphasis on the voice of the participants in the report. However, this research makes no claim to reflect all the aspects of action research; the collaborative problem solving and the action - reflection - action cycle which are key features of action research proved to be beyond the scope of the present project.

Because action research involves real people in real settings, and a real 'cause' in which the researcher is actively involved, it relies on the enlightening and motivating power of people's own words as authoritative statements on their experiences and views. While such events and statements can be analysed and interpreted by the researcher, first person accounts also need to be presented so as to minimise a researcher 'capture' of the meaning of the data. Anne Opie suggests that "the problem of appropriation and its solution lie within the researcher's way of working with the texts produced by that research; in other words, by the researcher's textual practice" (Opie, 1992, p. 57). She advocates what she calls "deconstructive textual practice", which makes available the evidence on which interpretations are based:

A deconstructive analysis requires the detailed accessing of the participant's world. It depends on the taping and full transcription of interviews which, although 'unstructured', generate their own coherence through their responsiveness to the concerns of the participant. The researcher, in the analysis and writing of her text, is engaged in a fluid process of identifying and questioning ideology (her own, not merely the other's), her location within the literature, the nature of her textual practice and the personal and political implications of methodology for the participants in the study. (ibid)

These strategies, Opie says, may mitigate, but can never entirely overcome, issues of authority and ideological appropriation. I believe that in the event, my self-identification as a parent talking with parents, and a commitment to sharing information, including the research report, so that they in turn could interpret my interpretation, worked towards further mitigation of these problems.

It was never intended, and it did not eventuate, that the research participants were exclusively female. Nevertheless, I wanted to employ a broadly feminist methodology. There is, it is generally agreed, a range of procedures which is consistent with such a methodology, though it is not the procedures themselves, but the way in which they are implemented and the use to which the resulting data is put that defines whether or not they are consistent with a feminist methodology. I therefore looked to Maria Mies as a researcher who

saw the 'double consciousness', the contradictory existential and ideological condition of women scholars as an opportunity for a 'new' methodology. Her guidelines for such a methodology, while no longer new, are, I believe, still relevant. They include:

1. conscious partiality, which is achieved through partial identification with the research subjects, and, Mies says, will not be too difficult for women who deliberately and actively integrate their double-consciousness into the research process;
2. the view from below, as a necessary consequence of the demands of conscious partiality and reciprocity;
3. active participation in actions, movements and struggles for women's emancipation;
4. participation in social actions and struggles, and the integration of research into these processes, which implies that the change of the status quo becomes the starting point for a scientific quest;
5. the research process must become a process of 'conscientization' (that is, the methodology developed by Paulo Freire for learning to perceive social, political and economic contradictions and to take action against the oppressive elements of reality) for both researcher and participants;
6. the appropriation by women of their own history through documentation and analysis; and
7. the collectivisation of women's experiences in an effort to overcome the individualism, the competitiveness, and the careerism prevalent among male scholars. As Mies states, this is relevant for women engaged in research, who cannot, if committed to the cause of women's liberation, choose their area of research purely from a career point of view, but must try to use their relative power to take up vital issues.

Mies suggests a movement away from interviews of individuals and towards group discussions, both as a means of getting more diversified information and to help women overcome their structural isolation in their families, and understand that their individual problems have social causes. (Mies, 1983, p. 128)

While wanting to retain the use of in-depth individual interviews, I did initially

plan to hold focus group discussions. Focus groups could, I thought, be used to set the research agenda, to follow up on the individual interviews with a shared feedback session, and to provide a forum in which to share the research findings. I looked at the theory and the methodology of focus groups, and planned an agenda that I thought would work well. I found, however, that my agenda was not shared by all of the research participants, and the focus groups did not happen at all in the way I had planned. While three of the participants were very keen to follow up the individual interviews with focus group discussions, their enthusiasm was not shared by the other participants, who did not see meeting together as a research group as a priority, and did not attend the arranged meetings. The result was that two of the participants attended what were to have been focus group meetings on different occasions and we conducted another in-depth individual interview on each occasion.

Ethical Issues

Because qualitative research constitutes a degree of intrusion into people's lives, it is important to consider how the research will affect them and what will be the consequences for those taking part. Having formulated a detailed research proposal, I submitted an application for approval (Appendix I) to the Massey University Human Ethics Committee. I was asked to appear before the Committee, which I did, to answer some specific questions about how I would safeguard the interests of the research participants. In particular the Committee wanted to know if I would be working as a social worker with families in the project. My reply, to the effect that I would be guided by the Committee on this point, reassured them. They felt, given my experience, that I had the necessary sensitivity to handle such a dilemma, should it arise. I found the experience of meeting with the Ethics Committee constructive and helpful in that it focused my attention on the details of my project: how I would approach participants; how I would deal with specific issues if they came up; what information participants needed to have, and so on.

Thinking about these issues raised the kinds of questions that have been suggested as a starting point for research undertaken in a cross-cultural context (Smith, 1986, p. 8). While some of the respondents in my project defined themselves as Maori, I have not characterised the project as cross-cultural research. Nevertheless, I consider the questions relevant and useful

in the current New Zealand context:

1. Who has helped define the research problem?
2. For whom is this study worthy and relevant?
3. Which cultural group will be the one to gain new knowledge from this study?
4. To whom is the researcher accountable?
5. Who will gain most from this study?

The research was conceived as a modified version of collaborative action research, with the parents as "primary researchers" who would define the research 'problem' as part of the research process. The parents themselves deemed the study worthy and relevant enough for them to respond to the initial invitation to take part, and to proceed to becoming research participants and seeing the study through to completion. The study was designed so that all the participants would gain new knowledge, and there was a specific commitment to make the research findings available to each of the participants and to the parent network through the group Parents of Visually Impaired. Because the concepts of power-sharing and partnership were central to the project, there was a constant focus on accountability and reciprocity.

I was acutely aware of the trust that was being placed in me as a parent, by other parents, and the potential for compromise that existed because of my complicated role in their lives: compromise of the effectiveness of my work with the families in my role as a social worker; compromise of the relationship between us as parents, and compromise of the integrity of the research and the finished product, the report. To guard against these potential problems, I did try to be very clear about what I was doing, and to be sensitive to the needs and wishes of the families. Even so, I felt the balance was difficult, and at times I moved rather uncertainly from one role to the other. For example, I turned off the tape-recorder when one parent became overwhelmed by painful emotion, in order to offer comfort in the face of a real dilemma and then I was ambivalent about where the boundaries lay between friend and social worker. In the end though, the boundaries are blurred, because to offer comfort is human, and that is what our alliances are built on - our humanness. As Dorinne Kondo says:

Boundaries between self and other are fluid and constantly changing, depending on context and on the social positioning people adopt in particular situations ... along a scale of detachment and engagement, distance and intimacy, formality and informality.

(Kondo, 1990, p. 31)

The tension between the two poles is, as she says, never fully resolved, but is often creative:

These multiple, relationally defined selves offer culturally specific possibilities for human fulfilment in the intertwinings of deep feeling and the inextricable connectedness of selves. And they also [...] offer other, culturally specific possibilities for domination and for the coercive, disciplinary production of selves.

(ibid, p. 32)

It is the possibilities for connectedness and the opportunities for relations of power that resist, rather than produce domination that lie at the heart of this research project and govern its methodology.

In reflecting on the research process, and on the mistakes, misunderstandings, doubts and anxieties that succeeded each other as I tried to develop the project collaboratively, and to aim for reciprocity in relationships, I was much encouraged by what a group of women researchers had to say in a collaborative work of self-disclosure about their experiences of research:

To a greater or lesser extent, we draw on previous and current personal/interactive/communication or other human skills (as a counsellor, a psychologist, a social worker, a nurse or a physiotherapist, for example) in the conscious use of self in research settings. [...] The doing of research, in the context of this book, is not fixed, predictable or predetermined. Authors here approach their work in a spirit of openness, even uncertainty, about its likely course and direction. Part of the research process, as we see it, is the need to negotiate meanings with subjects and allow frameworks for understanding to evolve through time. Reality is neither entirely fixed

nor given for all time. The use of self - the influence/impact of self - plays an important part in the unfolding of multiple realities. In this sense, research becomes part of a shared enterprise or a joint search for truth; a co-production of knowledge.

(Shakespeare et al, 1993, p. 6)

Thinking about the ethical issues of who controls the study and who benefits from it led me to consult another checklist (Zarb, 1992, p. 128) designed as a starting point for critical evaluation of disability research:

- (i) Who controls what the research will be about and how it will be carried out?
- (ii) How far have we come in involving disabled people in the research process?
- (iii) What opportunities exist for disabled people to criticise the research and influence future directions?
- (iv) What happens to the products of the research?

While I initiated the research and invited participation, it became collaborative from the time parents responded to the invitation, and in fact it was the parents who controlled the way it unfolded; for example, the focus groups I had planned to complement the individual interviews did not eventuate, at least not in the way I had envisaged.

It was the parents who controlled when the interviews would be, how long they would be, and what they, the parents, would say. I undertook to provide transcripts after the interviews, and to incorporate feedback in the findings. I asked for, and received, verbal and written appraisals of the research process, suggestions for future directions of the research, and ideas about what should happen to the report (see Appendix 5). I had hoped that whole families, or at least some family members, including children, would be participants in the research. This did not happen, and each of the six families was represented by just one family member, in each case a parent. On reflection, this was entirely practical, considering the ages and disabilities of the children, and the busy, committed life-styles of their parents. At first I felt a sense of loss of the people who were not a part of the research, and a sense of failure at my

inability to make it happen the way I had hoped.

However, as the project unfolded it became evident to me that its very modesty and flexibility contributed to its value as a model for both research and professional practice. Its legitimization came primarily from its reciprocity, as an endeavour shared with other parents; from my own commitment to challenging the traditional power relations of the parent-professional relationship; and from the opportunities it provided for people to tell their own stories in their own words. But I also became increasingly convinced of the value of this small-scale, replicable study as a strategy for linking research and practice. If practitioners were to practise with the constraints and freedoms of good research practice, if they were to see themselves, and the people they work with, in effect as primary researchers, and if parents were to become practised in the self-reflective and expressive process of research production ... there must be possibilities for productive alliances and lasting change. The study by Maria Mies, to which I have referred above, discusses the therapeutic value of making stories public, and Shakespeare et al (1993, p. 6) assert:

Active participation in research can, and does, lead to active participation outside research. Involvement in research often means people having an opportunity to recount their lives and experiences. Recounting is, necessarily a self-reflective process and may lead to important changes. People may well, through reflection, develop insight and awareness, an enhanced sense of self and, perhaps, some useful self-advocacy skills.

In accordance with the principle of informed consent, and to ensure that each participant in the research understood the reasons for and goals of the research, the ways in which it would be carried out, and his or her right to withdraw at any stage, a written statement of information (Appendix 3), preceded a consent form (Appendix 4) in each case.

The issue of confidentiality, originally assured by changes to names and identifying aspects of the texts, became complicated by the fact that some parents wanted to appear in their stories as themselves. I was delighted, and welcomed this self-disclosure for its contribution to the theories of the self that

this project aimed to contextualize. In practice, though, it proved quite difficult to work with. Should I, for example, name the towns these people lived in? Should I name the agencies they and their children looked to for support? How should I describe these people? The answers had to be provided by the parents themselves, in a collaborative process which developed over time. The result is a very fissured text, with layers of uncertainty which reflect my own uneasiness with claims to knowledge and 'truth'. This uncertainty is entirely in keeping with the practice of research, or any other practice for that matter, in which listening and wondering take precedence over knowing.

The Questions

The research questions I began with, and provided at each interview as a prompt for the participants were:

How do families get the information they need - about their child's condition, about the experiences of other families, about relevant services?

How do families give the information, about their own child, their own experiences and their own needs, to the professionals who are involved with their child?

What kinds of support do families want, and who do they want it from?

How have families experienced educational, medical and other service systems?

Are there any implications for practice arising out of these experiences?

These questions were intended to provide an initial framework for the interviews, but I made it clear to the participants that I did not want the questions to define or confine what they wanted to say.

I transcribed the taped interviews myself, kept the tapes in a secure place at my home, and provided a copy of the transcript to each participant after each interview. Comments were invited about the parents' impressions of and feelings about the transcripts. I became so engaged by the stories I was hearing, and so captivated by the shape and form they acquired as they were

told, as well as by their content, that I felt hesitant to engage in an analysis that would change their shape and add intrusive comment from me about what they 'mean'.

The Text

Reflecting upon the stories as narratives, I began to see them as parts of stories which could never be told in their entirety. Indeed they would probably not be told again in just the same way. This was illustrated to me when I operated the tape recorder ineptly and 'lost' part of an interview - though I returned with a better grip on my equipment, the resulting interview produced quite a different story. This is to be expected when, as Charlotte Linde points out, stories are told differently on different occasions (Linde, 1993, p. 51).

The unedited tapes and transcripts will become the property of the respective story tellers, and will be available to them to use for whatever purposes they may choose when this project is finished and the research report completed, submitted to the university and marked. The parents may use them for self-reflection, to remind themselves or their families of something or someone, to educate a professional, to celebrate a victory, to mourn a loss, to see where they have come from, or to gather courage for a battle.

As a researcher I was always committed to producing a report that would be accessible in language, format and style, and useful in application, to those who co-produced it. In wanting to let them speak in their own voices, I wanted to avoid appropriation. My solution to this dilemma is to take upon myself as researcher the responsibility of choosing the frame which will best present the picture or, to return to the narrative metaphor, of choosing the narrators who will tell the stories. I was, and I have remained, acutely aware of the possibility of colonisation inherent in such choosing, and it has made the project a task of alternate delight and despair.

Telling the Stories

Having obtained approval from the Massey University Human Ethics Committee and the Royal New Zealand Foundation for the Blind, I sent out a letter (Appendix 2) through the parent group PVI (Parents of Visually Impaired, formerly Parents of Visually Handicapped) to all parents of children registered

with the Royal New Zealand Foundation for the Blind in a geographical area stretching from southern Hawkes Bay to East Cape. Initially six parents contacted me to say they wanted to take part in the project, and to those six I sent the information sheet (Appendix 3). Having ascertained by telephone that they wished to proceed with the study, I then sent them out a consent form (Appendix 4) to sign and return to me.

This phase of the research took longer than I had anticipated, and even when I did finally gather up the family tape deck and some tapes and set off to record my first interview, I experienced a major setback with a parent who found that she simply could not face the prospect of speaking in the presence of the tape recorder, and withdrew from the research project. Participants had been assured right from the start that they were free to withdraw at any stage, but this was a sore test of my resolve and of my confidence in my own ability to organise and control this research project.

However, I did finally get started, and in the course of recording my first interview, with Doreen and her cousin, I asked her:

What made you reply to the invitation to be part of the research? Did you have something that you wanted to say, that you wanted to talk about?

Her reply was totally unexpected:

I didn't know, don't know ... I actually ... was misled, thinking you were [names a person with the same surname as the researcher] ...

the speech language therapist?

yeah, I actually said, well there's a silly woman ... why did she write to me when she sees me ... why didn't she ask me then? That's what ... but then when you come to the door I thought oh no! I actually thought oh no! I'm just losing it this year! [laughs]

We carried on from that point to discuss the changing names and faces of the professionals in her life and her child's life over the years, but this exchange caused me to wonder how well I had explained what I was doing, and even

whether what I was doing had any value for a person who had so many people in and out of her life that she didn't know who was who. In my discomfort I returned to the topic later in the interview with a suggested explanation of the misunderstanding:

Just to go back to what you said about how you weren't sure who I was ... I said to you ... I do wonder sometimes if there's such a stream of people that parents can feel, oh not another one, or ... do you have any thoughts about that ... that stream of people that pass through your life?

Not really. It's just like ... all of them ... all of them are there to help Chelsea, and me, sort of thing. But um ...

You don't get fed up with the sheer numbers?

Oh sometimes, but like before, when Chelsea wasn't at kindy they used to come here, or ... or we'd meet up at the hospital. Sometimes that turned into a chore.

When people would come here?

No, when I had to go to the hospital.

I was struggling to relate. I felt like Dorothy Atkinson in her chapter on relating in 'Reflecting on Research Practice':

I became very aware of asking questions and often felt like an interrogator. Whilst sometimes I wished it could be more of a conversation, my sense of responsibility for content and direction spurred me on.

(Atkinson, 1993, p. 65)

It seems to me, reflecting on the extract from our interview, that I had a theme, 'too many professionals' and I was pursuing it. While it seems that I was at least partly right about the 'stream of people', it was probably more a matter of place and time:

... now that she's at kindy they all go and see her at kindy ...

It's only, like I only get annoyed when people turn up unexpected ... because I normally have Monday, Wednesday and Thursday mornings that I've planned out. Oh yeah Monday - oh I'll spend that day at home

and catch up on housework, and Wednesday I might go, oh Wednesday, I'll have an hour and a half at so and so's place, and Thursday, if I don't know anyone's coming on Thursday and I've got that Thursday planned say just to run around doing book work

right, for your business

mm, and if someone turns up I'll go oh, oh I hate that, when they do that to me!

In this interview, more than in later ones, I frequently asked questions, and reflected back comments, as a way of checking out my understanding of what was being said.

After we had completed this interview and I had transcribed it, I paused for reflection and to gather my resources for another try. During this pause another parent came forward wanting to participate in the research. This brought the number of respondents back up to six, and gave me some much-needed courage and enthusiasm to continue.

My research group consisted then, of six self-selected parents, representing six families spread over a wide geographical area. The interviews took place at the participants' homes, three of them in medium sized provincial cities, and three of them in different small provincial towns. Three families were Maori and three Pakeha. All of them mentioned as a reason for becoming involved in the research the desire to help other parents who might benefit from their experiences.

Collaboration and Control

A major aim of my study as it was conceived was to encourage coalition politics in the interests of finding the best solution for each problem, or outcome for each situation. The research model I used in this project depends upon collaboration at all stages, from the definition of the problem or problems, the setting of the agenda, the enabling of the research participants to speak with their own voices, the sharing of information and understandings, the decision-making and action, through to the accessibility of the process and the final report to all participants.

It is intrinsic to this type of research that it is continually reflexive. The role of the researcher is one of collaboration with the participants. My aim was to encourage parents to assume the role of experts on their children, with professionals cast in the role of students of children and families. This meant that parents were assumed to be knowledgeable about their own children, and encouraged to see the knowledge they possess as valuable and important for professionals to acquire. During the time I was involved in conducting my own study, I took part as a parent participant in a study of the Individual Education Plan (IEP) process, in which parents, including me, were cast in the role of experts, on their children, and on the IEP process. Interestingly, I found it exhilarating to be re-created as one who holds important knowledge, about which it is worth doing research. I also found it interesting to notice that amongst that group of respondents also there was confusion about the research agenda, in that one parent arrived thinking that the group was in fact an IEP meeting, and an opportunity to talk about her child's progress, rather than about the process.

The immediate focus of my study was to generate discussion, dialogue and problem solving action within the research group, which was conceived as a community of interest. Although the research would necessarily be contained within a finite period of time, it was anticipated that by the conclusion of the formal research phase of the project, an autonomous self-help group would have been established and would continue to operate as a source of support, information and advocacy for parents and families, and of consciousness-raising and emancipatory potential for parents and professionals.

Not all of these hopes were realised in practice. I had planned group meetings, but these proved to be difficult to arrange. When it proved impossible to get all six participants together in one place at one time, there were two group meetings planned and carefully arranged to suit three participants each. In the event, only one parent turned up to each meeting. The two parents who did attend were happy to record their thoughts about the research process and those tapes and transcripts have been included in the interview data. Those parents expressed disappointment, as they had both wanted to have an opportunity to discuss the research and their experiences with other participants. I too, was disappointed, as it seemed to invalidate the

group aspect of the research project. On reflection, however, I understand what happened as an expression of the (differing) needs of the parents I talked to. All lead extremely full, busy and active lives. All have other family members in their lives besides the child at the centre of the study. All had given generously of their time and energy to record in-depth interviews. It seemed that for most of them at least, their expectations of the research project were met by the in-depth interviews and the promise of a final report, and they simply did not need the group process to feel 'empowered'. I had made some assumptions about what parents would find 'emancipatory', but it had always been my intention to allow the parents themselves to control the agenda, and a 'support group' was simply not on the agenda for enough of them to make it happen.

The report on the Otago Family Network mentions the need for ongoing reflection on partnership, control and "symmetrical dialogue", and comments:

A realisation emerged that the various roles that partners play do not have to be identical for an action-research project to proceed along collaborative, partnership lines.

(Ballard, 1992, pp 228-229)

As this project has proceeded, I have often felt uncertain, about issues of control for example. I have needed to be in control of the project, to organise and arrange it, to take responsibility for it, while at the same time trying to ensure that the parents also had a stake in the research and were in control of what they said and how they said it. I have subsequently co-presented a paper on the research with a parent as part of this process of collaboration and sharing of power.

Another area where control is an issue is the text. As Anne Opie comments in the introduction to her stories of caring:

Sociological texts generally subordinate the richness of the individual participant to the voice of the 'expert', as part of moving from a descriptive to an analytic account. Frequently, too, the extent of the sociological 'expert's' dependence on her participants in the production

of her more analytical account is disguised. Her words, rather than theirs, predominate. Although in my research publications I have acknowledged my debt to the participants and quoted substantially from their accounts, I am none the less aware that, in the process of the analysis, much of the richness of their accounts is inevitably suppressed or flattened.

(Opie, 1991, pp 9-10)

While acknowledging that I would like to have been able to include the stories 'uncut' as it were, the best I can do for the purposes of this research, is to follow the deconstructive textual practices suggested by Anne Opie to try to limit the appropriation of the text by the researcher. They are:

- (i) recognition of the limitations of the researcher's research and knowledge; (ii) the analytic reading of the participants' texts; (iii) some principles in relation to the incorporation of quotations from the participants' texts - what I am calling here the 'writing in of voices'; and (iv) issues of empowerment.

(Opie, 1992, p. 58)

Avoiding claims of authority, and appearing in the research as myself, in the sense of writing in the disappointments, misunderstandings and mishaps of the research, is an attempt to acknowledge the limitations of the research and of my own knowledge. The analytic, deconstructive or postmodernist reading is constituted, according to Anne Opie, by attention to the "paradoxical, the contradictory, the marginal, and by the foregrounding, (not suppression) of these elements." (ibid, p. 59). This demands reflexivity, and close attention to difference and marginality within a text. What she calls 'writing in of voices' involved paying attention to the 'how' as well as the 'what' of the texts, an awareness and inclusion of contradictions, and of the patterns as well as the content of speech. In practice this means attending to textual features, such as the intensity of the speaking voice, which may contribute to the interpretation. Empowerment, in Anne Opie's terms, has to do with acknowledging appropriative tendencies and using qualitative research methods which "can lead to an empowerment of participants on a personal and broadly therapeutic plane" (ibid, p. 64). Like her, I have worked to produce an account "which

reflects the fissuring of practice, the nuances and points of contradiction within accounts of that practice, and attends to the local conditions in the production of practice" (Opie, 1995, p. 39).

As had been agreed before the interviews, I gave or sent each participant a copy of the completed transcript of their respective interviews for their information and comment. Several said they found their own story profoundly moving, at least one was moved to tears, one marked some passages for deletion as irrelevant and rambling. Several commented on the "ums and ahs" with some surprise at what their speech looked like on the printed page.

Although the idea of developing a co-authoring relationship with participants has some appeal as a way of sharing control of the interpretation of the data, it is problematic both because participants and researcher occupy different positions in relation to the data, and because of the difficulties inherent in the geographical spread of the participants. I have chosen to use different colours in the text to represent different speakers, because I think this highlights the differences, not only between the researcher and the participants, but between the participants themselves. A consequence of this type of practice is that the voices are 'written in' in a very visible way which highlights their various locations and tends towards destabilisation of the authoritative narrative voice of the researcher. The intention is the creation of a kind of textual tapestry, which weaves in individual interpretations of events and people, as well as telling a collective story. This image reflects both the beauty of the postmodern landscape, where there is room for a rich partiality and the privileging of the standpoint of people with disabilities, children, old people, women, and so on, and its uncertainty, which raises the question,

If we no longer search for the 'truth', or even some approximation of it,
what are we doing?

(Shakespeare, 1993, p. 9)

I have given much thought to this question over the period of this research project. One thing I am doing is helping to tell a story. My multi-role perspective, as parent and professional as well as researcher, was intrinsic to the research design, helpful for the reflexive aspect of qualitative research,

and generally an advantage in terms of credibility and trust. While this was vital to the theoretical aspect of the research in its emphasis on identity, discourse and language, at the same time I found it challenging to manage in the interview situation, and also in relating to participants by telephone after the interview phase was over. During the interviews, I noticed that at times I was distracted by the strong emotions attached to memories that were sometimes evoked for me by something a participant said. Sometimes I acknowledged this, but if it would have interrupted the flow of the participant's story, I chose not to. When making a phone call to a participant, when I wanted to talk as a professional and as a researcher, I was very clear about which I was doing. I did feel awkward about making the transition so self-consciously, but there was no evidence that the parents felt any awkwardness. After all, as Len Barton asserts, research is "fundamentally a *social activity*" (Barton, 1988, p. 87). Indeed it could be that what Anne Opie refers to as "managerialist discourses" were having the effect on my thinking of privileging data collection over human connection. As Opie suggests:

Recognition of the need for increased accountability, the importance of developing priorities and recognition of resource constraints are issues which social workers cannot avoid and which influence their thinking about the conduct of their work. But the managerialist, organisationally-focused discourse suppresses a discourse of relationship.

(Opie, 1995, p. 11)

Feminist research of the 1990s, as well as aiming to be reciprocal, change-enhancing and emancipatory, is increasingly reflexive and modest in acknowledging that it can only ever present a partial view of 'reality'. It is tending towards "a more humble scholarship capable of helping us to tell better stories about a world marked by the elusiveness with which it greets our efforts to know it" (Lather, 1992, p. 95).

I see the modesty and hence the replicability of the present study as offering an opportunity to contribute to the generation of a model of theory and practice that has the potential for wide application in the community, especially in the field of disability, and especially where children, who are always relatively powerless, are involved. The doing and documenting of a collaborative

approach to both 'primary' and 'secondary' research are my current occupation, and have been my preoccupation during the period of this research project. The final commitment is to the writing and dissemination of a report which is accessible to the participants and to those who would gain from its understandings and implications for practice. These include service users such as Parents of Visually Impaired and service providers such as the Royal New Zealand Foundation for the Blind; that is, parents and professionals.

In Chapter Two I will outline various ways of thinking about children with disabilities, parents and professionals, in relation to the ways in which their lives, and our lives, and our relationships are constructed, and constrained by the social and political ideologies of the society in which we live.

Chapter Two

The Politics of Power

Identity has become the more problematic and contested as the numbers aspiring to sovereign selfhood have grown. The claims of these aspirants have withdrawn legitimacy from an indivisible sovereign subject. By making the sovereign self - both collective and individual - divisible, these claims have radically shifted the ground for a politics centred on reconciling justice, identity and difference.

(Yeatman, 1995, p. 210)

This chapter will consider some of the theoretical frameworks which can help in understanding how the lives of children with disabilities and their families are shaped by a range of factors which include: current political ideologies such as the consumerism and the managerialism of the New Right; social constructs such as ideas about disability; current welfare policy and practice; professional dominance, especially in the areas of health and education; and social positioning in respect of class, culture and economic situation. Together these factors make up what might be called the 'politics of power', an overarching theoretical framework which takes as its problematic the relations of power.

Relations of Power

I begin with a perspective on disability that views the social and physical environment as creating the principal barriers which exclude people with disabilities, while acknowledging the real physical limitations that are a part of living with a disability (Morris, 1991, p. 10). As has been highlighted by writers such as Jenny Morris, Michael Oliver and Robyn Munford, the exclusionary practices that limit the lives and choices of people who are seen to be 'different' seem deeply embedded in our culture, and to be part of our social contract. If we are to challenge the status quo in a way that can effect change, we need to understand how our lives, our identities and our relationships, are constructed.

The ideas of the French thinker Michel Foucault, and other writers who build on his thinking about 'power relations' and their effects, are helpful in coming

to an understanding of how relationships such as parent /child, teacher/child, teacher/parent, doctor/patient and so on, are produced and maintained. Foucault's concern is with how power relations operate to control both individuals and groups:

... the judges of normality are everywhere. We are in the society of the teacher-judge, the doctor-judge, the educator-judge, the social-worker judge; it is on them that the universal reign of the normative is based; and each individual, wherever he may find himself, subjects to it his body, his gestures, his behaviour, his aptitudes, his achievements ... The carceral texture of society assumes both the real capture of the body and its perpetual observation ...

(Foucault, 1979, p. 304)

Foucault's focus is on power relations at the level of the individual and his or her daily experiences in the family, school, hospital or prison. He calls this "a specific and new modality of power; a certain policy of the body" which, he says "required the involvement of definite relations of knowledge in relations of power; it called for a technique of overlapping subjection and objectification; it brought with it new procedures of individualization." (ibid, p. 305). The problem lies "in the steep rise in the use of these mechanisms of normalization and the wide-ranging powers which, through the proliferation of new disciplines, they bring with them" (ibid, p. 306). In some of his later work, Foucault's intention is to analyze power relations through the "antagonism of strategies" (Foucault, 1982, p. 211). That is, in order to understand what power relations are about, he turns to an investigation of the forms of resistance and attempts made to dissociate these power relations. He begins with the series of oppositions that have developed over the last few years: "opposition to the power of men over women, of parents over children, of psychiatry over the mentally ill, of medicine over the population, of administration over the ways people live" (ibid. p. 211). These struggles are characterized by a questioning of the individual:

on the one hand they assert the right to be different and they underline everything which makes individuals truly individual. On the other hand, they attack everything which separates the individual, breaks his links

with others, splits up community life, forces the individual back on himself and ties him to his own identity in a constraining way.

(ibid, pp 211-212)

These struggles are an opposition to the effects of power which are linked with knowledge, competence and qualification, the privileges of knowledge, but they are also an opposition against "secrecy, deformation and mystifying representations imposed on people" (ibid, p. 212). These present struggles revolve around questions of identity, with their main objective being to attack a technique or a form of power rather than a particular institution, group, or class. This is the form of power which applies itself to immediate everyday life, "categorizes the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him which he must recognize and which others have to recognize in him" (ibid). This is a form of power which makes individuals subjects, both in the sense of "subject to someone else by control and dependence, and tied to his own identity by a conscience or self-knowledge" (ibid). In the context of disability support services, the 'needs assessment' procedure can be characterized as an example of this type of power. Despite the rhetoric, which says that a needs assessment is "a way of putting together information about the support you need in different aspects of your life", and that "once you have worked through an assessment with an assessor and agreed on the support you need, support services can be arranged to meet those needs" (Ministry of Health, undated), the reality can turn out to be very different. For one of the people in my research project, for example, assessment became a protracted, enforced subjection to hospitalisation and a series of examinations and tests, with the results of those tests being used to demonstrate the dis-ability of the person being assessed and his in-ability to live in the way he wishes. In this way the person is subject to the assessment, dependent upon a favourable judgement to be allowed support services, and tied to and limited by his identity as a person with a disability.

This is the power technique Foucault calls "pastoral" power because it derives from the code of ethics and the *modus operandi* of Christianity. It has become secularised and spread out through the whole social body to become a series of powers located in the family, medicine, education, the workplace. In post

July 1st, 1995 New Zealand, the Regional Health Authorities (RHAs) are exercising just this kind of pastoral power. Uniquely not subject to government audit, yet committed by contract to economic efficiency, they have the power, on an individual and a community basis, to give or deny, and to take away, support services. In defending the decision to close the Templeton Centre, home of 450 intellectually disabled residents, the general manager of disability support services for the Southern RHA said "consultation was only one part of the decision-making process. It was not negotiation." She also said "The intellectually disabled had a right to live as normal a life as possible in society. The decision was not about cost cutting. Tenders from providers of care for the intellectually disabled would not be assessed on price." (The Hawkes Bay Herald-Tribune, Tuesday September 19, 1995, p.2)

While the debate raged in the media, with coverage on the Holmes Show giving the illusion of discussion and choice, residents and their families were assured that the decisions had been made, and the closure would take place. The language of rights obscures the effective removal of choice. The difficulty is that while adequate resources will be the key to accessing that right for each of the residents, resourcing was put off limits as a legitimate issue in the discussion by the SRHA's denial that it had anything to do with costs.

The Subject

Foucault suggests that the target nowadays is not to discover what we are, but to "refuse what we are" (Foucault, 1982, p. 216), and to "promote new forms of subjectivity through the refusal of this kind of individuality which has been imposed on us for several centuries" (ibid). I take this refusal to mean the kind of strategy employed by Jenny Morris and Michael Oliver, for example, in their refusal to accept the imposed view of their lives as tragic because of their disabilities, and their determination to embrace and promote and re-define their identities for themselves by telling their own stories (Morris, 1991 and Oliver, 1990) . As Jenny Morris says:

We reject the meanings that the non-disabled world attaches to disability but we do not reject the differences which are such an important part of our identities. [...] By claiming our own definitions of disability we can take pride in our abnormality, our difference.

Foucault argues that power is exercised only over free subjects, which implies that there is no relationship of power without the possibility of escape. Every power relationship implies, at least potentially, a strategy of struggle, and between them there is "a reciprocal appeal, a perpetual linking and a perpetual reversal The consequence of this instability is the ability to decipher the same events and the same transformations either from inside the history of struggle or from the standpoint of the power relationships ... it is precisely the disparities between the two readings which make visible those fundamental phenomena of "domination" which are present in a large number of human societies" (Foucault, 1982, p. 226). One such phenomenon is the 'deficit model' of disability in which, as Keith Ballard argues, "people are labelled as damaged or inadequate and are subsequently viewed almost exclusively in terms of their 'problems' or 'deficits'." (Ballard, 1994, p. 18).

Robyn Munford writes about how "the term 'disability' has been used to provide a 'fixed identity' for people with disabilities" and argues that the "so-called 'fixed identity' of the person with a disability becomes the means by which all other aspects of a person's life are defined" (Munford, 1995, p. 7). Jenny Morris is one of a number of writers on disability who describe this phenomenon "from inside the history of struggle". She writes about the "lack of the voice, of the representation of our subjective reality" (Morris, 1991, p. 8) and explains how "it is non-disabled people's representations of disability which dominate the general culture" (ibid, p. 10). As Robyn Munford points out,

the challenge is to resist the meanings attributed to 'difference' and to show how they are socially constructed in ways which can be used to 'essentialize' the characteristics of the 'identity' of the person with a disability.

(Munford, 1995, p. 9)

Resistance in this sense depends upon understanding, recognising and exposing the 'relations of power' and the ways in which meaning is attributed to the lives of people with disabilities (ibid, p. 10).

Resistance

In a recent attempt to define the characteristics of resistance more precisely than Foucault himself does, Neil Brenner argues that Foucault conceives resistance purely in terms of reactions or counter-functions which are distinguishable from instances of power only by their dysfunctional consequences on the dominant context. Therefore he cannot analyse modes of resistance "in terms of their own specific contents, trajectories, and conditions of existence" (Brenner, 1994, p. 699). By describing power and resistance purely as aggregations of functions, Foucault misses the "projects, strategies and experiences of the human agents which "inhabit" or "bear" them" (ibid, p. 702).

In her account of life in a Japanese factory, it is precisely those projects, strategies and experiences that Dorinne Kondo explores in her argument for a more complex view of power and human agency. In a context in which people "consent, cope and resist at different levels of consciousness at a *single point in time*" (Kondo, 1992, p. 224), she sees a term like 'resistance' as inadequate and suspect. Her view of the agency of people who resist sees them "caught in contradictions, constructing new arrangements of meaning and power as they craft their lives" (ibid, p. 225). Indulging in "nostalgic desire for "authentic resistance" might blind us to the multiple, mobile points of potential resistance moving through any regime of power" (ibid). It is in those moments, those opportunities in people's lives where the personal becomes political, that there is potential for strategic invocation for particular purposes. These are the small everyday acts of resistance to the powerful ideologies. Theresa describes such a moment:

Dr [Ophthalmologist] at first didn't really give us a lot of information - it was big words, big medical words, or a pat on the head and don't worry dear! - until one day I wrote down a whole lot of things and I went and made the appointment and I asked for a good amount of time because I had a lot to ask him. He was very willing to answer, and since then he often - well, he tells me things now anyway. And I've always got the impression that he's often thinking of Carol and what things he could do for her to give her more vision, and thinking of the impact of it on her schoolwork, her education. That often comes through in what he says

to her.

Another example of strategic multiple and local resistance in which the personal becomes political in a person's life, is the response to a new maternal serum screening for Down's syndrome from Bridget Snedden, national co-ordinator of the Down's Association, and mother of Alex:

"People need to know that it's okay to have a child with a disability," she says. "They have to know that there are two sides to the issue. It shouldn't automatically be assumed that they are going to terminate."

She worries, too, that in the long term, families who opt to keep their Down's child will be seen as irresponsible, and that the few Down's people who remain will be seen as abnormal. "I don't want my son to end up being a freak."

Snedden is involved in the education evenings for the Auckland pilot programme. She is also available to talk to women who screen positive, and says that those who have contacted her so far have been reassured to discover that there is life after Down's. And very good life, too, for both parents and child.

"Alex wouldn't be Alex without his Down's syndrome, and I really like that about him. We're really lucky to have him in our family."

(Listener, July 1-7, 1995, p. 29)

I have chosen to reference this text at some length because it is a current, localised, contextualised example of what Dorinne Kondo refers to as the "*multiplicity* of sometimes paradoxical and creative effects" of any action (Kondo, 1992, p. 225). There is, for example the tension between the way the article describes Alex as "like any other boy his age", and the language of difference and specialness used by his mother. What effects does this have on "the stereotypes about intellectual handicap" and the "fear and ignorance about the syndrome" (Listener, July 1-7, 1995, p. 29) that constitute part of the dominant ideology? This is a specific instance of the "dilemma of representation" produced by "the intertwinings of power and identity in the disciplinary production of selves" in particular contexts - "Is it possible to avoid the otherness of exoticism and ineffable strangeness on the one hand, and the cultural imperialism of appropriation - "They are just like us" [...] - on the other?"

(Kondo, 1990, p. 304). Alex's mother, in challenging some assumptions about people with Down's syndrome, is caught up in a complex multi-faceted debate about, for example, what constitutes a 'good life', what is 'normal', what it means to have a 'choice' of whether to 'terminate' or not, and what it is that is being 'terminated'. The words themselves become sites of struggle in the "complicated web of contradictions and ironies which bind us and which we in turn fabricate as we live out our lives" (ibid, p. 225). Mary's story illustrates this struggle:

At their conference last year, which I attended, a panel of people up on the stage just repeatedly throughout the opening day called the two hundred odd folk with disabilities that were there 'handicapped'. And so they asked in General Business whether anybody had anything to say about anything, and because that's something that I feel quite strongly about, I stood up and I didn't say that I had heard them speaking. I just said that I wanted to talk about language, and the use of it, and what I did was, I relayed a situation that Justin had said to me. You know for years I used the word 'handicapped' and then he said to me, I don't like that word ... I don't like you using it. I am not a handicapped person. A handicap is for somebody who plays golf. I have a disability. And those words stuck in my mind, and so since that day I've changed my way of thinking.

Mary went on to describe how at the close of the conference the person at the head of the organization

took absolutely no notice, and every single time where he should have used the word 'disability' he used the word 'handicapped', and it almost seemed to emphasize it, because here was someone asking that he at least think about it - didn't mean a thing! ...

Behind this sort of reaction lie what Jenny Morris refers to as "the hidden assumptions about us which form the bedrock to most of our interactions with the non-disabled world". As she goes on to explain:

It is often difficult for us to identify why someone's behaviour makes us

so angry, or feel undermined. Our anger and insecurity can thus seem unreasonable not just to others but also, sometimes, to ourselves.

(Morris, 1991, p. 18)

It is precisely because these assumptions are hidden and will generally be denied by the non-disabled world, yet nevertheless characterise the daily experience of Jenny Morris and others, including Mary's son Justin, that they need to be made explicit. Jenny Morris does this, explaining how she looked to feminism, "with its central tenet of 'the personal is political' to translate [her] subjective experience into a wider social and economic context" (ibid, p. 4). In order to effect change, as Morris explicitly sets out to do in her book (op.cit) subtitled "Transforming Attitudes to Disability", it is important to name and confront the prejudice: the particular challenge then is to find ways of fighting back which make use of existing possibilities as well as seeking out new political opportunities. Michael Oliver, writing about the politics of "disablement", concludes that change is inevitable, that the wind of change is blowing, and that "the direction that wind takes will depend upon more than just disabled people themselves" (Oliver, 1990, p. 133). This is the kind of thinking that has contributed to the development of a 'politics of difference'.

A Politics of Difference

Identity politics was, as Michelle Lunn points out in her writing, "the organising principle for radical feminist analysis and is an important aspect of the disability pride movement" (Lunn, 1992, p. 3). However, relying upon assumptions of shared identity can mean not only that "those outside the magic circle of lived experience are silenced and excluded" (ibid), but also that opposition to the inequalities of power is defused and fragmented by a gaze which focuses on only one aspect of a person's life and presents it as the 'essence'. In her paper, Michelle Lunn argues for the strategic use of essentialism and specifically for the acknowledgment of "bodily differences and lived realities" (ibid, p. 5). In her writing about the body as a site of struggle, Robyn Munford uses Foucault's concept of the 'technologies of power' as a framework for understanding how "the 'bodies' of people with disabilities are continually intruded upon" by professionals who observe, examine, assess, classify and rank them "in order to determine their position in society" (Munford, 1995, p. 10). An example, from my own research, of certain

'technologies of power' being used to try to dispose of 'difference' for the purpose of classification and ranking comes from Mary's story:

So life there has not been like what we thought it was going to be, because another issue that arose at the school was that a physiotherapist turned up at school. It was something that obviously the school had arranged, because nobody else did. She turned up from Wellington, and went into the classroom and she must have had a walking frame because Justin hasn't got one there, unless he was using someone else's. But he had a really unhappy session with her, and actually spoke about it afterward, so that's how unhappy he was, but she tried to make him walk. She went in there, without reading any of his case notes, without knowing anything of his background, and said to him, when he said, I can't walk, she said, yes you can, because Matthew can. This is another student in the school. This has been one of Justin's problems there, that he's being compared to someone who has cerebral palsy, but who is actually able to 'weight bear'.

What this woman failed to realize is that Justin's not able to 'weight bear', and he tried to tell her on this particular day that he was not able to stand, that he can stand on the walker, but it's using the top part of his arms to support himself. So he actually wasn't able to do it, and she growled him and told him that he ought to be able to do it, because, you know, look, Matthew can do it, so you should be able to too. And that for Justin is really undermining. He really feels that, if he says he can't do it and then someone says yes, you can, especially someone who really doesn't even know him, who has never read anything about him ... I found out later on that she actually has not read any of his background notes ... she would have realised that the only reason that he stands on a walking frame is for postural drainage; it's nothing to do with walking, it's just to get his body in an upright position. He can do that for short periods at a time; he gets out, or you assist him out of his wheelchair, he puts his arms in the gutters of the standing frame ... but it's only for postural drainage. It's nothing to do with walking.

This story tells of the effect of attempts to impose a certain identity and to

define what a person's body can and cannot do (Munford, 1995, p. 14). For Justin, the effect was to 'undermine' - literally to take away the ground from under his feet. As Robyn Munford argues, "the 'body' is both a reflection of social processes and also a site of struggle", and the challenge, in developing political strategies for resistance, is not only to make these 'social processes' transparent, but also to make explicit the multiple 'identities' of people with disabilities and show that they are an integral part of mainstream society (ibid).

In her writing Jana Sawicki also builds on Michel Foucault's ideas to take feminist theory a step further towards a politics of difference in which "difference can be a resource insofar as it enables us to multiply the sources of resistance to particular forms of domination and to discover distortions in our understandings of each other and the world." (Sawicki, 1991, p. 28).

For Sawicki, Foucault's emphasis on normalisation as opposed to violence represents a major explanatory advantage of the disciplinary model of power. If patriarchal power operated primarily through violence, objectification and repression, women would not subject themselves to it willingly. "On the other hand, if it also operates by inciting desire, attaching individuals to specific identities and addressing real needs, then it is easier to understand how it has been so effective at getting a grip on us" (ibid, p. 85). She acknowledges the inability of radical feminist discourses to explain how the interests of some women appear to lie with the system of male domination, and how some men, "even physicians", are potential allies in struggles against domination. She sees significant political advantages in applying Foucault's disciplinary model of power to a feminist critique of the new reproductive technologies. Using Foucault's model of the social field as a field of struggle, consisting of multiple centres of power confronting multiple centres of resistance, we can go on to look for the diverse relationships that we occupy in relation to other technologies, and for the many intersecting subject positions which constitute the social field.

One technology that has affected the lives of a group of people in a dramatic way is the Australian Human Pituitary Hormone Programme (1967 - 1985). People who received human pituitary hormones for infertility or short stature have been advised that they are now at risk of contracting the fatal

neurological disease Creutzfeldt-Jakob Disease. The private experiences of these people need to be linked to "the context of multiple discourses within the public sphere" (Little, 1995, p. 3). For example, there is conflict between the counselling service and the funding body, the Pituitary Hormone Task Force, which "wants us [counsellors] to control clients and keep them calm and quiet" (ibid, p. 6). Being at risk of a disease is, says Little, "an emerging discourse within discourses of health that expands the range of subjects for management and administration" (ibid, p. 8). Political action in this situation has meant taking the private pain of people who have received treatment for infertility or short stature into the public arena by means of a variety of strategies, including; counsellors supporting clients' protests at the way they have been treated rather than regarding it as an individual problem to be treated by therapy; the people themselves and their supporters asking public questions about how and why this was allowed to happen, and legal action against those who authorized the programme but failed to monitor its effects. The relevance of this to my present project is that it emphasises the desperate lengths our society requires people to go to in order to conform to its normalising standards, in this case motherhood and a stature that is not too short. It also emphasises the extraordinary power that the medical system has to initiate and maintain treatments, even after they are known to be harmful. It shows too the kinds of ambiguities and contradictions we face in relation to institutions, systems and individuals with the power to both help and harm us. The nature of this power, and the political strategy to counter it, is described by Oliver Sacks in his writing about his own experiences as a patient:

... it was often I myself who prohibited, or inhibited, free speech and action - that part of myself which was now the institution internalised. And now, for the first time finding myself with other patients, I would see this in them where I failed to see it in myself; and I would see that something or someone was needed to break the barrier of prohibition or inhibition - whether it was someone 'giving permission', or the sudden insight that no 'permission' was required.

(Sacks, 1984, pp 123-124)

In Mary's story about Justin and the physiotherapist, resistance at the time was precluded by the power of the institution per se, and by the kind of

'internalisation' of that power that Sacks refers to. However, as Mary explains, the 'barrier of prohibition' was eventually broken:

So he's had a huge issue with this physio from Wellington. So you know, there's sorts of things like that that have cropped up at school that he hasn't had to deal with before. What this does, is that it undermines how he thinks about himself. And so he told [RNZFB social worker] first, and we had a meeting, [RNZFB social worker], myself, [social worker] from the CCS and Justin's physio from the hospital, and [RNZFB social worker] brought it up there, and so he resolved to write a letter to this woman, and tell her really that she had no right to speak to Justin like that. On the day she told him that he had an attitude problem ... the only reason he couldn't do these things was because he had an attitude problem. So he told [RNZFB social worker] about it, and [he] wrote and sent me a copy of the letter, and it was a good letter!

In the face of 'technologies of power' and 'relations of power' which are undermining of the autonomy of people with disabilities, it is alliances and coalitions such as Mary describes which offer hope for a 'politics of difference'.

Discourse and Practice

I use the term 'discourse' here in Fairclough's sense, to refer to the way in which language and linguistic practices influence how people think and what they do (Fairclough, 1992). By examining how discourse and language contribute to the formation of the social space in which we live, and its possibilities, we can open up for consideration a range of subject positions that arise from different discourses, and the ways in which individuals may experience "multiple and contradictory subjectivities" (Loveridge, 1992, p. 44). In the following example Sarah describes the conflicting emotions arising from her subjectivities as a mother, and as a patient:

I had one cuddle of him in the Intensive Care, and I felt totally uncomfortable about it the whole time. I was really scared. I didn't want to ... there were just tubes out of him everywhere. you know, monitor lines or whatever you call them, and I just ... they put me in a lazyboy and they said oh you know ... I felt I had to do it, but I didn't want to. I

was just holding him and I just felt fearful for him the whole time. I just wanted him back on that bed all attached up nicely. I didn't get any comfort from it at all, or I felt I wasn't giving him any in a way too. That was in Intensive Care. That was just the once.

Loveridge argues that to explore the ways in which meanings become embodied in our experiences and give rise to particular subject positions we need to return to the events and experiences of our everyday life, to explore the interplay between lived experience and discourse, and what people then *make of discourse*" (ibid, p. 45). An example of this is the interplay in the *Listener* article between the lived experience of Alex's mother, the credentials, training and experiences of the writer of the article, a range of medical perspectives and opinions, the law, the health and education systems, the economy, the geographical context (the maternal serum screening test is available only through laboratories in Wellington and Auckland), and the discourse surrounding disability and human rights.

During my research interview with Violet, I was continually made aware of the rich 'interplay' between discourse and practice. The whole interview highlights the impact of her previous experiences as a mother on her work as an early intervention teacher, and the cumulative effect of her own learning experiences and the education 'discourse' on her choices for her son. The following story is one of many examples:

I guess in the IEP ... I think it needs to be an empowering thing, and I think that needs to be brought up a bit more in the meetings themselves for parents. There are a lot of parents that are really, like I say, they're really on to it, but there are also a lot of parents who say, like myself in the beginning, you know it's not until you go away with the IEP that you sort of think hmmm, yeah but is that ... ? ... you know, how is that going to be? ... and, I don't quite understand that ... and things like that. And like I say it wasn't until I actually got more educated and things that I actually saw how you learnt too. Because you don't really have an understanding about how you really learn, and until I actually learnt and did papers on child development, that I actually got to see how we actually learn, and I often viewed the IEP as ... at times ... being a total

waste of blinkin' time - myself personally. And also some of the people, parents that I actually worked with. I like the idea of being set small goals for short periods of time, because then that gave you - you know it was more ... what would you say? I think the short term goals, and the shorter IEPs were a lot better, because then you had something to work ... you know if you say something like a year down the track, or six months ahead, that's too far ... like, you know, if you say in three weeks or six weeks' time, if this hasn't happened, and we feel it should, review it, and like, set small steps, like he needs to be doing this and this and this. And until that's happened, well, you know you need to **change** the steps, not necessarily change the goal, but change the steps to get to that goal. And I think the more of that type of IEP, for some of the parents I worked with as well, that seemed to be the better one. I know for teachers it was a real hassle, you know, and then they saw that the pressure was on to achieve it, yeah, and that meant more input from them and things like that, and for some teachers, not all, it was like, well, we know that they're not going to get to that point, within that time, and yet the parents, they could see that it made just a little step.

I guess that's the hardest thing about all of it in their education, is that a lot of children, you know it's only a small progress that they make, which for them is **large**, but for us who are working with them, and as a parent, a lot of small steps you don't really notice. But you **have** to focus on them, because that's the only way they're going to progress, through the small steps. There were some of the IEPs that I have seen from health services in the old days - used to be like six month - this big fat paperback. I don't know, it just took too long to get through, and when you've got a thick piece of paper - well, you just didn't bother, you know, just sort of went oh yep, yep, because I said, oh it's just a whole lot of stuff just written down. Say if you had one piece of paper, with the small steps, then you've got less to have to look at. I mean, like I said, as I got more educated it didn't seem to be a problem, but in the beginning it was. It was like sh..! ... and I mean a lot of the things, and even at Homai it used to be the same thing. I used to come back and just go aach! and then like when I felt up to it I would sort of get it out and read a page at a time and sort of try and take in what they were trying to say. So I quite

liked it when I got to be one of the staff, got to work with other parents personally, and I found that the one piece of paper was far better, because as soon as it started to go like this [indicates thick volume of paper] it sort of put them off. And so yes, the one sheet seemed to be ... in the beginning, until they actually got more into the process of the IEPs and once they realised that they weren't paranoid about that piece of paper, they got confidence and ...

In the educational discourse which Violet describes in this story, the language used in the meeting and in the report is part of the 'relations of power' which work in this case to mystify, intimidate and silence the parents, and in Violet's analysis, to provide some sort of justification and absolving of responsibility for the professionals.

Language and Power

Another of those 'technologies of power' which are hidden by the rhetoric is the way in which language can be used to mask the political interests of servicers. An example of this is the use of the word 'care', which John McKnight calls "a potent political symbol" and it is easy to find examples like 'careworker', 'caregiver' and 'Medicare' or 'educare' in which the symbolic link between care and love works to obscure the political and economic issues of service behind a "mask of love" (McKnight, 1977, p. 73). An example of the potential of language to mystify and obscure is the use of the term "strategic over-servicing" by auditors KPMG Peat Marwick to describe the [doctors'] practice of falsifying records by inventing visits to help a patient qualify for the high-use health card (*The Dominion*, September 13, 1993, p. 8).

In the article already referred to about screening for Down's syndrome, we are told that as a result of "more thorough screening programmes to detect Down's syndrome fetuses, healthy fetuses will also be lost" (*Listener* July 1-7, 1995, p. 28). The language masks the professional agency in this image, as it masks the personal characteristics obscured by the terms "Down's syndrome fetuses" and "healthy fetuses".

McKnight wrote in 1977 about how the conversion of service to business in modern society is reflected in the language: educational "products", health

"consumers" and a legal "industry" (McKnight, 1977, p. 69). There is an increasing focus today on the role of language in the construction of knowledge and the production, maintenance and change of social relations of power. This has been called the "linguistic turn" in the social sciences, which focuses less on what is true, and more on how particular discourses produce "truth effects" (Lather, 1992, p. 96). Consider, for example, the following excerpt from *Health Matters* July 1995, news from the Minister of Health:

Sickness benefit and invalid benefit are higher payments than the unemployment benefit and discriminate on the basis of disability.

(Shiple, 1995, p. 2)

Add this to the statement on the same page that:

The Government is certain that New Zealanders want a welfare state that responds to those in need within the resources that are available.

and the Government's admission that it intends to review sickness and invalid benefits with the aim of reducing expenditure by \$8.5 million in 1995-6 and more than \$20 million thereafter (*Hawkes Bay Herald-Tribune*, Friday, July 14, 1995, p. 2). The "truth effects" of this information on people with disabilities are likely to include fear that the benefit may indeed become in-valid, and among the "truth effects" on the health professionals required to administer the review, is likely to be an imperative to cancel eligibility for a certain percentage of benefits.

The power of metaphor to shape reality is part of Foucault's "microphysics of power", and is well illustrated by what is currently happening in the business world. A newspaper article describes how "successful companies across the world are ditching military hierarchies and language for values and images from the performing arts", and goes on to explain that "Adopting the theatre-circus metaphor means staff are stars, recruitment and selection become auditioning and casting, and strategic planning is replaced with scenario planning" (*The Dominion*, September 1, 1993, p. 18). With the re-structuring of the New Zealand health and education systems, and the increasing dependence of the voluntary service systems on contracting to the RHAs, this

kind of "cultural and social engineering" (Fairclough, 1992, p. 239) will undoubtedly spread.

Fairclough acknowledges that there is a growing risk of discourse analysts being "integrated into bureaucratic and managerial agendas". However, he also asserts that technologies of discourse, like other technologies, "open up possibilities in various directions" and could also be used "in pursuit of change from below". He argues, for example, for "a 'critical language awareness' element in the language education of all school children, which would provide them with the knowledge to initiate change in their own discourse practices, and the discourse practices of their community". Through "consciousness", he suggests, people "can become more aware of constraints upon their own practice, and of the possibilities, risks and costs of individually or collectively challenging those constraints to engage in an 'emancipatory' language practice". It also involves awareness of language variety; for example, a historical awareness of "hegemonic processes of language standardization and the interests which lie behind them", and sees the development of language awareness and language practice as "mutually reinforcing" (Fairclough, 1992, p. 240). The exercise of power in modern society is increasingly achieved through ideology, and especially through "the ideological workings of language" (Fairclough, 1989, p. 2).

A statement made in the context of the proposed closure of the Templeton Centre, an institutional setting for people with intellectual disabilities, is worth analysing to see just how this exercise of power is achieved. The SRHA general manager of disability support services was reported in the press as saying that: "The intellectually disabled had a right to live as normal a life as possible in society" (*The Hawkes Bay Herald-Tribune*, Tuesday, September 19, 1995, p. 2). This statement appeals to the discourse on human rights and disability rights and to the philosophy of normalisation. By privileging the 'rights' discourse it tends to obscure several other possible sites of contestation: for example, it could be suggested that 'the intellectually disabled' had a right to be referred to as "people who have intellectual disabilities". There is a major site of contestation in the word 'normal', about what is normal and for whom. There could and should be major debates, on physical, economic, and philosophical grounds for example, about what is

'possible', and for whom, in this context. Finally the phrase "in society" carries within it certain assumptions; for example, about what or who constitutes 'society', and about whether 'society' has the capacity, the will, or the resources to care. It is unclear, for example, whether 'in society' means in the families who are saying they can not cope, have never been able to cope, and will not be able to cope in the future without resources and support structures.

Discourse Technologies

Fairclough sees interviewing, teaching, counselling and advertising as examples of "discourse technologies" in Foucault's sense of technologies of power (Fairclough, 1992, p. 215). He shows how they establish a close connection between knowledge about language and discourse, and power, and how they can be used to bring about discursive change through conscious design. Discursive practices can have different values in different strategies - what Foucault calls "the tactical polyvalence of discourses" (ibid, p. 221). They can be appropriated, resisted and rejected, or accommodated and marginalized. For example, Dina Bowman and Melanie Virtue, in their book about mothers of children with disabilities, comment:

Philosophical buzz words have become bureaucratic jargon. The developments in policy have not been matched with the necessary funds or structural change. At worst, 'community care' can mean care by women with little or no support; at worst 'integration' can mean attending the local school with little or no support, often in a hostile environment; at worst 'normalisation' can mean having one's disability and special needs ignored; at worst de-institutionalisation can mean moving out of institutions to live without support and ending up homeless. ... The language used to espouse the philosophies of the disability rights movement has been adopted by economic rationalists. At a time of recession and decreasing government expenditure, women and their children with disabilities are increasingly caught in the gap between the philosophical rhetoric and the resource-starved reality.

(Bowman and Virtue, 1993, p. 3)

The increasing reliance on control through consent accounts for the tendency in contemporary discourse towards what Fairclough calls "simulated

egalitarianism" . A good example of this is found on the cover of *The Best of Health 2*: the sub-title of this booklet is *How We Decide on the Health and Disability Services We Value Most* (my underlining). Similarly a booklet published in 1990 by the Ministry of Education was called *Introducing the Education Family*. Unfortunately, however, it was not long before one member of the family, the Parent Advocacy Council, was found to be dispensable and disappeared without trace. Fairclough writes of "integrating people into apparatuses of control which they come to feel themselves to be a part of (e.g. as consumers or as owners of shares in the 'share-owning democracy')" (Fairclough, 1989, p. 36). Using the metaphor of the family may work on one level to consolidate consent by reassuring people that they are part of a shared enterprise and that they will be looked after. Removing part of the "family" arbitrarily could work to undermine that consent and compliance and encourage resistance.

Writing about the construction of the subjectivity of students who are integrated into the regular school system, Genee Marks observes:

Individuals may resist or contest the way they are constructed by policy documents and perspectives, and actively choose to construct their own subjectivity as other than compliant and conservative. Adopting such a position does not necessarily guarantee emancipation or empowerment however, but rather involves individuals in constant negotiation and renegotiation regarding the ways they are constructed.

(Marks, 1994, p. 75)

Structures of Oppression

It is not only language and discourse that shape or 'construct' people's lives, but structural elements as well. It is the 'practice', the 'previous lived experience' that Brian Fay addresses in his attempt to understand the oppressive features of society. Fay's assertion is that oppression is very much a physical matter which "leaves its traces not just in people's minds, but in their muscles and skeletons as well" (Fay, 1987, p. 146). He illustrates his point by showing how schools are physical structures as well as social institutions and the learning that goes on in them involves the physical bodies of students and teachers as much as their minds. "Schools, like all places in which novices

are taught to be members of a particular group, perform their function of shaping their particular pupils into acceptable identities by directly training their bodies" (ibid, p. 148).

Michael Oliver, writing about disability from his own experience, discusses the effects on the structuring of disabled identities of "crucial significant others in the lives of disabled people ... those vast array of professionals who either write things about or do things to disabled people" (Oliver, 1990, p. 62). Jenny Morris writes from her own experience of disability about how the assumption that the lives of disabled people are intolerable and costly dominates the development of genetic screening, the debates on abortion and euthanasia, and the issue of "allowing" disabled babies to die (Morris, 1991, p. 62).

In her story Violet told, with great sadness, about how Shaun has not learnt to communicate effectively, and she went on to talk about his lack of access to orientation and mobility services:

I often felt that he could have learnt to use a stick earlier ... you know, we just couldn't do that because he might have hit somebody with it [laughter]. So all of those opportunities, moments - like I remember asking [orientation and mobility instructor] why is it you don't teach young children to use a cane? Because I remember reading an article from an overseas magazine, because we can get magazines from the other blind institutions over there in America - we get in contact with other parents - and there was just an article I read about a young mother who was insisting that her child of three or four, that they teach her to use a cane, because you know why not teach them that young, and all the hassles and the problems that she had. And [orientation and mobility instructor] just sort of explained to me that the reasons they don't like to teach children that young who are totally blind to use a stick is so that they will help with that homing in, how to home in with the other senses like distancing and all of those type of things, without the stick being there. And this woman actually, her husband made a stick for her daughter, because she felt that children at that age are usually becoming quite independent, and why should it be any different for blind children? Why should she have to rely on people to guide her

when she could actually do it herself - that was her argument and I often wondered about that with Shaun as well. I've seen things sort of set up with rails, and we've tried to incorporate that here, but it was very difficult. It meant sticking to one route how to get about ...

Violet has experience of, and understands very well, the 'structures of oppression' which operate to control people's lives, either denying or granting those 'moments' of opportunity.

Similarly, Martin Sullivan, an academic and writer who is also paraplegic, writes of his paraplegic research subjects:

Almost all said that their rehabilitation in the Otago Spinal Unit consisted solely on body work: physiotherapy, etc. They were sure the medical authorities were trying to turn them into particular subjects through this extreme disciplining of the body...

(Sullivan, 1993, p. 345)

This 'disciplining of the body' is what Justin experienced in the physiotherapist's attempts to make him walk, and also what Shaun experienced in the denial of his opportunity for independent mobility. These experiences are vastly different, but both represent attempts to turn people into 'particular subjects' through professional 'disciplining'. I turn now to a discussion of the way in which professional opinions and 'expertise' dominate the lives of people with disabilities.

Disabling Professions

While professionals generally think of themselves, and are thought of by others, as enabling, yet the professional dominance of the mid-twentieth century has been characterized by Ivan Illich as "The Age of Disabling Professions" (Illich, 1977, p. 11). Illich describes the process which has taken place so that "... it is no longer the individual professional who imputes a "need" to the individual client, but a corporate agency that imputes to entire classes of people their needs, and claims the mandate to test the whole population in order to identify all those who belong to the group of potential patients" (ibid, p. 18). So it is that the discussion document entitled *Support for*

Independence for People with Disabilities: A New Deal and published jointly by the Ministers of Welfare and Health in 1992, could plan to identify who is disabled and who is not, and consequently who should receive services and who should not. As Robyn Munford points out in her chapter on 'Caregiving' in *Disability, Family, Whanau and Society*, such a plan requires a standard or 'norm' for the measurement of disability (Munford, 1994, pp 276-277). Similarly the latest special education recommendations suggest indexing students on a scale of one to five according to their support needs. The terminology is new - a Needs Assessment Agreement (NAA) replaces a Section 9 Agreement, and Supplementary Resource Units (SRUs) replace discretionary resources, but the context remains the same: students will still have to "qualify" for scarce resources, and qualification will still be by professional assessment (summary of Mitchell and Ryba report in *The New Zealand Education Gazette*, 15 March, 1995).

Professional dominance extends its influence to include pedagogical and social 'treatments', and combinations of these so that, for example, a child at school can be the subject of, and subjected to, management by what Illich calls a "pedocratic" (Illich, 1977, p. 25) team made up of specialists such as the speech therapist, child psychologist, social worker, school counsellor, and one or more teachers. Rod Wills describes the power of such a team, and its effects upon his child and his family:

This situation, of parents knowing what children and families needed, yet being constantly confronted by opposition from an inflexible and 'arrogant' system, seemed to find its way into the relationships we had with many professionals. For example, the therapist who used to visit us would listen to us and be supportive, answer questions and agree with our views. But, when decisions had to be made, The Team had to be consulted. They clearly knew what was best for our child, better than we ever would. We were never part of The Team.

(Wills, 1994, p. 256)

Writing in 1977, Illich predicted that the days of professional dominance were numbered, that people would begin to challenge it more and more strongly by the questions they asked and by the style of life they consciously created. It

seems to me writing in the mid 1990s, that the dominance of the professional ethos, Foucault's pastoral power, has been somewhat shaken, both by the rise of managerialism on the one hand, and by the kinds of challenges and questions that Illich predicted. For example, a major and very effective challenge to medical omniscience and omnipotence was mounted by women journalists Sandra Coney and Phillida Bunkle with regard to the so-called 'unfortunate experiment' at National Women's Hospital, where women and female children, without their knowledge or consent, became part of a medical experiment which put their health and their lives at risk through experimental non-intervention (Coney, 1988).

More modest, but nevertheless effective challenges to professional control were carried out by some of the parents in my research. For example, when Theresa asked for an appointment long enough for the ophthalmologist to answer her written list of questions, the result was not only immediate compliance with her request, but a marked and sustained improvement in communication between the specialist and the family. Another example is the battle Mary fought in support of her son's decision to live independently, against the judgement of the G.P. that that would be impossible because Justin needed twenty-four hour care. The battle was long and hard, but it was won by Justin, who has succeeded in his wish to choose his own lifestyle. Another, much more structured and overtly powerful challenge to professional dominance, is the recent rise of managerialism, particularly in the health and education sectors.

Managerialism

I argue that it is important to understand this phenomenon because it has the potential to radically destabilise the professional dominance of the mid to late twentieth century. By this I mean that professionals are already being made to account to managers who are not necessarily, as they have hitherto been, professionals themselves. Professionals are also more accountable to their clients or patients than they have ever been, and this dual accountability has had the effect of eroding some professional power, and, in some cases, of aligning professionals more closely with the consumers of their services.

An example of the rise of managerialism and the current struggle between

managers on one hand and professionals and their patients/clients on the other was the claim by Children's Hospital Trust chairman Dr Paul White that children who should be treated at the Starship Hospital were being cared for at other hospitals because the Crown Health Enterprises did not want to lose the dollars the children represented in health funding. Consultants Coopers and Lybrand were investigating the best use for the vacant sixth floor of the Starship and Dr White was concerned that "accountants might decide the future of the country's only centre of excellence for children" (*Sunday Star-Times*, August 21, 1994, p. A5).

Schools, too, are currently contested sites: in a 1989 analysis of *Tomorrow's Schools* Roy Nash predicted that we were probably entering "a period of intense struggle for the control of education and schooling" (Nash, 1989, p. 113). He suggested that while deschoolers like Illich, and social and cultural reproduction theorists such as Bourdieu may have "undermined liberal belief in the power of schooling as an agent of social and economic transformation", yet it was right-wing advocacy of market power and the concerns and concepts of the right which clearly now "dominate the discourse of contemporary educational politics" (ibid, p. 114).

There is clearly a struggle going on between the competing discourses of managerialism, professionalism, and what John McKnight calls "the human necessity to act rather than be acted upon; to be citizen rather than client" (McKnight, 1977, p. 78). The re-creation of children and parents as consumers of educational services, and of patients as consumers of health services assumes that citizens are enabled because they have become consumers, and consumers have the power to choose. The rhetoric is that of choice, flexibility, responsiveness to the community. The following example is taken from *The Best of Health 2* :

Traditionally decisions about who should get what services have been left to individual professionals in consultation with their clients or patients. Or they have been made on an *ad hoc* basis by politicians and health board administrators. There has not been a lot of general public involvement.

(NACCHDSS, 1993, p. 4)

What this does **not** say is that the old health board administrators made their decisions according to the instructions of the board members, who included citizens elected by the public to represent public interests, or that the new system of CHEs and RHAs includes no such representation. The old system may have been "a patchwork of services" (ibid, p. 13), but the new one looks set to become monolithic, not only in its capture by managers of professionals, but in its assumptions about the homogeneous nature of the community's values and priorities and about the improved options that the environment of choice will provide for informed consumers. The paradox lies in the contradiction between the illusion that choice is available as a right, and the actual situation where opportunities to exercise choice are being withdrawn.

Education is another area where the rhetoric promises an environment of choice, while the reality produces stories of choices that are limited by lack of resources and by exclusionary attitudes and practices. I introduce the school as a site of analysis because experiences of schools and schooling are so important in the lives of children and their parents.

Experiences of School

Education is a key theme in this study because education is seen in our society as so important that it should be both compulsory and available to everyone, and because so many of the struggles of children with disabilities and their families revolve around schooling. The critical question of what happens in schools is a major focus in the writing of Henry Giroux. In his development of a 'pedagogy for the opposition', Giroux sees schools as social sites, acknowledging the importance of the hidden curriculum, the one that is transmitted tacitly through the social relations and routines that characterize daily school experience (Giroux, 1983). He sees as crucial the task of analysing how the hidden curriculum functions, not simply as a vehicle of socialisation, but also as an agency of social control which functions to provide differential forms of schooling to different classes and groups of students. This view sees schools as sites of both domination and contestation, and power as a force which works both on people and through them. For Giroux schools represent "contested terrains in the formation of subjectivities, but ... the terrain is heavily weighted in favour of the dominant culture" (ibid, p. 66),

and there are economic and political constraints as well, so that while the “gaps and tensions in schools need to be used and unravelled to extend their radical potential” there are clearly conditions “whether they stem from an authoritarian principal, a homogeneous right-wing community, a conservative school board or an unreceptive faculty” which it may be extraordinarily difficult to resist (ibid).

Giroux introduces “a critical notion of ideology” which “contains both a positive and a negative moment, each of which is determined, in part, by the degree to which it promotes or distorts reflexive thought and action” (ibid, p. 66). Ideology becomes a critical tool when it is used “to interrogate the relationship between the dominant school culture and the contradictory, lived experiences that mediate the texture of school life” (ibid, p. 67). This becomes particularly important for the students who experience every day the pain of humiliation and powerlessness because their own “lived experiences and sedimented histories” (ibid, p. 68) are at odds with the dominant school culture, as is the case for Carol in the following example:

She missed out a lot of stuff because she was being taken out of the classroom to learn the typing, and she missed out on being with her friends, doing the things that they did, and also on the instructions she was to get, for the homework or whatever. So she always felt she was on the back foot, and it took a long time to sort of suss that out.

Justin experienced the pain of humiliation and powerlessness on a daily basis:

stuff like ... he would come home from school at Intermediate and say that, you know, the teachers made him sit in the corner because he couldn't read, but, don't say anything, Mum, or I'll get into further trouble ... don't you dare go down and say anything! I'll be right. And so this is what was happening because he couldn't read. He was just left to do other stuff, or he'd be left to play with blocks or, you know, this sort of thing with a jigsaw rather than get on with the reading.

For disabled students this occurs, as Michael Oliver points out “because

teachers, like other professionals, also hold to this (personal tragedy) view of disability, curriculum materials portray disabled people (if they appear at all) as pathetic victims or arch-villains and their education takes place in a context in which any understanding of the history and politics of disability is absent" (Oliver, 1990, p. 93). This means that classroom experiences need to be structured to give students "opportunities not only to affirm their own experiences but also to examine critically the ways in which they have become part of the system of social reproduction" (Giroux, 1983, p. 68). Building on Freirean notions of resistance and social change, Giroux suggests that "the concept of resistance ... must become an analytical construct and mode of inquiry that contains a moment of critique and ... an interest in radical consciousness-raising and collective critical action" (ibid, p. 110).

In his approach to literacy, Freire "moves from critique to cultural production to social action by linking (the) notions of culture and power within the context of a radically informed pedagogy" (ibid, p. 226). Freire's central notion of "conscientisation" refers to "the interface of critical reflection and action as two separate but interconnected moments in the process of individual and collective emancipation" (ibid, p. 227). What is at stake here, as Giroux points out, is "the goal of giving ... students and adults the tools they need to reclaim their own lives, histories and voices" (ibid).

A 'Communicative Democracy'

Radical pedagogy needs a discourse "that illuminates the ideological and material conditions necessary to promote critical modes of schooling and alternative modes of education for the working class and other groups that bear the brunt of political and economic oppression" (ibid, p. 235). Giroux sees the starting point for such a discourse as centring around the notion of the public sphere. Substantive democracy, in his analysis, has largely been subsumed by "formal democracy" in contemporary society and collective discussions have given way to publicity campaigns, advertisements and "other forms of legitimation" (ibid, p. 237). In 1995, for example, in New Zealand we have seen a plethora of documents issued by the Ministry of Health expressly to inform and to reassure us about the health reforms and how they will improve our lives, while there is no forum for any effective, local, democratic discussion, as we have seen in the case of the Templeton Centre affair.

A theory of democratic discussion useful in the current context is proposed by Iris Young, who suggests that in a "communicative democracy" story-telling can complement arguments because narrative fosters understanding across differences without making those who are different symmetrical:

Since everyone has stories to tell, with different styles and meanings, because each can tell his or her story with equal authority, the stories have equal communicative value. [...] Such a theory of democracy needs a broad and plural conception of communication that includes both the expression and extension of shared understandings, where they exist, and the offering and acknowledgement of unshared meanings.

(Wilson and Yeatman, 1995, p.149)

A research methodology such as the present one, which uses a narrative approach, links in with this idea of democracy in the sense that it aims to enable people's stories to be told, and heard, in order that better services and better ways of working with those people can be developed.

The Struggle for Change

In such a 'communicative democracy' a radical pedagogy, then, must be viewed as having "an important but limited role in the struggle for oppressed groups to reclaim the ideological and material conditions for organizing their own experiences" (Giroux, 1983, p. 237)) and schools will have to be seen as one of a range of significant sites for revealing oppressive ideologies and reconstructing emancipatory relations. For example, members of those groups will have to become actively involved in the shaping of school policies and experiences, so that rather than being the objects of school policies, they become the subjects of the policy making process. The point here is to link the personal and the political in order to understand how power is "reproduced, mediated and resisted at the level of daily existence" (ibid, p. 240). The interface between theory and practice is not at the point where "radicals" provide prescriptions and "parents, workers and the oppressed" receive and utilize them, but it is at the point where these various groups come together and "raise the fundamental question of how they may enlighten each other, and how through such an exchange (of theoretical positions) a mode of

practice might emerge in which all groups may benefit" (ibid).

This kind of resistance at the level of daily existence is familiar to many parents, as Mary explains:

I do belong to lots of committees, and it's for that reason, that you think you might gain something which is going to help them in the long run. There's the sharing ... if you're with parents of children who have a similar disability you're sharing the information and when Justin was younger I belonged to committees of children who were older, but even though they didn't have the same sorts of disabilities they'd tell the younger parents about what was happening at that time, and you thought, Oh God, that'll never happen to me, it's five years away. Well, five years was like an eternity away when he was young, but it comes so quickly that you're soon in that position. But what you can do is then share your experiences with younger parents coming up. It's that sharing of information. It's finding out about things from parents that maybe you should have learnt from government departments and from doctors and from specialists that you've never had the opportunity to learn because nobody's told you. So you do find out a lot of information about organisations from other parents.

Radical pedagogy, whether within or outside of schools, involves linking critique with social action, and therefore involves taking risks. As Giroux points out, commitment to a radical transformation of the existing society always places an individual or a group at risk of loss - of a job, security, or friends. These are the kinds of difficulties Kate Soper has in mind when she notes that we "frequently confront situations where an acute sense of responsibility for self-change goes together with a no less acute understanding of why this cannot be viewed simply in terms of an existential project, and why it would be too purely voluntaristic to suppose that it could" (Soper, 1991, p. 127).

Parents are also only too familiar with the kinds of risks Soper is talking about, in terms of their relationships with educational professionals for example, and what they often feel they risk losing, apart from status or 'face', is security for their child. Mary explains:

... if I ever was going to kick up a fuss about anything, he would immediately say, no I don't want you to. I mean he'd tell me what his problems were, and pass them on to me, but at the end of the day he didn't want me to say anything in case he got into trouble as a result

In an attempt to avoid the paralysing equivocation which our postmodern times can produce, Soper argues for the possibilities of a "synthetic approach, one which combines alertness to the deficiencies and crudeness of much traditional value-discourse with alertness to the self-defeating quality of the attempt to avoid all principled positions in theory" (ibid, p. 128). Radical pedagogy is such an approach - according to Giroux, it needs to be informed by "a passionate faith in the necessity of struggling to create a better world ... a vision ... that celebrates not what is but what could be" (Giroux, 1983, p. 242).

The parents I talked to demonstrated eloquently and specifically their faith in a vision of what could be. Those visions included ideas about parents getting together to support each other, 'education' and 'health' getting together to make services more coherent and accessible for families, better resourcing for schools in the form of teachers and teacher aides who are trained to work with children with disabilities, social workers who are trained to work alongside families with children with disabilities. These are visions about services

that listen to parents and that will advocate for children. Services that will help parents stop the prejudice and rejection that children with disabilities are subjected to in education, health and welfare policy and practice. Services that will assert the value of all people.

(Wills, 1994, p. 263)

It is not possible to gather up such a rich array of the visions individual parents may have for their children and themselves and reduce them to one unifying "vision". However, some words of Mel Bogard, mother of Sallie, convey something of the attitude that informs many:

My philosophy, endlessly in process, reflects more trust and confidence in the universe than the anxious urgent fix-it fury of those difficult early

years. I hope. I hope. I hope.

(Bogard, 1994, p. 69)

It is in the linking of the notion of cultural production with the processes of critical reflection and social action, that the theories of Freire, Giroux and Fairclough meet. Freire puts it like this: "Within the word we find two dimensions, reflection and action, in such radical interaction that if one is sacrificed - even in part - the other immediately suffers. There is no true word that is not at the same time a praxis. Thus, to speak a true word is to transform the world" (Freire, 1972, p. 60).

In this chapter I have taken Foucault's ideas about power and Dorinne Kondo's concepts of identity and put them alongside a range of theories about discourse and language to construct a framework within which we can begin to understand why things are the way they are, and to construct a vision of how they could be for children with disabilities and their families.

'Speaking a true word' and thereby 'transforming the world' (ibid) is the focus of the next four chapters, in which the parents tell their stories, beginning with stories about families, because that is where children begin.

Chapter Three

Families - Creating Lives

Lives are narratively constructed, made coherent and meaningful through the “biographical work” that links experiences into circumstantially compelling life courses ... The process is artful, a complement to the play of difference, but it is locally informed and organized.

(Gubrium and Holstein, 1994, p. 697)

The Family as Subversive

The primary challenge of this research enterprise has been that of finding a way for the participants' stories to be told in all their variety and richness, while at the same time situating them in a theoretical context. My aim has been to contextualise the narratives socio-economically, culturally, historically and geographically in a way which keeps them available, accessible, and recognisable, to their own narrators and to people, both professional people and lay people, who want to use research to inform action (Ballard, 1994, p. 302).

In this chapter the parents tell stories about the experiences and achievements of their families in withstanding, and resisting, practices that are disempowering. The stories illustrate the creativity and resilience of people as they struggle to overcome the barriers that are put in their way as they seek to take control of their own lives. As Mary says:

You get greyer! Some things I've been successful in and some things I haven't been successful in. It depended on who the teacher was and whether you could talk to them and ...

The stories in this chapter show from the parents' own perspective, how disability affects, and is understood by, the families in my study. Their stories are set in the context of the current New Zealand social and political climate, and are complemented by the experiences of other families who feature in the recent, mainly New Zealand, literature.

As Ferdinand Mount asserts in his recent history of the family, it is possible to "suffocate the evidence of the inner life of the family" and to assume "that this inner life is directly and exclusively shaped and controlled by economic and political circumstance" (Mount, 1992, p. 220). Mount sets out, using the evidence contained in both public and private documents, as well as the family's very survival as an organization, to demonstrate the naturalness and the historical resilience of love, marriage and the family. He characterises the family as being in permanent revolution against the state (ibid, p. 162) and speaks of the family as the "ultimately and only consistently subversive organization", the "enduring permanent enemy of all hierarchies, churches and ideologies" and the only organization which has continued throughout history and still continues to undermine the state (Mount, 1992, p. 1). The family is the site of resistance against interference, and its most dangerous enemies, says Mount, may turn out to be

the armies of those who are 'only here to help' - those who claim to come with the best intentions but come armed, all the same, with statutory powers and administrative instruments: education officers, children's officers, housing officers, architects, planners, welfare workers, and all the other councils, agencies and task forces which claim to know best how to manage our private concerns ...

(ibid, p. 173)

Researchers have been amongst these intruders into the private domain, and numerous studies have explored "the effects of handicapped children on their parents and siblings and have tried to determine the bases of successful adjustment" (Darling, R.B and Darling, J, 1982, p. 49). Clinical studies have tended to conceptualize the situation of parents of children with disabilities in terms of guilt and its consequences, and numerous expressions of parental pathology have been reported. Various studies have suggested a number of variables that may be correlated with parental acceptance, including parents' personalities and personal needs, social class or socioeconomic status, parents' educational background, race, religion, ethnicity, age and sex of the child and of the parents, parents' self-acceptance, presence of normal siblings, length and stability of the marital relationship, whether the pregnancy was planned or unplanned, and parents' reasons for having children (ibid). In

these cases, the parents have been subject to the value judgments of others, for example about how well they have 'accepted' or 'come to terms with' the disability of their child, and they have lost their individual voices amid the generalizations of others. Such studies are likely to favour the accounts of professionals over those of parents and their children. Rod Wills describes how his reading of such research confirmed his own experience of the attitudes of some professionals:

... the idea that there is a 'grief cycle' can all too readily be used to explain, at a superficial level, what is happening. Yet parents rarely describe each other as 'being in denial' or 'not having accepted their child, yet'. When parents say to professionals that they do not accept these descriptions of their situation, then they are likely to be further labelled as non-compliant parents'.

(Wills, 1994, p. 252)

Writing in the same recent volume of research studies which present personal accounts of disability (Ballard, 1994) Colleen Brown agrees:

As soon as parents speak out, find a popular voice, possibly a media voice, the labels attached to the child get redefined and stuck to the parent. There is a certain viciousness in the eternal categorising in which our society appears to enjoy dabbling.

(Brown, 1994, p. 232)

Keith Ballard also writes of having heard some professionals accuse parents of being 'unrepresentative', 'articulate' or 'middle class' as if these 'disorders' cancelled out the viewpoint the parents expressed (Ballard, 1994, p. 300). Labelling, of children and of parents, was an important theme for the parents in the present study.

Labels and Language

Much of the language that is currently used to describe people with disabilities derives from a 'personal tragedy' model of disability (Oliver, 1990). As Robyn Munford asserts in her critique of historical definitions of disability, this view focuses on the individual's impairment and takes no account of the disabling

environment created by the structural constraints of our society, such as poverty, class, discrimination and physical barriers. This view, which has contributed to the individualisation and medicalisation of disability, has been challenged by writers such as Oliver (1990) and Morris (1991), and continues to be challenged by writers on disability who stress the need to acknowledge both the physical needs of living with a disability, and the limitations imposed by society (Munford, Georgeson and Gordon, 1994, p. 267).

Mary spoke of the powerful effect of labels in shaping Justin's life:

At that stage I was pregnant with my third child, and to be honest I couldn't manage the lifting of Justin, to be pregnant and to be lifting him. He was I think eight at that stage, and so it was suggested by a local psychologist that he may be a 'suitable candidate' - those were their exact words - to attend the school at the Queen Elizabeth Hospital in Rotorua, so Justin went there for two years, and while he was there he was assessed by their school psychologist, who said that he had an intellectual disability - 'handicap' was the word that they used, and that he had to come home. And in hindsight that turned out to be a good thing, because he was then back in, you know, just the community, whereas at the Child Potential Unit in Rotorua he was only with other disabled young folk. But that label has created such a ... what's a word I could use? It was such a wrong thing to have been given to Justin, because on the day, on the day when the assessment was made, he couldn't read, he couldn't write, he couldn't do anything. But what it wasn't realised was that he actually couldn't see. And nobody had picked that up prior to that. So he was given this label of 'intellectual handicap', and was sent home from Rotorua, because the Child Potential Unit only has children with physical disabilities, not with intellectual disabilities. And so from there, he came home, and because he was given this label he was sent to {Special} School, the IHC school here, but within three months the headmaster said, Justin doesn't belong here - let him out. So at the end of that year I did take him out, but at that stage he was at intermediate school age, and he went to intermediate here.

Violet spoke of her own response to what society communicates about disability:

And I guess for myself that has also been a learning curve, because for a long time my only concern was that Shaun was totally blind, and **maybe** he may have some brain damage, but if he is going to be intellectually handicapped ... that was something that I never used to accept, and I had to really ... the signs were there ... you know, at four he seemed to plateau, and then he started to progress in small ways, but it sort of got slower and slower, and that was really difficult. And I guess for me personally I kept not wanting to deal with the fact that he could also be actually handicapped, intellectually handicapped. And I remember saying to a friend that I don't know if I could cope with that, with Shaun being intellectually handicapped. I guess because I always had this image about - some sort of image that I had - I don't know what it was. And that was actually before I went into my other work, and I learnt lots more ... [laughter] and how intellectually handicapped people learn heaps. You know, it may not be all the things that we aspire for them to be, but they learn lots.

She also spoke of the response of some professionals to the things Shaun did:

So eventually we decided for him to come home, because there was also, that's when a lot of the behaviour things started to come up, and appear ...

Nobody really knew. We often wondered about that. I mean it hasn't changed even now. But at the time we used to wonder whether something had happened to him ... because just suddenly he was doing this, you know. So we sort of often wondered whether something had happened, and we often sort of said in meetings, has anything, like has he had an accident or something? They'd say, no, the behaviour is attention-seeking behaviour.

Professionals can also create another barrier for parents of children with

disabilities by labelling and categorising parents in the way that they label and categorise the children. As Colleen Brown says, "there is an urgency for parents to continually drive home to professionals the individual differences and needs of each family and each child, and to resist grouping and categorising" (Brown, 1994, pp 238-239). Mary objected, for example, to the labelling implied by a television advertisement:

I'll talk about the IHC ad that was on telly last month, because I objected to that, to the head office in Wellington via our committee. It was an ad where they had a [photo of] a family, and then they said, this child is a child with an intellectual disability, and then, this is on the telly, the photo was ripped in half and the father left the home. Then the photo was ripped again, and the child left the home ... **but** the IHC can bring it all together. I mean **what a load of rubbish!** In a committee meeting, because I'm on the IHC committee, I just objected so strongly because what they were doing was laying the blame of that family breaking up on the child. You know that family could have broken up because of any number of reasons, but they were laying the blame fair and square on the shoulders of the child with a disability. The interesting thing was that people on the committee are mostly parents, and some of them said, oh it doesn't matter, you know, my son, my twenty-four year old son wouldn't be any the wiser anyway. It didn't bother her at all. I said, but that's not the point. Because he can't understand doesn't mean to say that we stop fighting for his feelings, and his rights.

Allied to the theme of professional labelling and the dominance of the professional viewpoint is the theme of not being listened to and of the views of parents and children not being valued or regarded as valid.

Not Being Listened To

This is very often related to the giving and receiving of information. Mary said about this issue:

That's such a huge issue with me, because unless you've got a professional who's willing to accept that people other than themselves

have opinions, it's really hard to give information and know that it's going to be taken for what it is. You know, just throughout Justin's life, the information has been passed on, but because you're a parent, I think you must be thought of in a lesser way than from say being passed from a professional to a professional, and you know, you think about school IEPs for one, where you and I both know this Alison, that if I'm there having my say, and I often have my say, it's not taken as well as if I have a support person supporting me. I'm reasonably assertive, and so people who don't have that assertiveness must just get trodden into shreds, and this is the feedback that you get from parents, is that they were **not** listened to ... they were **trying** to give information out about their child, but they really, you know, they can't. The feeling that they were made to feel was that what did they know?

Frank also spoke of not being believed, and Theresa said that although she thought she was listened to, she felt that sometimes what she said was dismissed. She spoke of wanting:

support and acknowledgement for the things I know about **my** child - like that was very important for her to be as normal as possible, to be part of things with the other kids. The last couple of years at school have been quite tearful for her. The end of last year and this year it's a whole lot better.

What's made the difference ... do you know?

Probably her having grown up a bit. Some things having changed the way she wants them changed, i.e. that she doesn't get taken out of the classroom for typing any more. So she's got listened to. At one stage she said the IEPs were about her, so she wanted to be there - I think we've only had one where she's been there.

Mary's story about a physiotherapist who turned up at school, went into the classroom with a walking frame and insisted that Justin could walk illustrates this same point:

... but it's just that undermining what he says, and he said afterwards, she just wouldn't listen to me, she just wouldn't listen. He didn't know at

that stage that she actually hadn't read his school notes or anything anyway. She just came in as a physiotherapist. So you're battling that sort of thing as well. I mean that's a recent one, in the last month. It's kind of ongoing really, these sorts of problems. And as Justin's getting older, and he's able to speak for himself, it actually hasn't got any easier for him, and I don't know why. I don't know why he's not accepted for what he's saying. I really don't know, whether it's his personality that makes people override what he's trying to tell them, I don't know. For issues like that, which are quite important issues ...

I guess it's how I felt as a parent, when Justin was younger, and I would go along to the doctor, or the school, and them not listening to me. This is now what's happening to Justin. He's now in a position where he's speaking for himself, and a very similar thing's happening to him, that has happened to not only myself as a parent, but to other parents as well. This is quite a common theme, that we're not listened to. But if we take along a professional person with us to speak on our behalf, that person is listened to before we are. And so this is a similar sort of thing that Justin's now finding himself in, because he's speaking for himself down there, and I'm not able to speak for him. You know, I'm not on the spot to be speaking for him, and he's getting the same sort of feeling back, that I have had in the past.

Violet spoke of trying to get a message across, but having difficulty being believed, or taken seriously:

I didn't have a lot of family support, because people had this impression that I was coping really well ... [laughter] I looked fine, even when I was having my mental breakdown, which is what happened eventually. It wasn't until I actually got to the point where the doctor realised that I **was** having this breakdown, because all before that time I kept thinking I was doing really well. And yet I would go and visit him and drop ... I wouldn't actually say ... because I didn't know either! You know I thought I was coping. But when I reflect on the things that I actually ... I was actually telling him that, I'm not coping. So this time round when I had my marriage ... when I went through a separation, I actually went to the doctor and said, look, I don't know how I'm going to be. This is

what's happening for Shaun, but if things come to a head I want you to know what's happening in my life so if I do ... not cope or whatever, you'll know what's going on. And he says to me, oh, will you ring me up and let me know if you're going to have a breakdown. But he said well, knowing the person that you are, he said, I think you will cope with what's going to happen. Well, I said, I don't know about that, but I said, I'm letting you know what's happening in my life just in case ... you know, because I felt in the past, you know, because you have this lovely smile, or whatever else that you might have, to help you cope with all the ... yeah, and I felt at one stage I wasn't coping, but because I have the experience now to know that now when I'm not coping I go and find people that I know will help me, and I actually went and found my own counsellors this time round. Yeah, and I had no problem doing that. I knew I had to help myself. It's interesting isn't it? [laughter] You have to be so forceful about it, and then that's taken many years of, of I guess of self-empowerment. And a lot of things as parents we have to do ourselves anyway - it's a continual battle.

Battling, fighting, struggling and the need for assertiveness by parents are mentioned frequently in the New Zealand literature (Wills, 1994, Brown, 1994, Munford et al, 1994) and were important themes for the parents I spoke to.

Being Assertive

Sarah spoke of the need to be assertive and the energy it takes to do that:

... you have to insist, you have to become so assertive ... for your child, you know, and in the end you don't care whether these people like you or not. I mean you want to be pleasant, but if they're not being co-operative or if they're not trying to help you as much as you think they should be you've really got to stand your ground, and simply insist, and be assertive, and that is also very tiring. Yeah, you feel you're battling all these people ...

It's absolutely insisting, becoming very assertive and asking ... because often you need referral, for a lot of these other things . . . But you have to be really insistent, and if that paediatrician is not going to help you, you

change him, you know, if he's not going to be helpful, or organise other caregivers, or people to visit you or professionals to see your child, or if you're not getting any joy out of that person ... and it is hard to do ... because you trust these people, or you put your trust in these people, and as we found out with our G.P. they're not all as competent as each other, and you've got to find out who's best for you, as a family, or as an individual, or who is best for your son, because if you have a special needs child, there are people out there who specifically deal with that area, and they are professionals in their own right in that area, and they know more about that condition or that vision loss or whatever, than that paediatrician or that G.P. The G.P. knows so much ... so it's a matter of being able to combine these people. You have to do it. It shouldn't be that way, but it does, it falls on your shoulders, and you might have to change personality yourself just to get what you want.

Many families speak of the roles they have to take on, not only in confronting, but also in placating and keeping on side with the professionals who hold knowledge or resources they need for their child:

Apart from being stropky, we need to constantly reassure everyone that they are doing well, talk about our son's development, explain, explain, explain a lot of things that are really nobody else's business. ...

If being a regular parent meant doing a third of the things parents of children labelled disabled have to do, then the human race would rapidly become extinct.

(Dixon, 1994, p. 77)

Sarah spoke with concern about parents who are not assertive:

For his sake I'm so pleased he's got the type of parents he's got, because there are people out there who would just have done as they were told, or done as they were advised by the one person, like the paediatrician, that was it. Instead of finding out or becoming informed themselves, or asking questions and things like that and not just accepting that ... like we were. We were motivated to get out there and do what we could and not just accept, oh well, wait and see. But there

are people out there who would have done that, and I felt that would have been a year lost.

Violet mentioned these parents as well. She said:

But I have found in my work that the less educated parent finds it very difficult and is not as confident to ask. It's not that they don't want to - it's just that they're not as confident.

This is a crucial aspect of parents' experience, and in my estimation, it is an aspect which is in urgent need of further careful research. My research seemed to indicate that the experiences of Maori parents in this regard may be different from those of Pakeha parents, as their respective reactions tend to be as well. The experiences of some parents indicate also that professionals who may be quite willing to explain sometimes assume, incorrectly, that if parents don't ask, they don't want to know.

Mother's Work

The Otago Family Network study concluded that an interest in disability issues was primarily the domain of mothers, and where both parents were involved it was usually mothers who initiated the first contact (Ballard, 1992, p.16). This is consistent with the recent New Zealand literature on caregiving (Munford, 1992, 1994; Craig, 1992, Sonntag, 1994), and with my own study, where the only father who took part in the research project was the only caregiver in the family. This father, Frank, has noticed the prevalence of mothers at meetings and in the public arena:

I'm always loathe to sort of say, well what happened to Mr ... Generally it's Mum looking after the child, and often the other parent is not around and there may be a partner or somebody living with them or various partners coming and going. But it appears to be a follow-up from handicapped kids that Dad is tired of the constant problems involved with handicapped kids and disappears from the scene often. It often leaves Mum to cope on her own, and Mum turns into a very strong-willed person, fighting for everything they can get, fighting the system, fighting for something for their kids, and if that's the consequence, I find

that pretty soul-destroying. At least Bruce has had two parents and a family background for most of his life, but I find circumstances of other handicapped children very difficult, very trying, and again I think it's fairly soul-destroying if one parent is left to shoulder a very big burden.

Sarah spoke of needing to provide her own support:

... I don't have any family support ... I've got a brother and mother overseas, and that's it. So it has been from my own strength, and I give myself the support I need. I mean Mark can support to a degree, but he's got to get on and go to work and things like that, so I'm at home with David all the time ...

The parents talked about how the sorts of barriers they encounter also impact on other family members and on the family as a whole.

Family Stress

The parents' stories support Ferdinand Mount's idea, introduced at the beginning of this chapter, that families put a great deal of effort into managing their own concerns and protecting themselves from interference (Mount, 1992). As the parents explain, their efforts to protect the family are often threatened by the pressures arising from the disability. Mary spoke, for example, about the effects on the other children:

You know, sometimes it takes its toll on you as a parent, and as a family, because you take it out on the other children. I mean I can't speak about a husband, because he hasn't been around for a while, but it certainly takes its toll on the family.

Frank talked about his daughter who

has always supported Bruce, but at times feels as though there's one hundred per cent support for him, and not much left for anybody else at various stages.

Sarah talked mostly about David, but said:

I could go on and talk about Emily, and things like that ... she was really good, but we were very conscious that David got all our attention. We were very careful not to exclude her, but I know she felt ... and that came up down the line. I know she felt left out, or he got more special attention at certain times. I mean she was going to school, thank goodness, she had her time at school, the big school girl. But she was very obsessed with his blindness, and she wrote stories, David is blind ... and she'd tell about it every day, you know that was a big thing of hers.

Theresa felt that her younger daughter was affected emotionally and physically:

That sort of thing caused a lot of problems with Holly ... why did Mum have to go? Mum was always going away and doing things with Carol, and to the doctor all the time ... yeah, a bit of sibling rivalry there, for Mum's affections and attention. We didn't realise a lot of it until later on. She asked me later on, why did **you** have to go away, why couldn't Dad go?

...

I think that is part of, certainly at the start, to Holly's urinary problems ... I think that was one of the ways she could get Mum's attention.

Doreen also talked about the relationship between her two daughters:

We went to [city] for the music therapy and a dark room session with Chelsea, and we went and did some shopping and bought all these fancy coloured light things for the dark room back here and it was the very first time I didn't buy anything for Christy, because normally I do always come back with something for Christy, and soon as we got home she goes, Mum what did you buy for me, and I said I actually bought you nothing today, sweetheart, and she says, but who are those things for, and I says, for Chelsea, and I says well, I always buy things for you and not for Chelsea sometimes, and she goes oh that's alright eh Mum. But I wonder what really goes on in her head about the extra attention

sometimes, extra stuff ... Some parts I think I've come across a bit of jealousy, but really she has been terrific, right from the word go ... she's never even hurt Chelsea

Violet felt a lot of sadness when she looked back and thought about what had happened for her family:

It was funny. I guess ... in some ways I took the family for granted. I didn't have extended family at that time, just my immediate, like my children, and I think I had one sister here ... but she's a lot younger than I am, so she was sort of, she had been living with us for a while. And my husband's parents were really good, and they did as much as they could, because they were working. And I had several friends who were really good, who sort of came and [...] I was trying to get on with coping and I felt if I was coping they [the family] would be as well, and so it wasn't until many years later, after I had ... because I had to learn to get communication skills, and I did that by getting some counselling, individual counselling myself, and it wasn't until that time and after that time, and I went and did community service and worked with Parentline and things like that and had to go and learn communication skills, that it got me thinking about my children, you know my other children. And a lot of things I just took for granted with them, and with my husband as well.

And so once I guess I'd learnt how to communicate properly myself, to a point where I could talk about my emotions, that's when I actually started to talk to the children about what was happening in their lives and how they felt and it was really interesting what came out. And like how they in turn felt rejected at some stages, and particularly the oldest girl, because we ended up sending her off to boarding school, and she actually felt like she was being sent away, because we weren't coping. And so she felt like she was causing a lot of problems too, and in actual fact in comparison to the other two, she wasn't [laughter]. She was actually quite good! ... and in comparison to Shaun none of them ... [laughter] But [...] there's a big age gap between her and the other two, and so for those two, but for her in particular it was very difficult,

and she had no problems in expressing how she felt about situations, but we had problems accepting it - that she didn't like to be seen out in public with Shaun. That was an embarrassment for her, because she was coming in to those teen years. The eldest boy, he was so involved with sports and that, that he was away out of town a lot so that excluded him a lot from some of the responsibilities, and the oldest girl always felt that she was always having to be responsible for everybody, and the younger daughter always felt that she was missing out.

It was interesting because, you know, they **seemed** happy enough. I mean a lot of the decisions we made, we didn't include them in the decision we came to, so they did feel excluded. Like we'd be out and about and I'd have Shaun with us and she [the younger daughter] would just say "I'm not getting in the car" or something like that, and then her brother and sister would sort of jump on her case and say, oh don't be so stupid ...yeah ... it wasn't so bad when he was young, but as he got a bit older ... and even now she doesn't particularly like to be seen with him ... yeah, because she's nineteen and Shaun will be sixteen this year. And of course, Shaun always seemed like he was getting new this and new that, and she always felt that they, **she** felt in particular, out of the three of them she felt that she was the one who was getting missed out the most. And of course when the older two weren't around, and there was the responsibility of looking after Shaun, as it is now, because she's here ... she looks after him very well. She's actually quite a responsible person. And I think at times we've placed her in too much of a responsible position.

I didn't really know this until my daughter, the oldest girl, when she moved away, and she got a bit older, and we got to actually talk about things, and she was able to talk freely about it, she often said that she actually felt guilty for what happened to Shaun, and yet it had nothing to do with her. And the same with the eldest boy. And at times when he's here, because he's married now, and has a family of his own - they've had Shaun several times and looked after him - he still finds it difficult to deal with a lot of Shaun's behaviours. He says ... I don't know, he just finds it difficult to have the ... You assume that your children are going to

love each other, and love ... you know? He said it was difficult because he knew that he cared about his brother, but sometimes I guess because he felt so worked up, and because he, the oldest boy in particular was - the girls are quite outspoken - and he's very quiet and so he didn't ... It wasn't until things went wrong at high school for him that I realised how we had neglected him, simply because he was the child who just got on with things and never said anything and, you know, the quiet one. Yeah, it wasn't until things went wrong at high school that we realised just how much we had neglected him. Because, and I remember saying to him, out of all the children, I assumed that he would cope, because he had that quietness about him, and he seemed like he was, but he really wasn't. It was hard to sort of come to terms with.

And they talked about their anger ... like they felt angry a lot of the times because we wanted to do a lot of things as a family but we couldn't, because we had to find someone to leave Shaun with, because he was ...oh! That still sort of didn't happen a lot. I think, I don't know whether it was because we felt that he should be involved, we always felt that he should always be involved with family things, outings and things, but there were times when we didn't actually make time just for the other children. We didn't learn that til they were a lot older, and then it was, it just seemed a little bit too late ... [laughs] ... mm ... it was quite sad too, but ... but we did do a lot of things together, and ... I think in some ways as they become parents themselves, whatever they've learnt will help them.

Many parents speak of the strain on their own relationship, and Mary had this to say:

Yesterday coming back from somewhere that I'd been to, somebody said to me - we were talking about Justin - and how was he getting on at the moment - they said, Oh do you think that's why you and John split up ... you know, the fact that Justin has a disability? This was a parent, a person who also has split up from her husband, and her child has a disability, and we were just discussing whether our husbands left

because of that. But I don't believe that. That may have been a small portion. She thought in her case that that was the reason why her husband had left, because he couldn't cope with their child with a disability. But I think that's just a cop-out. You know it may be a small contributing factor, but I think if you're in it, you're in it regardless of whether it's good or bad ... you know, if you're in a family situation or a marriage. And I think for people to go using that as an excuse, I don't accept at all.

Violet indicated that it was an issue in her family:

And then I had to sort of tell my husband [that Shaun was blind]. I came home, had my howl and everything else, you know the whole bit ... [laughter] always by myself ... it seems to be my pattern, with a lot of things. But also, the marriage wasn't doing too well at that time too, and I wasn't sure whether to tell him or not. I didn't particularly want to, I actually didn't want to, because I didn't want him to make a decision on whether or not he was going to stay in the marriage for that reason. I wanted it to be because he wanted to be there, not because he had a duty to perform.

The impact of disability on the lives of parents, and particularly the lives of women as mothers of children with disabilities draws the role of parents, and especially mothers, into sharper focus. As Dina Bowman and Melanie Virtue comment:

Mothers of children with disabilities experience motherhood writ large, the problems they face are an exaggeration and exacerbation of the problems facing all mothers. While all mothers experience lack of sleep, loss of income, social isolation, low status - babies eventually grow up.

(Bowman and Virtue, 1993, p. 2)

As Violet's account of efforts to arrange family outings and family time demonstrate so powerfully, and as Janet Dixon explains, ordinariness can be very elusive:

I spend a lot of energy in organising what for most people would seem like very ordinary experiences. I suspect this is true of most caregivers with children who are disabled. You see, that is what we want: ordinary experiences helping to make our children ordinary.

(Dixon, 1994, pp 71-72)

Hopes and Dreams

Sometimes coping means an adjustment to parents' hopes and dreams for their child, for example the kind of adjustment Sarah talks of:

For this next year I'm now focusing ... I know that he won't start kindy til he's three and a half. He's already enrolled. I enrolled him at two, and the head teacher there knows of his vision loss, and so he might be classed as special needs, and he might get in a bit earlier, and they might have to get a teacher aide. I mean we're going to have to assess that all when he's there, and that's something we've got to deal with down the track, so he won't start til at least the end of the year, and probably the beginning of next year. So that's something we'll work up to dealing with and coping with. Potty training is the next thing. And getting him into his own bed. He's still in a cot. But they're normal things. The kindy one's is bit more ... I do worry about him being there a bit ...

So I try not to think too far ahead ... just sort of taking a bit at a time. We do worry that he won't be able to drive. That's a real ... we do think about that, because that's a real adjustment in life skills that will need to be coped with. I mean it can be coped with. You can get around that, but I just think, oh it's just a loss of independence, not being able to drive.

For Carol too, there are adjustments to be made:

On one of our visits Dr [ophthalmologist] at the Low Vision Clinic told her, don't let your eyes stop you from doing whatever you want to do. You can do anything you set your mind to, except drive a car and fly a plane. So we talked about that on the way home ... [she said] can I go

bungy jumping? I said, the only thing that'll stop you going bungy jumping is your mother! I told her that if she wants the experience of actually driving the car, there's no reason why she can't do it in a paddock with somebody beside her and actually learn how to drive the car, and the same with going in a plane. She'll never be able to do it on the roadway or go by herself, or get her licence.

I don't think she's missed out on any experiences because of being vision impaired. If anything she probably ... we might have gone a bit out of our way to make sure she had some experiences. We've never stopped her ... from doing anything. She can go to camp and everything. That's probably why we don't see the need for her to go to special camps and what not.

Sometimes professionals can be less than encouraging, and can add to the pain of lost dreams, as Mary explains:

When I think of the future that a certain psychologist said that he would have, and how he's actually ended up being, they're just so far apart, that I feel like sending a copy of Justin's School Cert results to this psychologist and saying, up your nose! I feel like it. I haven't done it yet. [He said] that he was an intellectually handicapped young man and that his future placement was within IHC and so this was the future that his parents should follow for him ... which was what I did, because I didn't know any different ...

So yes, I have thought one day, when I'm organised and I can sit down and write this up, when Justin is in the flat and life is going well for him, I'll do that one day.

Sometimes it is social practices that exclude, sometimes physical barriers which cause dreams to be lost, as Mary explains:

He's invited kids his own age around, and they've come once, but they've just not come back again. And it's because his ... what he wants to do is just sit round and talk, and listen to records, and ... I don't

know what other young folk do, but when he's asked them back again, there's always been some reason why they can't come, and that's been a particularly sad part of it really, because he's always had the same desires as other kids. He's always wanted to ride a bike, and climb the tree, and now that he's seventeen, going on eighteen, he's spoken about his driver's licence, but I've just had to tell him that ... you know, he knows it's never going to be a reality, and so instead of focussing on that I have had to just steer him off into some other direction, but it won't be a reality that he'll ever get his driver's licence. But it doesn't ever stop him wanting to get it. The fact that he can't walk I think has just held him back in so many ways.

There is a cruel irony in the fact that so often the hopes and dreams parents have for their children with disabilities are so ordinary, and yet so unrealisable. For parents in the literature (Ballard, 1994), as well as the parents in my study, there is often such a disquieting mix of emotions to contend with around their expectations for their children: a fierce determination to maintain hope for the future, tempered by sadness at the physical limitations of their children's disabilities, and fuelled by frustration at the limitations imposed by our society. As Colleen Brown says:

The uncertainty of living from day to day can smother parents' dreams, and dreams are said by Marsha Forest and Evelyn Lusthaus to be one of the enduring parent rights.

(Brown, 1994, p. 241)

Public Lives

For many families an ordinary lifestyle remains elusive, and sometimes they have to go to extraordinary lengths to advocate for their child. This can mean talking about private aspects of their lives, and again the stories indicate the parents' resistance to being subjected to professional scrutiny in the course of getting help for the child. Violet's words convey clearly what it feels like to be on the receiving end of such intrusive 'help'. She says:

And I was by myself, and that was the hardest .. I think it must have been the hardest thing I ever had to face. And like I was saying

because things weren't going too well between my husband and I, I think that all added to the ... you know, and having to make, it seemed to me like having to make a major decision, and realising that I wasn't coping as well. That's when sort of I realised there were a lot of things I wasn't coping with. And I felt that that was all sort of put under a microscope ...

It can also mean becoming involved in committees and public campaigns in an effort to bring about social change. Yvette, one of the mothers in Sonntag's study, said: "I sort of feel I've worked most of my life for IH and I've done a lot of work really behind the scenes: organized all sorts of parades and shows and you name it - I've done it. I've been on all the committees..." (Sonntag, 1993, p. 98). Mary is familiar with this way of life:

You attend meeting after meeting after meeting, and if you've got a child with a disability, or with more than one disability, you belong to every organisation that you can possibly belong to, because you think that you're going to gain something.

The advent of Tomorrow's Schools seemed to present an opportunity for parents to advocate for their children. Frank talks about this:

My wife was on what they used to call a School Committee, which does the fund-raising I guess for extra things, just menial tasks. They obviously had some sort of grant but the rest of the money they needed to raise themselves by various things - galas and organized events like that spring to mind. But when Tomorrow's Schools came in my wife refused point-blank to go in and tell the principal how to run his school. She'd been a teacher and knew how difficult it was to talk to principals and change their minds. So she didn't feel inclined to move up a step, and she suggested seeing I was a retired civil servant it would be right up my alley, and for some reason or another I got conned into thinking it would be just a cake walk! ... But after six years of that, it's not been a cake walk, and special schools didn't exactly get off on the right foot, mainly because they'd been forgotten about completely, and it was only long lobbying that Tomorrow's Schools eventually recognized that they

did exist, and that they needed funding. We've battled for people like Bruce for the last six years. Funding has never been adequate.

Parents often have to expend enormous energy becoming what Sarah in my study called "your child's expert". As Rod Wills comments:

Parents soon realise that they are the experts on their own child, and many, through sheer frustration and often necessity, become experts on their own child's disability. These situations lead to parents becoming education decision-makers for their child and then to realising that they know more about policy and practice than many of the professionals making decisions that affect many children.

(Wills, 1994, p. 260)

Having gained this knowledge and level of skill, parents may continue to be involved in advocacy by giving presentations at conferences, sharing their secret hopes and fears, exposing their feelings and re-living personal pain. They do it, as Colleen Brown says, "because they see it as a necessary and powerful advocacy on behalf of other parents and other children" (Brown, 1994, p. 237). Mary describes one such experience:

So at this conference in Rotorua, I relayed Justin's story, and said that I have now had to change how I was talking ... that I've realized I'd done it wrong for many many years, and so I've changed because my son wanted me to change, and at the end of that ... I didn't say anything about the people on the panel, just that we should all just look at our folk who we care for, but at the end of my little bit of a speech, the amount of people that applauded just made me feel so good, because the conference contained mostly parents, and mostly people with disabilities. It was just amazing, and people came up to me afterwards and said, we just so agree with what you had to say, but we're too scared to say it.

Sometimes, and it is important to notice it and to celebrate it when it happens, professionals do support parents in a way that leaves the control in the hands of the family. Doreen talks of feeling supported and encouraged by the

professionals who are involved in Chelsea's life:

All the services that I have now are just ... are terrific ... especially after coming back from Lilli Nielsen [seminar on working with children with visual and other disabilities] and seeing [physiotherapist] going, oh we're going to do ... try that, we're going to do this, and I think it gives me a burst of ... of go ... mm ... you come to a place, come to a standstill, and you go, oh, she's not doing anything else, so you, sort of like you're going downhill, and then something else happens, and that gives you a burst, more burst of energy to carry on.

have you gone out looking for some, any kind of services, or are they ... have they just ... rolled in?

they've actually just rolled in ... as the time has come

the right person's turned up

the right person's turned up ... like um, [social worker] was excellent, she was with CCS, like she didn't ... really do anything with Chels, you know, didn't do any work, but she'd come round and we'd just talk, get a few things off my chest.

While it is important to remember that all parents, as all children, are different, it is also important to acknowledge that, as Colleen Brown says,

even the most informed, assertive parents still perch uneasily on the edge of their chairs during meetings, often expecting the worst.

(Brown, 1994, p. 238)

We have to ask why it is that way, and what the barriers are for parents in this situation. Colleen Brown asserts that most parents would say that it is because power is stacked in favour of the professionals, and here Foucault's analysis is helpful in understanding how various 'technologies of power' work to maintain 'power relations' such as those between parents and professionals. One such 'technology' which frequently operates to reinforce this imbalance of power is what Robyn Munford has referred to, in her work on the caregiving role of women, as the "subtle mechanism" of "time and waiting" (Munford, 1992, pp 92-93).

Waiting

Being a person with a disability often means waiting and uncertainty: waiting for services, for equipment, and especially, for appropriate accommodation, and uncertainty about the future. Frank explains:

I guess currently I'm concerned about getting Bruce into permanent accommodation just to allow him to finish his education with a stable background, and then to progress onwards from there. Spending so much time in my company, I would doubt whether that's helping Bruce's future. Long-term, that isn't able to continue indefinitely, because at some stage I'm not going to be around. Whether that's near or far distant, I would hate to think of Bruce just stagnating into being in my company when I'm old and decrepit. That appalls me, and that was always Audrey's philosophy that Bruce, soon after he turned fifteen, needed to be, not quite out on his own, but sort of moved in to a more compatible community for his sake. I've got no illusions that the best place in the world for him is the IHC. It's I guess, the best available, and he's slowly being infiltrated in to that community. When it's mentioned that he's about to go, he's ready to pack his toothbrush and swimming togs and be ready to move, so I guess somewhere along the line he's going to go under those circumstances and not return. So my future life - I'm not quite sure what it's going to be involved with [...] I'm scared to think [...] Whether I'm rushing to get Bruce involved in another world to give me a chance of moving myself into another world, I don't know. I'm just concerned at getting Bruce settled. I guess some day in the near future those activities will change tack and I'll be involved in having Bruce home for a week or a fortnight once a year as a holiday for him. I guess we may settle Bruce, but my life-style might change - for the better, or the worse, I don't know.

Justin, at the time of the interview, was also still waiting for suitable accommodation, as Mary explains:

He still hasn't moved into the flat. This is another thing that I don't think is right. He has so far been given five dates of when he should have been able to move into his flat, and it's **still** not ready. It was going to

be the 28th of January. Then it was going to be the 25th of February, the 16th of March, and 31st of March and then Easter. And he still hasn't moved in, because the builder started building the flat that he's going to move into with his flat-mate, and then he went off and built a show home next door, so that that would be completed. And the reasons that he gave for the flat being delayed were just ... oh the wood hadn't arrived for the edging or something, the windows hadn't arrived, and yet miraculously the window arrived next door for the show home. Now that the show home is finished next door, has a garden and concrete paths and everything down, the builder has gone back to building this flat. So, you know, that's just an example of the sorts of things that people with disabilities put up with. You know, it just irritates me so much. I mean, I'm sure that if you and I were waiting for a flat to be built, we wouldn't put up with that, would we? We would be on to that builder, and we'd say to him, you said you were going to have it done, and when I've said that sort of thing, he just said there's nothing we can do about it because we're waiting for the windows. There's no contract. But the end result is that I'm not going to let Justin sign a contract with him, because if he has broken his date five times, there's no way he's going to push Justin into a contract for, say it's finished in June, something for May or June next year. I said to Justin, I would like you just to sign to the end of the year, then if you want to renew it, you renew it for a full year. But do not sign a contract which is going to take you into mid next year, because if you wanted to move on at the end of your school year, you can't do that because you're hooked into this flat, with the rent. You know, if the builder doesn't agree with that, I would fight that, on Justin's behalf, because the contract [was supposed to be] from the beginning of the school year to the beginning of the [next] school year. So you know that's another battle.

Informal conversations with parents, as well as my own observations, raise the question for me whether 'waiting' is another of those issues about which parents may feel strongly, but for reasons of culture, natural reticence, politeness or political astuteness, that is unwillingness to antagonise or upset a professional, are often unwilling to assert themselves.

Parents as Professionals

One of the questions I had was about what happens if parents **are** professionals. Does it make any difference to their experiences, especially in their relationships with other professionals? Certainly parents' knowledge is frequently devalued, as the following remark by Keith Ballard shows:

I have heard some professionals accuse parents who speak out of being 'unrepresentative', 'articulate' or 'middle-class'. These professionals apparently see each of these 'disorders' as cancelling out the viewpoints the parents express.

(Ballard, 1994, p. 300)

Colleen Brown also argues that even assertive, professional parents often feel they are "at the mercy of professionals" (Brown, 1994, p. 238), and this seems consistent with Hornby's findings in his review of fathers of children with disabilities. For example Jay's parents, a lawyer and a psychologist, "were advisors in a professional capacity to a host of state and local mental retardation agencies ... Sad to say, neither of us was fully prepared for some of what lay ahead. We learned, for example, that the community could be inhospitable. Some friends and colleagues recoiled when Jay went to shake their hands, as though he were contagious" (Hornby, 1992, p. 369). Interestingly, this father considers that Jay "has helped him accept his own limitations, thereby adding to his personal and professional integrity" (ibid, p. 370).

Another father, a clinical psychologist, "emphasises that, because of his training and position, they should have found it easy to obtain competent professional assistance, but instead they were forced to experience a series of traumatic interactions with professionals which echoed the complaints he had so often heard from other parents" ... he writes of "referral ad infinitum", "professional ignorance" and "the deaf ear syndrome" (ibid, p. 369). It seems that even potentially powerful parents experience a feeling of powerlessness in the face of the relatively more powerful professionals upon whom they are dependent for the medical and educational wellbeing of their children. Violet certainly did:

When I went into the professional world I was more of a threat to teachers. It was more difficult. There were times when I would go to an IEP and I would literally say, I'm a parent today. I'm not Violet the intervention teacher. I'm a parent, so I'm going to be emotional, so you know ... or something like that, just to let them be a little bit more relaxed, but at times I felt that because they knew that I worked with the department I did work with, I was more of a threat.

It seems that these experiences of relative powerlessness may impact upon professionals who are, or who become, parents of children with disabilities in a way that may influence their subsequent professional practice. The lived experiences of people whose shifting identities expose them to contradictory experiences of relative power and powerlessness have major implications for disability theory and practice as they are informed by thinking about power and identity. The following comments from the Clinical Director of the Spinal Injuries Unit at Burwood Hospital, Professor Alan Clarke, are telling:

"Since my accident I have suddenly discovered how badly the whole process of rehabilitation has been addressed by the medical profession and by health professionals. There are few doctors who know what is needed.

Thus resources have not been allocated in that direction. Rehabilitation facilities have tended to be marginalised, and also the people needing rehabilitation have suffered."

He believes health services have been progressively 'captured by the professionals'.

"The professionals delivered what was considered to be the best, and patients had little choice. [...] There is nothing like the frustration of a severe disability to show up how little professionals listen to their patients."

(G.P. Weekly, 20 April 1994, p. 11)

These observations about professionals and by professionals themselves must raise major issues about the training of health, education and welfare professionals, as well as about the rights of people with disabilities to be listened to and treated with respect. Often, it seems, the inability of

professionals to offer this kind of support to families means they have to cope by themselves, or turn to other parents.

Supporting other people

As Mary said,

Nobody - **nobody** understands what it's like to have a child with a disability, other than the parent of a child with a disability ...

Because nobody else really understands, parents of children with disabilities often find themselves in the position of having to support friends and family.

As Violet explained:

I guess too because when you talk about families, and you know you talk about your concerns like with friends and families, because they haven't experienced it a lot of times you're having to help them understand as well. And a lot of times you just want someone to understand your position first, and that's why I've actually listed professional first. Because when it comes to dealing with your family, to be able to get something across to help them ... because I always found that I had to actually had to help them cope with their ... you know, that they couldn't cope with disabilities or something like that. And with friends, they wanted to help and that was really good and a lot of times it was just listening, you know a listening ear. And in turn you were helping them also, because like, being around a disabled person brings out a lot of emotional issues for some people. It, you know, wasn't a problem but I think in the beginning I would have preferred professional help.

Sarah also talked about coping with other people:

You're also coping with a lot of people coming round and they actually, all they could ask ... they were so concerned, they were concerned for us and David and that, but they really wanted to know that David's blindness wasn't permanent, that was the biggest thing, oh it's not permanent, he is going to recover from it, he's going to get better, and

of course we, you know we only told them what we knew, and we didn't want to give **them** false hope and we said, well no, it could be permanent, this could be it, and people just don't believe it, or they can't accept it, it's very hard for them to deal with. You know, they can deal with him getting meningitis and being in hospital and being treated for it and coming home and maybe still needing some time to recover, but to have permanent damage from that, that was really devastating for a lot of people.

It is often professionals, as well as friends, family members and other parents, who require the support of parents of children with disabilities. For example, Robyn Munford, Sara Georgeson and Janice Gordon warn of the expectation that social workers can have of people with disabilities and their families "to be politically active in the struggle for resources" (Munford et al, 1994, p. 282). As a parent myself, I have experienced that kind of pressure, and it can be very hard to resist, especially if it comes from a person or an organisation on whom your child is dependent for professional services.

Mel Bogard, Colleen Brown and Rod Wills are all parents who have been very much involved in the campaign for resources, understanding and respect for their children with disabilities (Ballard, 1994). As Mel Bogard says:

Over the years since first writing our story I have continued to write submissions on disability issues. Some friends and I even made a television documentary, telling it like it is, as the mothers of children with disabilities. I now choose to leave this work to others, and concentrate on relationship building ...

(Bogard, 1994, p. 69)

What these stories, and the stories in my research, all reveal is the amount of energy needed to undertake this kind of support work. Another strategy which takes energy to implement, and one which parents of children with disabilities often have to work harder at than other parents, is planning.

Planning

The parents identified this as an important issue, and Frank talked about the

planning that was involved, and the lengths he had to go to, for him to have a lifestyle he could manage:

Bruce needs a routine to keep him functioning reasonably well, and so knowing what that is going to be every day for weeks ahead, you can sort of plan to do other things in the hours he's away, and the weekends he may be out of your care. It's a case of planning in advance, and sort of knowing that things and events are coming up and you want to be involved in something, and planning for Bruce's welfare while those happen. Just getting up each morning and saying well, what do we do today, doesn't quite sort of work! Being involved in other organisations, it's a constant sort of battle to decide when you want to mow the lawns, and if the weather interrupts that, your routine is mucked up for anything up to a month. If you think you're going to mow the lawns a couple of days, then that will allow you to do this, this and this ... But without maintaining a life-style yourself I think a few months of Bruce would come close to pushing you round the final bend ...

It allows you to cope I think, knowing that you've got to get through this next fortnight of whatever's involved, whether it's just sort of keeping Bruce or preparing for something in the hours you might have free from Bruce, and then moving in to those activities, assuming what you need to do, and then back to standard routines. But without a bit of pre-planning ... and often with a caregiver I've planned many months ahead the days when I need her assistance, or need her to be involved, and she'll ring up occasionally and say, I've got Bruce down for tomorrow straight after school ... is that still required? And we compare calendars and decide, yes, that's definitely still required, and so she needs support and pre-planning as well, for her life-style to go on.

Strategies closely allied to planning, because they need careful planning to make them happen, were 'time out' and finding a good caregiver. Doreen talked about the first holiday she and her husband had by themselves after Chelsea's birth, the first time she had ever been away from Chelsea, and described how she came back "recharged". She thought all parents needed time out, and for Frank too, that was really important:

But I guess you must get a break. I can't visualize **any** family that could survive supporting a child without extensive breaks away. When people say they haven't had a holiday for three or four years, I sort of wonder how their mentality is holding up under those sort of circumstances. It's very easy to have a long spell with Bruce and feel like screaming - I don't know what for, but you feel as though you want to scream.

As Frank explained, having a good caregiver was an important part of this equation, and that can be a complicated and expensive business:

Finding good caregivers helps you to have a slightly different life-style. I've continued to be involved in other things, and at times I've had a reasonable break to take part in other activities, and a caregiver's offered, or given a service so that I can get out of town for a while. I guess the Aid to Families is for that reason, not just to give a babysitting [service]. But I've realised a lot of parents can't use up all their Aid to Families because they haven't got suitable caregivers or caring family members that will take over the responsibility of looking after a handicapped child for a period. A lot of two parent families are able to cope better in that respect, provided Mum and Dad are happy to go off and do things on their own, and get away on their own for breaks.

We've had one [caregiver] for a very long time, and she started off taking Alison for Brownies or something, Girl guides or something like that, and she was a member of the same church as Audrey, and they sort of took up a ... well, got to know each other, and she was just a casual babysitter for a while, for Alison, and then for Bruce, and then it sort of moved into a bigger responsibility for Bruce, and she's been around for most of Bruce's later life, I guess for the last ten or twelve years anyhow as a very constant caregiver, and she would be the one person that would be well versed in Bruce's habits. It was friendship, and I guess if you haven't got a friend, you can now use a family member that you couldn't use before. When those, when family and friends aren't available, then you turn to organizations I guess like IHC that will supply caregivers and run a babysitting organization, their

version of Aid to Families and Family Support in various ways. There is a support - there is community support I guess if you can ... but again it all costs money. Nobody works these days for nothing. No welfare organisation can survive without being paid for their services. I guess we've paid out a fair amount of money over the years, apart from the Aid to Families. We've been able to use some of the services to a greater extent than the twenty-eight days. Bruce now being on the pension, I guess allows me to use IHC services to a greater extent.

Mary talked about the difficulties parents can experience in finding caregivers, and how they are hindered by the changing environment and the changing rules imposed on families by the government:

Another issue is the Alternative Care issue, where the people that parents most trust are their family members, and the reimbursement for them is very little compared to if you have a stranger come in to your home to look after the child. It is bizarre, and I think Social Welfare has said that if you're the grandparent or the aunty or uncle of a child with a disability, then you ought to do it for nothing. But what they don't realise is the amount of strain, the amount of stress and strain that having a child with a disability can put on the parents, and their family situation, let alone an aunty and uncle who they trust, but who only comes in every now and then and has even less skills to deal with it. So that's what they don't understand, is that they may very well be a family member, but you get them because you know you can trust them, but they have as little skill as what a total stranger does, but they get reimbursed a hell of a lot less. I've never had Alternative Care, so it's never been a problem with me, but it's just another issue that comes up. It's Aid to Families now, it used to be called Alternative Care. [I haven't used that] since Justin's been living within the IHC. Even though I had him home for three of the seven days, you're not eligible for it. You have to have had him in your care for twenty-four hours, and seven days, which is fine. It doesn't worry me at all, because I have my break during the week.

In 1993 New Zealand ratified the United Nations Convention on the Rights of

the Child, Article 23 of which gives special and wide-ranging rights to children who are mentally or physically disabled and to their parents. In addition the Human Rights Commission Amendment Bill has become law and bans discrimination on the grounds of disability. New Zealand has a Commissioner for Children, Laurie O'Reilly, who in succeeding Dr Ian Hassall, has affirmed his intention to be more proactive than his predecessor on behalf of children, and has indeed undertaken inquiries on his own initiative into cases of violence and abuse. We also have a Health and Disability Commissioner, Robyn Stent, who is in the process of drawing up a code of rights, which will further protect the rights of people with disabilities.

However, even though children and their families have a measure of protection under the law, as Rod Wills comments, "[r]ights alone do not meet children's needs" and "[t]he law is a blunt tool with which to shape and mould societal attitudes" (Wills, 1994, p. 259). It is, in the end, up to parents to battle for their children, and to try to find their way around the rules and regulations, which can seem arbitrary and unfair, especially in a rapidly changing environment.

The Community

Accessing care and support in the family and community is a major theme for parents in the research literature (e.g. Sonntag, 1993; Hornby, 1992). Families are increasingly caught between unwarranted assumptions about the nature of the community, and a shrinking welfare state based on a free market model which equates freedom to choose with wellbeing. The fact is that freedom of choice without resources is not empowering. Frank's story reflects the anguish of families caught between the New Right rhetoric and the resource-starved reality of the 1990s:

One of the aims - I'm not quite sure if that's the nice way of putting it - I guess government policy has been that families look after their own, and communities look after their own people, and large institutions where handicapped people have been held over many years, these large establishments are slowly being closed down, and handicapped people - intellectually and physically - are being moved back into their own communities. If families can't cope, and some of them don't even

get asked whether they can cope, and when people who are middle-aged are returned to mothers and dads, often mothers and dads are of a very old age. I've seen family members returned to the family home where Mum and Dad are in their seventies, and they haven't been able to cope with their child at an early age, and how they're expected to cope in later life is always beyond me. That is the worst of the situation, but others of school age are returning to communities and often it's - they close one big establishment and have to buy small places in the community to house these people, mainly because families can't cope. They've been out of their care for many years at times, and to suddenly have them returned to families and communities as an accepted policy is not quite ... it doesn't agree with my thinking.

Colleen Brown, in writing of the costs to families involved in challenging the "powerbrokers", seems to confirm Mount's view of the family as enduring, capable and constantly subversive:

It seems to me that, post-Picot, many of the finely-forged parent groups have had to retrench, saving their energy to work for their child's needs at the local level. With so many professionals disappearing from the education scene, many of our supporters and advisers vanished. It has taken time to grasp hold of the ever-changing new system. Sadly, the parent voice might never be heard again in the way that was so carefully nurtured in the mid 1980s. It is not to say that parents will not find other ways of getting the message across - they will. It will be a different way, responding to the 1990s. I have complete faith in parent energy. It may wane from time to time, but it doesn't die. From time to time the flame flickers and is rekindled to meet the ceaseless challenge of ensuring that our children's rights are recognised and that they can take their place in society as they deserve ...

(Brown, 1994, p. 244)

As Colleen Brown says, parent energy does not die, but, as Violet explains, it can be very costly:

... with these children you're more involved and you know, they'll

always be your child. It's so true ... I guess in that sense because you've got to be a lot more involved than what you would normally be in their lives. And the energy levels that you need to do it! I've been to several meetings for parents with intellectually handicapped children, and the parents I've met there - wonderful people! But like their children are a lot older, and they look so tired! You know ... I don't want to look like that when I'm that age! I don't want to ... you know ... but you can see the writing's on the wall. And I guess now that we're looking at care ... I find that there's not enough support, particularly for children that have more than one disability. It's really difficult, you know.

Ferdinand Mount's idea of the family as the "ultimately and only consistently subversive organization" (Mount, 1992, p. 1) and the site of resistance against interference is well supported by the stories I heard from the parents in this study. They speak tellingly of professionals who have intervened in their own and their children's lives in ways that have not, ultimately, been helpful. The argument that the family as an organization has a natural resilience and ability to survive, and an aversion to being managed by the state or any other hierarchy or ideology, merits attention from such organizations, with their armies of those who are 'only here to help' (ibid, p. 173).

This chapter has set out to identify, acknowledge and document these difficulties for families. It is important that the issues be identified by the parents themselves, in order that strategies may be developed by families for the subversion of the power structures they encounter, and for their own survival. It is crucial that professionals become educated about issues for parents and about how to avoid strengthening the power structures and engaging in social control.

The following chapter looks specifically at issues families face in dealing with medical systems and personnel, with a particular focus on the current health regime and disability support services.

Chapter Four

The Medical Maze

Medicine always claims that experience is the test of its operations. Plato therefore was right in saying that to become a true doctor, a man must have experienced all the illnesses he hopes to cure and all the accidents and circumstances he is to diagnose ... Such a man I would trust. For the rest guide us like the person who paints seas, rocks and harbours while sitting at his table and sails his model of a ship in perfect safety. Throw him into the real thing, and he does not know where to begin.

Montaigne, *Essays* 3.13, cited in Sacks, 1984, Preface

It can be argued that current health reforms in New Zealand, introduced to bring market realities to the delivery of health, have burdened the system with so much bureaucracy that it has become a maze, not only for the patients, but for the health professionals as well. Carmel Williams, editor of *New Zealand Doctor*, commented recently that the medical profession now has two main purposes: providing care for patients and giving RHAs something to do. She also noted that the recent re-definition of a GP is no longer looked at from the patient's point of view, and that the RHAs are determining who should be paid GMS on the basis of which doctors are entitled to collect the subsidy, not which patients are entitled to subsidised care (Williams, 1995, p. 2).

Another article in the same publication reports: "The new policy for reviewing patients on long term sickness and *invalidity* benefits was drawn up by Income Support before negotiations with the GPA even started" (my italics). The heading for this item reads: "GPs pawns in benefit reviews" (*The New Zealand Doctor*, 29 September, 1995, p. 1). The critical question about who has the power to make decisions about the allocation of resources is difficult to answer when the GPs are complaining that they do not have enough medical information to review patients, and when the stated aim of the policy is to reduce expenditure.

The public health system is visibly under pressure. In an environment where there is an increasing emphasis on rights and a Government policy of

commitment to minimum national standards of needs assessment for people with disabilities, there is concern that funding restrictions, rather than policy statements, will determine what happens for people with health and disability needs. It is not clear what happens, for example, when the right to appropriate standards of service and the right to make an informed choice are limited by lack of resources. Although the new (since July 1, 1995) process of needs assessment and service co-ordination is supposed to focus on the needs, and recognise the knowledge and experience of the person being assessed, and their caregivers and family/whanau, it is not yet known how well the practice will match the policy.

My aim in this chapter is to analyse the discourse of medicine - that is the ideas, language, practices and institutions that contribute to the construction of a medical environment in which people assume identities as patients, doctors and nurses and a range of other health professionals - by privileging the parents' stories about how it impacts on their lives, and on the lives of their children and families. All the stories began with some aspect of medical intervention, through which they entered what Sarah described as

... this whole new world, and it changes your whole life

I have organised this chapter around themes that were important in the parents' stories.

The Hospital

The hospital, or as it is now to be known in New Zealand, the Crown Health Enterprise, is one of the major sites of the technologies that make up the discipline of medicine. Sarah's entry into this new world was sudden and traumatic. It happened in February 1994, when her son was rushed by ambulance and helicopter to hospital with meningitis. In the midst of what was an extremely traumatic experience, she was tremendously grateful for the medical expertise which was available for her son:

these guys are just so confident and cool and calm and you put your whole trust in them, you know, if anybody can save them, you know they can ...

the staff were just fantastic, they were really reassuring, as reassuring as they can be, you know ... I mean they're just so efficient and professional. I really admired that expertise. I was just so glad it was there. You never think you're going to need it - you never think your family will need it, or your child will ever get into that sort of state that you need that sort of help, but you're just so pleased, so grateful that it's there.

So you're in this whole new world that you've never experienced before, and it's, you know, your son's ... you can't ... do anything for him, he's just in the care of these professionals, which is ... I felt relieved that he was in intensive care. I never felt afraid or fearful or anything because I just felt he was in the best place for him to be saved. I thought if anybody could save him, it's these people here, you know, even with all the machines and everything.

The hospital became for a time the centre of the family's world:

We were there - oh we had friends in [city with base hospital] - Mark stayed with them the first night and I was in the unit. They had a couple of beds for parents so I stayed there the night and came back, and then Mark went back and got Emily, and so took time off school or the weekend or whatever, and took her back because we really wanted her with us, not in the intensive care unit, but these friends could look after her and at least she was in [the same city] and there was no ... we didn't want all this travelling back and forth. And I stayed in hospital with him, in the children's ward. They had rooms for parents and I stayed there, and Mark stayed with Emily at the friends' place, but I would go home every evening and see her for an hour or so and just have that time with her and settle her into bed and then go back to the hospital. But you don't sleep properly and you don't want to eat or drink, you have coffee or whatever, but your mind ... your body just goes on automatic ... you do what you have to do to survive, but your whole focus is on the child, and dealing with **all** the people who ... deal with him ... all those professionals, the doctors and the ...

It was a place of safety and security where all those professionals were firmly in control:

And then on the fifth day, after five days they decided to move him down to the children's ward, and he hadn't woken up from his coma, and I was just so beside myself over it ... I couldn't believe it. And then ... I had a big cry ... cause I just didn't want him to move from the Intensive Care. I thought he just needs that care. I didn't want him to go into the children's ward ... and then you get it out of your system and you get ready to cope.

...
I had one cuddle of him in the Intensive Care and I felt totally uncomfortable about it the whole time. I was really scared. I didn't want to ... there were just tubes out of him everywhere, you know, monitor lines or whatever you call them, and I just ... they put me in a lazyboy and they said oh, you know ... I felt I had to do it, but I didn't want to. I just was holding him and I just felt fearful for him the whole time. I just wanted him back on that bed all attached up nicely. I didn't get any comfort from it at all, or I felt I wasn't giving him any in a way too. That was in Intensive Care. That was just the once.

...
And of course you don't want to leave the hospital. He'd been in there twelve days, but it's still a shock when it comes round, because we expected him to be in a bit longer because he wasn't you know he couldn't see, and he hadn't walked, could hardly even sit up. We just thought he needed to make more progress or something. But they wanted us, they said for him to go home, after seven days [in the children's ward], he'd had the drip out for a day or two and that was really scary, and you're sort of, because you feel so protected there too, and everything's there and the people, the professionals are there, the advice and the help's there. And I didn't want to bring him home ... you know I just wanted him to stay until he came right. But you also know that you have to go home, and so we brought him home.

Back home, though, the family felt very much on its own:

So he came home, and you're literally chucked out in a way, and you get this note to give to ... that they send to your G.P. and you get it, and that's all, and the follow-up for his hearing test, and that was it. They were going to do some things in hospital like another chest x-ray, to make sure the pneumonia was all cleared up and all that sort of thing ... course they never got round to doing that, and there wasn't any follow-up as far as ... they weren't going to say, oh the public health nurse is going to visit, or you must go and see your G.P. or your doctor. I mean I made that decision.

Frank and his family have had numerous experiences of hospitals, and have learnt from them over the years:

Hospitals and Bruce have never been the most compatible, and we've eventually got to the stage where he doesn't stay in hospital overnight because that's too difficult for him, too difficult for staff, and too difficult for family, I guess. The only times he's been in overnight he's had some family member or caregiver sharing a room with him and being on call all the time.

Bruce doesn't speak very much ... ah, doesn't speak at all, but he can let out an awful yell if he really wants to, and when you can hear that echoing from one end of the [city] hospital to the other, you realize that he is under stress!

Hospitals have never been his thing, but we learn to cope with him and do things that suit him more than hospital routines just going ahead. So day trips in to have minor operations done, check-ups and what have you are just during the day time. Overnight stays are just too difficult for everybody concerned. It got to the stage it was just ... hospital staff couldn't cope. We left him heavily sedated one night sound asleep and he woke up and he screamed for something like two hours. We get a call at 3 a.m. in the morning to come and do something because they just can't cope. They learn, and we learn in the same process.

Doreen spoke of her extreme apprehension about going into hospital and her

relief at getting home:

Three days after Chelsea was born and we were flying into [city] ... my thoughts just, oh well, four months prior to having Chelsea my grandmother was in ... hospital and she'd just had an operation because she'd just found that she had cancer, and we were wondering how far it had got, and of course she died up there, and I was there the whole two days, her last days, and never had anything to do with hospitals ... I said I'd never, never come to [city] hospital. That's how I felt at that time, and then I was told I was going to that hospital special care unit and I went Oh God! ... because Mum, she knew, cause she heard me say, cause she was with me when she heard me say I'm **never** coming to [that] hospital. Mum goes, that'll be alright, special care is really good, Doreen.

I was, like I'd flown down there myself, and Joe had only just, we'd just, we'd only just gone into business, and at Christmas time too, being busy, and Joe had said oh, he'd come down the next day, and I went, oh good, you'd better, cause I was just freaking out to the max! And um, course he never made it, cause he got tied up at work. So I think I thought, oh well, never mind, Mum's here, got to pull socks up. I had a cry and a big howl, and a big sulk, and everything, but after that Mum ...

And when we actually got home and found out, well not so much why, but what was wrong, it was alright.

For some parents, the hospital can be the site of some complicated and confusing events. Violet talked about her experience:

I guess for us with Shaun being premature, we were told that there were going to, there may be some ... complications with Shaun because he was so small. We were constantly told that because he was so small, he may have all these problems, and things like that. So we were already, I guess, basically informed that, you know ... they didn't actually think that he would survive. While he was in the incubator and things, he did okay, because you know, you get forty-

eight hours, and if you survive forty-eight hours, then it's twelve days. And if you survive that time, well you're doing okay, and he was doing okay, until he got an infection in the lungs around about the tenth day. He was ready to come out of the incubator, and doing really well, when he got an infection, and so after that things went rapidly downhill. He had to have a blood transfusion and a whole lot of different things, and they also said then, as he had to be in the incubator a little bit longer, what could happen to the vision ...

So that was okay, and they just mainly focused on that, on just the vision, and then we came home when Shaun was out of the incubator, that was at about six weeks. and then he came home. He was born at the beginning of October and he was out of the incubator for a few short weeks, and beginning to ... you know how they have to wait for them to put on weight.

At the very beginning, Violet remembers feeling a mixture of emotions in response to the events that were going on around her:

I guess for some parents it's not a good thing. I don't know, but for me personally I think ... because they sort of whisked him away, and then [G.P.] came and saw me and said, oh would you like to see your baby? And I remember thinking ... I remember saying to him, no, I'm too scared to see him in case he might die. You know how you get that bonding and then he'll die, and then ... And he said to me, well, I think it would be better for you if you did see him, even if that may happen - it would be better for you. So I thought about it, and oh, okay then.

So I had to walk down with my drip and everything else that was connected to me. But I was really shocked. I really wasn't prepared for what I saw, because when I saw him that was when he was being dragged off and he looked quite biggish. And I was so shocked at how tiny he was.

Later, when Violet talked about her reasons for becoming part of the research group, she spoke about the spiritual aspect of her experience:

I had always been concerned at the way that the health service or the professionals had taken care of babies I guess, and how they seemed more concerned about keeping the baby alive, but in doing so not really taking into account the spiritual ...

Well, as a mum being in the unit with Shaun when he was in the incubator I always felt that - at times I felt he was angry, and also sometimes when I used to hear the other babies crying I felt they were crying out of anger ... I guess the intrusion into their bodies, and ...

But there must, there needs to be ... something more. I believe anyway that there needs to be some research done into the other s[ide] ... into the whole ... wholeness of the baby rather than keeping it alive. I know doctors and nurses have a real strong belief that, you know, they have to do their best to keep them alive, and I believe that's important, and they ... you often hear them say, well, if they didn't have the will to survive they wouldn't have. So that statement in itself suggests to me that they sometimes think about whether ... yeah, about the other side of things, about what the baby ...

Because we believe that when babies are born they have a strong spirit, in its pure, purest form when it's first born, and so imagine the intrusion into that, and maybe something needs to be done to acknowledge that part first before ... I dont know.

She appreciated what was done for the family:

...when Shaun was in the incubator when he was first born the doctors weren't sure if he would survive, so they asked us if we wanted to have him blessed, and that was really good.

and suggested that there could be even more acknowledgement of family needs:

And that's difficult for the professionals because I know that, you know, time is an important factor, isn't it? Like you know, as soon as they get

the baby out they want to be giving it ... oxygen and all the rest of it ... But I mean, they knew way beforehand that Shaun was going to be that way, that he may die. That could have happened way before he was even brought out, so that, like, before I even got taken into the theatre ... to come together and say a ... but I didn't sort of ...

...

You know it gives the family that opportunity, because, you know, there are Christian families who may have a need to do that as well. I'm just talking from my own perspective. I know we tend to do it quietly on our own. I don't know, to me it always seems to bring a different type of atmosphere. It may not change an outcome, but ...

Mary's experience of the premature birth of her baby was hard to understand at the time, and still is:

Justin is now seventeen, almost eighteen years old, and he was born nine weeks early. Prior to him being born I had had pains in my back, but I didn't realise at that stage that that was a sign of going into premature labour because I hadn't started attending ante-natal classes at that stage, and I actually had a back-ache for about forty-eight hours prior to that and I just remember being in bed all the time. But both Justin's father and myself just didn't realise that that was a sign of premature labour.

It's a claim that I've followed through with ACC, but we got to the review stage and it was turned down. So you can take it another step on, but I didn't follow it through. But I've got two letters which say that the most probable cause, those are the exact words, of Justin's condition was the dose of pethadine that I was given at his birth. But the hospital records don't show it because I was given pethadine by my doctor prior to leaving [town] where we were living, and then I was given pethadine by the hospital, and the only stuff that's showing up is the hospital records, not the stuff that was administered by my doctor from [town]. So the ACC found that what I was given at the hospital was not an unreasonable dosage, which is fair enough, because what I was given at the hospital wasn't, but there's no record that I was given it prior to

being taken by ambulance.

Managing the System

I have likened the medical system to a maze because it is made up of many avenues to service; the connections between them are not always obvious; they all lead somewhere, but not necessarily where you want to go or where you think you're going; and it looks daunting from the outside and confusing from the inside. Negotiating a system like that is a difficult experience for parents with a child who is sick, or diagnosed with a disability, or both, and even after many years, it is common for early remarks and events to be seared on the memory and recalled with painful clarity. Looking back, Mary still doesn't really know what happened and why, and she is still looking for answers, trying to find a way through the system.

Since going up to Homai last year and speaking to Dr [paediatrician] and he said there is some reason that Justin is like he is, because with that Apgar score at birth, there's just no way that he could have ended up with the disability that he has. So that's kind of where I'm at. You know, I'm really thinking, should I take this a step further, and investigate it, and I think, oh golly, I can't be bothered. You know, I'm kind of in two minds about whether I'm going to follow it through. I'm still in two minds about whether I'm going to pursue it a bit further.

But also the ACC had Dr ... who is actually Justin's paediatrician, look at the case that I made to the ACC, and he said that because Justin was nine weeks prem, that this wasn't an unreasonable thing to happen, that these sorts of things happen to prem babies. But my answer to that was that many, many more people [who were] premature babies do not end up with disabilities than do, so something more has caused it. It's not just the fact that he was nine weeks prem.

... so these sorts of things don't tie in for me, so I kind of am at that stage where I wonder whether I should take it further and pursue it, or whether to just leave it be.

Violet's initial experience of the medical system was different, but also

confusing, and difficult to understand and to try and make sense of:

Another thing, when Dr ... had told me that Shaun was blind, and he had contacted the paediatricians and I went in and they said, look ... because that was when we could claim the ACC, and they actually did all the forms for me, because we think ... and I know Dr ... felt that ... that they did all the things that they thought were right, like they had the monitoring machine and it was the first time they'd ever used it, and you know, the whole thing ... and out of all the premature babies, because there were quite a few born around that time ... that Shaun would be okay.

It was something that came across from them, how they just felt really bad about the whole thing. And I couldn't quite put my finger on it. I kept thinking well, how come they feel so bad? Because from my point of view, from what information they had given me it was like, there was that fine line that he could lose his sight, and other things may happen, because he needed the oxygen to stay alive anyway. So my interpretation was that, well, we were lucky to have him alive anyway, regardless of whatever complications may appear. And so I sort of accepted that, that okay we're going to have this kid that may have some complications, whatever they may be ... and not to be given the whole thing, I guess that's what made me so angry. It was like, here I was ready to accept, okay, this could be it. And I guess I had prepared myself for the worst, and so only to be given half of the picture ... seemed like we got dribs and drabs along the way.

Lack of information also contributed to Sarah's negative experience of coming home, which was, in contrast to the safety of the hospital, scary and confusing:

And so, you know, here we are, we brought him home ... and they couldn't tell us anything, you know, about the vision or anything like that. With everything with David at that stage, they didn't know, well, it just could be permanent, this is it, or ... you know, the paediatrician's famous words are, wait and see. But he didn't know ... this could be it, or he could improve. But he didn't know if it was permanent or not. but

as far as ... we sort of wanted to ... we didn't want to give ourselves false hope in that oh, he's going to get all better, he's going to get all his vision back, or ... we wanted to be prepared for the worst so that we could do the best for David. So we had to accept that he may be totally blind and this might be permanent, so what are we going to do? What do we need to do to help him and to help ourselves because it's a whole new area for you. You're so ignorant of what to do, you know. You have this normal healthy child, and you're in the normal healthy system, and all of a sudden you haven't got one, and you're in this whole new world, and it changes your whole life.

Doreen also talked about her experience of not knowing, and having to learn, about the services:

The first experience I had was with, the first service I had experience with was the occupational therapist, and the physiotherapist, and what I did was, I picked Chelsea up, especially me knowing, not knowing what a ... occupational therapist did ... she come in, and saw Chelsea and picked her up and asked how Chelsea was and said how happy she is, and that's all she did and then left. And I come back to [home town] and saw the O.T. up here, and I actually told the O.T. up here that if she was only going to pick Chelsea up and ask how she, how she was, then I, I won't bother coming up.

But ever since that first day we did, did a lot of work, and it was, you know, the first time I've seen an O.T. and she was holding, she was just holding Chelsea not ... not knowing what they do, and ... but when we come up to [home town] it was just completely different, because I actually told her how I felt, and she says, no, we're here doing work, and work we did ... aaah!

But I have also learnt that ... with having Chelsea, with my first child being a ... normal child, and I, I'm always such a rush-rush person that I ... having Chelsea I had to slow down, and that's where patience had to come into it.

Having Chelsea has made a big difference to the pace of Doreen's life, but there have been some very positive experiences in relation to the people who have come into Chelsea's life:

But it's been ... interesting ... the last three years, meeting ... all kinds of people ... All the services that I have now are just ... are terrific, especially after coming back from Lilli Nielsen [seminar] and seeing [physiotherapist] going oh, we're going to do ... try that, we're going to do this ... and I think it gives me a burst of, of go ... mm ... you come to place, come to a standstill, and you go oh, she's not doing anything else, so you, sort of like you're going downhill, and then something else happens, and that gives you a burst, more burst of energy to carry on.

Sarah, by contrast, felt she had to generate that energy all by herself:

it was very tiring, all the work, all the phoning, all the talking to people, filling out forms and that, it's very tiring ... instead of a lot of it being made available to you, like at the start, or even before, while you're in hospital or something ... given information that this is what's available. You're just ... you're out there, and that was it, and you're on your own. Community services ... well, you find them! It was a bit like that, but just as well we were, I was motivated to do it, because we just wanted to do what we needed to do for David, for his benefit ... you know these people are out there, and they're there to help you, but it's just plugging in ...

and as she explained, that can be very hard work:

And then of course with the paediatrician, we actually had to ask, because we wanted a diagnosis on his vision. We wanted to know ... we wanted him checked out by an eye specialist ... and so we actually had to ask the paediatrician, then and there, **insist**, you know, you have to insist, you have to become so assertive ... for your child, you know, and in the end you don't care whether these people like you or not. I mean you want to be pleasant, but if they're not being co-operative or if they're not trying to help you as much as you think they

should be you've really got to stand your ground, and simply insist, and be assertive, and that is also very tiring.

Theresa reflected back on the maze of health professionals that she had to work her way through in search of a diagnosis and services for her daughter:

It was probably the six week or three month baby check - the Plunket Nurse found that Carol wasn't focusing and wasn't following. So she just advised us to go - next time we saw the doctor - to mention it to him, which must have been when she was three months. He then said it was probable, possible that she was blind. I think he was unsure as to whether to send us to the Child Development Unit first, or to the ophthalmologist first, or t'other way round. But we went to the Child Development Unit first and they sent us to Dr [ophthalmologist]. And then [he], a few weeks later, put her into [city] hospital overnight for examination under anaesthetic, and then he organised for us to go up to Auckland for an electro-diagnostic test ... there was only the one test I think that they could do up there at that time. I think basically that established that she could see, but she was ... delayed development ... whatever that means.

But then every time we went to see Dr [ophthalmologist] it was ... it sort of would come out that she was short-sighted and had the nystagmus and I don't ... she's never been definitively diagnosed as yet ... because we went to ... we were sent to the Child Development Unit in [city], then I got a visit from the visiting occupational therapist, and she put me on to applying for the Handicapped Child Allowance, and I think later on it was the Crippled Children's Society as well, which we decided we didn't need to belong to. And then I got a visit from [RNZFB social worker] and that was through a friend of a friend. John's parents had heard that their grandchild was possibly blind or had visual impairment, so he called round, so that's how we got in touch with the Foundation for the Blind ... certainly didn't get any of that sort of information from the doctor. It took me getting the form from [social worker] and giving it to Dr [ophthalmologist] for him to do his bit to get Carol registered with the Foundation. He didn't consider it was necessary.

Frank talked about what it's like when your child has more than one disability:

I guess I'm involved in a child with more than one handicap, and that always makes treatment or support from one organization never enough ... I sort of find myself living in two or three different worlds. Bruce with his no speech sort of puts you in a situation, and while he's got no speech, and then you realise he's stumbling around because his eyesight is very poor as well, and that's really got nothing to do with his non speech, and then sort of his intellectual ability then sort of overrides both those sort of cases, and you ... you're not just focusing on his eyesight I guess. I've got, you know, sort of other ... worries is it? ... or you know other needs to look after on his behalf.

The parents' stories indicate some of the confusion, the uncertainty, the feeling of stumbling around in the dark, and the frustration of having to work so hard just to get from one part of the system to another, with no guarantees that the necessary links and referrals will be made by those who should know.

Information

Information, or lack of it, or difficulty in getting appropriate information, can create very real barriers for families trying to access services and create opportunities for their children. Violet remembers her own experiences very clearly:

I remember feeling really really angry, and the early childhood worker actually gave me his file to look at. They had the information, and I didn't, and it wasn't offered to me either. She said, do you realise you are entitled to this? I said, no, nobody told me that I could have it, or that we could have it ... that information. She said, oh yes, as parents you're entitled to it. Any treatment that your son's had, you're entitled to know about. Well, every time I asked questions when I was actually in there, nobody ever said anything to me. She said, well it's just, you know, who you ask. Every time I asked, it was always a nurse, and they would only give as much as they were allowed to give, and in actual fact the nurses were really good.

When I reflect, I think a lot of the things that, the type of information could have been a lot more basic stuff, how she explained it to me. I mean the doctors could have been right ... you know, maybe if they had told me too much at once it might have been too much to cope with, but how do you know unless you actually are told? I think I was angry because I would have preferred to have the whole picture rather than part of it. Because we were working a lot with Shaun, and still didn't understand why we were doing certain things. And I think the physio thought that I knew, and so she just carried on with what she had to do. Well, I **didn't** know, and nor did my husband, and when we came home, I think that was the most, I think it was about the only time I ever showed real, that I was really **angry**. I think I would have preferred to have known and been given the whole picture.

Violet spoke, as a Maori woman, about the impact of her culture on her experience:

But we didn't know our rights ... we didn't. I think being who we are, which is Maori, also - and I've spoken to different ones about this - we tend to take the professionals at their word, and so we have a tendency to really trust in their judgement, and yet it went against some of the things that we felt personally. This is my own personal experience with certain things with Shaun, and I don't think we ... like a lot of the things needed to be repeated and repeated until it actually sunk in.

Violet spoke also of how her own experiences influenced her work with Maori parents:

Because I dealt mainly with Maori parents, and they in particular didn't realise that they had a lot of rights ... to information, and information in particular in the medical files. The majority of them I spoke to didn't realise they could access that. They saw the piece of paper that the doctors gave, but no-one actually said to them, you have the right to actually see it. And even when they got told, they still didn't trust it. So I actually went along with them to actually ask if they could have their file, and it wasn't until they actually got it in their hand, and it was like, ooh,

we do, we do have this right ... you know, this is fine. And I used to see this in young Maori people, and they were sort of like, am I really allowed to open this damn thing? And I would say to them, some of the medical terms might be ... you know, so we're allowed to ask. And so when they got to work at it, and got to ask questions about some of the medical terms, the empowerment that actually occurred was absolutely incredible, you know. Then after that, to know that they could ask questions and they were going to get answered ... you know, they may not be the answers they were wanting, but that they were going to get some answers anyway, and the fact that they could keep asking questions ...

Sarah spoke of feeling ambivalent about the information she was receiving:

He came and took me away into the office there and spoke to me and he was very serious. I mean he gives you the worst possible scenario. I mean they do that these days, don't they? There's no sort of ... I mean you know in your heart probably it's ... good, but it's also really hard. You don't really want to hear it, you want to just hear that he's going to be alright. So he just said what it was, and what the possibilities were that the outcome of it was going to be because David was still in that ... he was such an extreme case that there was still a chance that he could die or he could be terribly brain damaged or whatever. He was in that ... they say 95% of cases recover and they're fine, there's no complication; then there's 5%, and 3 of the 5% have problems; and then there's 2% or whatever that die. So he was very straight about it, and I mean I was pleased to know. I mean I was horrified to know what it was, you know, and I was thinking even at that stage, I was getting very ... thinking it could have been prevented.

She talked about the anxiety of not knowing, and the need for the family to get enough information that was appropriate, about their child:

We were very worried that the optic nerve was damaged, and of course we'd heard that if that had been damaged then the blindness was permanent, and we were hoping like anything that that wasn't

damaged, but we needed that to be checked and diagnosed that it was alright or not, and of course we took him along, and he checked him all out and he said no, that the optic nerve wasn't damaged, and that was a real relief. But the damage was at the back of the brain, and then he made the diagnosis of the right haemianopia. And at least you had it, that this is what he's got, and this is ... [ophthalmologist] was really really good, and quite happy to write copies of letters to everybody, you know like you, and [itinerant teacher of learners with visual impairment], and I got him to send one to [hospital doctor] and the G.P. and no worries about that, so that was really good. And then, you know, we could become informed on the condition and what the outlook for it was, and then it was something we could tell people too, well, this is what he's got. It's quite hard to explain a right haemianopia, so even now we just say, well, he's got vision loss out of the right eye, because that just makes it easier. When I try and explain what it is, people sort of don't really understand.

She talked about the importance, for her family, of finding out:

that's helped us immensely with knowing, being informed, about his vision and what we can do, and what we can do to help him, and just also being reassured that what we are doing with him is right too

She also emphasised the difficulties parents can experience in trying to find out, and the skill and stamina that can be required:

For his sake I'm so pleased he's got the type of parents he's got, because there are people out there who would just have done as they were told, or done as they were advised by the one person, like the paediatrician, that was it ... instead of finding out or becoming informed themselves or asking questions and things like that and not just accepting that ... like we were. We were motivated to get out there and do what we could and not just accept, oh well, wait and see.

Doreen also talked about the difficulty of finding out:

The pupil in her eye was ... larger than the other one ... we thought, that's funny ... so we went back to Dr [paediatrician] and saw an eye specialist. But they didn't give me much information. All they told me was, was the skin condition and that was about it. Yeah, but I sort of picked up that something was wrong because of her head control. Because I can remember packing Chelsea up to come back to Wairoa, and her head was so floppy, I looked at her and I thought, I'm sure a one month old baby should have more head control than that. I was down there for a month ... oh mind you, I just didn't really worry about it because I was just so glad to come home.

And then when I come home I was seeing Dr [paediatrician] once a week, and then I got more information, then when I was more settled at home. I think it was just, to worry about her skin lesions and that. They saw her for the first four weeks after we left, after we left hospital. Then it was once a month, and then when I saw her eyes, when we noticed her eyes, I actually made the appointment to see Dr [paediatrician]. But I, like they told me bits and pieces, but that's when something's come up, like her sight, then we'd go. And plus they didn't, I think they didn't know much about it themselves, so they had to go back to the books every time, because like the sight, you have to go back to see if that's, comes with the skin condition.

She spoke with appreciation of staff who gave what information they had in a helpful and supportive way:

I don't think that, like I don't think they could have done any more than what they did. I think they did, they did everything that they knew at that time. See, like when they finally did get the information on it ... they've got a record up there and when I went to Homai they actually gave me a, just a short version of the skin condition, and what I read there was, she's got the severest of the cases, except for the spina bifida. That was the only thing she missed out on, that she didn't get.

... they've just done a chromosome test, about a month ago, and I go and see Dr [paediatrician] about that in a couple of weeks' time. They

found some abnormalities ... I don't know what it means yet, but when I get up there I'll ask, and tell them to translate it.

And like, with me and Dr [paediatrician] we've just got on really well. Like she's always said, if you need anything to ask, ask me, and if you need me to, to tell me to translate, please do so, because sometimes you know how they babble on in medical terms, and you wouldn't have a clue what they mean.

Doreen's animated expression of appreciation for a professional who made more than one deliberate attempt to break down possible barriers to effective communication indicated that she felt free to ask for a 'translation' if she needed it. This experience was not shared by other parents in the study, and in fact language difficulties proved to be significant for several of them.

Language

Ideas about language having the power to mystify and obscure meaning as well as to communicate meaning are useful and important for understanding the way that many parents experience 'professional' language. For example Mary spoke about the language that medical people have used in relation to her son, and the far-reaching effects that that has had for his life:

We had been to see Dr ... the eye specialist, and he, Justin says he speaks a foreign language, and I guess in a way he does, because we never understood what he said. But after going to him from the time we came to [city] when Justin was about seven or eight, probably for about four years, because while Justin was in Rotorua [at the Queen Elizabeth Hospital] he was still seeing Mr [the same ophthalmologist] down here, but he never actually said that it would be a good idea to enrol with the Foundation. It wasn't until I actually began not to understand what he was saying that I took Justin away and we went to Dr [a different ophthalmologist]. So that was just a private choice to do that, and the first thing ... he tested Justin's eyes, and he said, oh of course you're registered with the Foundation, and it was just like, excuse me? what are you talking about? ... and he said, oh you must be!

And so that was the opening of a whole new, a whole new ball game really. He would have been, he was in his last year at intermediate, so he would have been about twelve I think ... and so that just opened up a whole new world for him. The school were then advised that they had to use, you know, white chalk on blackboard, or black pen on ... and it just opened up a whole new world. But at that stage he'd had no formal reading, because he couldn't see the print, and because nobody picked it up ... nobody. No doubt Mr [first ophthalmologist] had picked it up, but he hadn't told us! He'd not mentioned a word in English, as Justin says, so that we could actually understand. I mean, I didn't for one minute **think** that there was anything wrong with his vision, because he just never said, in so many words.

Mary's reference to a foreign language indicates the degree of mystification that was in fact occurring in her case. Violet also spoke about how she would have liked information that was useful to her and that was given in language she could understand:

One of the things I felt I would have liked would have been a list of things ... yes they told me about the blindness, but I think I would have liked maybe a list of things that they thought also may occur, or happen, in plain English ... possibilities. And then as you went along during his lifetime you could have gone, oh no, that didn't happen. Yeah, I often thought about that, and you could tick them off and say, oh yes, at such and such an age, that happened, or ... a list like that ... and in plain English, because I mean they tell you, you're told a lot of things verbally. But I mean a lot of it washes over you, and sometimes when you're sitting in a quiet moment you sort of wish that you had something tangible to reflect on. And also the notes the doctors do for the files, half of us laymen can't understand, because it's all in medical jargon ... and unless you actually go round asking lots of questions ...

I've often thought a list would have been quite nice ... like the maybes ... this **may** happen, we're not sure, or these things could occur. When I think about it, for me that would have been a lot simpler instead of trying to remember everything, you know, and you had to keep asking and

asking. And every time you kept asking it was like ... ah, sometimes you felt stupid, and a lot of parents I've spoken to often said they felt stupid about asking the same things again, because they weren't sure, you know? So at least if you had a list you could say, well could you explain this again to me?

Frank also talked about the difficulty of remembering all the long words:

The technical terms have been so long and so many that it's very difficult to recall it off-hand.

The use of language which has the effect, if not the intention, of masking the political interests of the powerful is one of the 'technologies of power' to which Foucault refers in his analysis of how power operates at the level of daily life. Metaphor is powerful to shape reality, and if the language is characterised as 'technical', 'foreign' or 'jargon' and the effect of its use is that people feel stupid because they can't remember or understand it, then it constitutes a major barrier to parents' ability to access information, and an effective smokescreen for the political interests of the user. When technical language is necessary for a careful explanation, then the attitude of the person using it determines whether it is being used for power or precision.

Attitudes

Attitudes encountered by parents can also be seen as barriers, and Frank uses a powerful metaphor to describe his experiences and the barriers that as parents he and his wife had had to try and break through:

My wife I guess wouldn't accept being fobbed off, and she wouldn't accept the reasons we were given when Bruce was younger as to what his problems were, and constant battering at doors I guess and banging on tables broke through often a medical barrier, that people like Bruce were just sort of classed as no-hopers and therefore the parents' responsibility, and they were almost told that they would need to care for handicapped people in their own environment. But we were not prepared to see Bruce just cast into an institution, which were available in those days, and we just sort of kept on hammering, kept on

trying to find out what Bruce's problems were. His eyesight was very obvious, that when he looked at something from about two inches away, and obviously couldn't see it from any further away, you realised his eyesight was poor, if not almost non-existent. For a period he was obviously deaf and he was not making any sound at all, and very very seldom cried ... and with no sound, obviously no hearing and poor eyesight, his future didn't really look great. But by keeping on with people, ear specialists I guess they were, were able to say that Bruce's hearing problem was caused by a throat problem which is also tied up with his no vocal expression.

Uncooperative, or unconcerned or obstructive attitudes were a common barrier that parents experienced in their search for support for their own efforts on behalf of their children, and Sarah spoke with great feeling about how she experienced this:

And we had the paediatrician's appointment, and of course he was appalled, you know he ... that we had got in touch with the Foundation for the Blind, that we had got in touch with all these other people. He couldn't understand it, you know, he didn't think it was necessary, and you know, in turn appalled us, because we wanted to do what we needed to do for David, what we felt was best, because he needed help, and he was only giving us so much and that was it. And we needed help as a family, you know ... these other people that come in, they give you ideas to cope with everybody in the family, like Emily and Mark and me and that, and to deal with David.

So we just sort of had to not worry about him really, you know, but we were ... angry sort of at that too. Whereas we could have got a lot more positive stuff from him about it, or he could have made it a bit easier and got all this referral done for us, and we could have just been in the system, or got in to see these people a lot easier. He was ... he just had one perspective on David and that was it. There's lots of things ... the form he wouldn't sign - Foundation for the Blind - so we thought right, we're going to have to do this without you, and you know, that was it, we thought well, we can do this without you, we don't need your

permission to do this

Mary too, had experience of professional insensitivity and dismissiveness:

I also think that professionals shouldn't - I'm going back to Justin's birth here - I think professionals shouldn't give out information they don't know **anything** about, because when he was born, and he was nine weeks prem, and at ten months old we were told as a family that he had cerebral palsy, but at that stage it didn't mean anything to us, because we'd never experienced cerebral palsy before, and so it was just like being told the time of the day really. But I recall at the time the doctor saying to us, don't worry, because by the time he's three, he'll be up and walking, and you know, that still sits in my mind today. But then, in the home, one of the nurses said, oh, you know, do you want to swap him with another one? Just such **insensitive** stuff! Or that was an insensitive thing, not the thing about the three years old. It was like being told something that really was just a pie in the sky thing. And of course when that doesn't eventuate, you feel quite disillusioned.

Another incident that I remember was, I had taken Justin to the paediatrician - this is when he was young - and said, you know, this is what he's doing - I feel there's something wrong, and I'd been put off for a couple of visits, went back because I still felt that something was wrong with Justin, and he said, oh well, I'll refer you for Justin to have an EEG, whichever one it is for the brain, and he gave me a referral letter. Well I opened it on the way to the [large hospital] from [smaller city] and it had "this neurotic mother ...". So anyway I got there, and it turned out that that was his epilepsy - the scan showed that he had epilepsy.

But this has happened on several occasions where parents have opened a referral letter, and I **always** open a referral letter. You know, where you're thought of in this way, as just a neurotic parent, and yet you often feel that parents know best what's happening in their children's lives. So unless you've got professionals on the other end who are prepared to accept the information in the way that it's given,

sometimes parents are banging their heads against a brick wall.

Violet also talked about the anxiety of being labelled in a particular way by professionals:

And then I had to go to the assessment. It was done so differently in those days. You went to see a psychiatrist, and he did his observation up there in the assessment room, and ah, I didn't particularly like ... and I mean as soon as you hear psychiatrist eh, it's like, Oh God, you're going to be named a ... a mad mother or whatever ... or a bad mother. And I was by myself, and that was the hardest ... I think it must have been the hardest thing I ever had to face.

Violet's words, and the feeling with which she conveyed them to me, indicate the extreme power imbalance that characterised her experience of an encounter with a particular professional. It is my fervent wish that words like these will convey to professionals an understanding of the power that lies in even a word such as 'psychiatrist'. Violet's story shows the power of the professional 'gaze' to strike fear into her heart, and paralyse her with self-condemnation. This power imbalance means that asking questions or negotiating over issues is likely to be extremely difficult, and asking for a second opinion or a referral elsewhere is usually ruled out as not even an option. One issue that several parents expressed concerns about was the problem of medication for their child.

Medication

Getting appropriate medication, appropriately prescribed, for a child was a theme which was important for several parents, and indeed it has been an ongoing issue for Violet. She describes one battle over this issue:

And then of course when Shaun started to have epilepsy, and that was a few years later, and that came up as a regular issue then, and we had quite a battle with that. The matron felt that he had to have medication. My argument was that if he didn't fit on a regular basis, why would you need to go to all this need for medication. Her complaint was, her concern was the trauma that it caused for her staff. And I thought well,

why are they in the job in the first place, because half the children that were there all fitted anyway. But I mean they could keep them nice and placid on medication [laughter]. So I had a big battle with her.

I gave in, against my better judgement. And we saw our son when he came out of hospital, and we both stayed up there that time, and that was really good, but he was like a zombie, and we didn't particularly like that, so we had lots of arguments about it. And we saw him go from a nice slim chappie to a big ... whatever, because they were giving his medication to him in a milkshake, and he just put on so much weight. It took his body ... you know it takes a lot for the medication to work through the body.

It was Doreen's family who noticed the effect of a particular medication on Chelsea and urged her to stop it:

They gave her some medicine. It was actually quite a ... I think of it as quite a laugh, cause my Mum she's had nine children, and she really doesn't need her grandchildren on her doorstep as well. And because Christy is such an alert, well she was an alert two year old at that time, and Chelsea had this medication which just about used to knock her out ... it did ... she was on it for about, how long ... three months, yeah, about three or four months. It used to just knock her out, and Mum would go, oh yes, I'd have Chelsea any day ... one drop a day and she's an excellent baby! But it's quite a joke you know, because, you know, she's been through nine children ... anyway. Dad used to always say to me, **stop** giving her that medication, she's not getting anywhere with it, and I says yeah, but you have to, she might have a fit ... epilepsy.

And Mum, Mum come with me to do all the tests, and see if she did, and then they changed it. Then I said to Dr [paediatrician], I says, oh this medicine really zonks her out. I says, don't get me wrong, she's really good at night, and if you give it to her she's, you know, when you put her to bed she stays there. Having Christy, she used to be up four or five times a night [laughter]. And so they changed her medication, and even Dad, you know, actually noticed, you know, really noticed a

difference ... see, she can do more now!

Because of the devaluation of parents' knowledge that is common amongst professionals, even assertive parents find it almost impossible to challenge a professional judgement. Even if they manage to do that, they are likely to face a full-scale battle to be heard, understood, and acknowledged as having a valid opinion. Prescribing, then, could be described as a 'technology of power' in which the power resides overwhelmingly with the medical professional who does the prescribing. Another of the mechanisms which works to maintain professional supremacy is the medical examination or assessment.

Assessments

Examinations and assessments are part of life for parents of children with disabilities, to the extent that they have become a taken-for-granted, regular part of 'qualifying', for assistance from the state, or for referral for 'special' services. Mary spoke of the frustration of having to get a medical examination done and a form signed every year for Justin in order to "justify" for Social Welfare purposes the fact that he still had cerebral palsy. Yet there is a sense in which assessment and examination operate as "a disguising ideology", in which "both assessors and the assessed have its true nature hidden from them" (Withers and Lee, 1988, p. 188). It is in effect a ritual of Foucault's disciplinary power, subjecting individuals to a form of surveillance which is intended to divulge the 'truth' and establish or maintain eligibility. William Staples talks about the "small acts of cunning" that constitute disciplinary practices in contemporary life, and characterises the examination as "a ritual knowledge gathering activity that employs "hierarchical observation" (surveillance, information collection, and analysis) and "normalizing judgments" (the assessment of an individual's activity set against standard specifications)" (Staples, 1994, p. 647). As he points out, those being assessed become "partners" in a process where the power is in the arrangement not the assessor, and the assessment is generally accepted as benevolent, even desirable. Thus the powerful aspect of assessment is hidden from both assessed and assessor, compliance and quiescence are encouraged, and resistance is seen to be self-defeating and indeed neurotic.

As a young mother, I well remember the turmoil I set up for myself by my non-compliant, ungracious reaction to a home visit by a medical practitioner who came to review our eligibility for the Handicapped Child Allowance - as if the odious name wasn't enough! I experienced the visit as an intrusion, and I felt demeaned by the process. The doctor himself was pleasant and courteous, and 'only trying to help'. It is this hidden aspect of power relations, the structural inequality between parents and professionals, that often causes a feeling of powerlessness and anger in parents. Withers and Lee suggest, in their analysis of assessment as "power in disguise" that the process of negotiation is one key to the "decoding" of assessment. Mary's story about Justin's assessments illustrates both the powerful nature of the system, and the victory for families when negotiation works:

I'll just have a talk about the Social Welfare and the absolutely ridiculous stuff that some parents have to go through. If you've got a child with, I don't know, maybe it's with any disability, but I'll talk about cerebral palsy, if they're born with it, it's never going to go away. It may improve, their abilities may improve, but the fact that they've got cerebral palsy is never going to go away, but what you have to justify to Social Welfare each year is the fact that they've still got it, and that is a very frustrating thing. Justin was thirteen when I finally got a letter from Social Welfare saying that we didn't have to go through this yearly review, that they accepted that he had a permanent disability. And he has very obvious disabilities, someone who's never walked in his life ... thirteen! I have the letter, quite close to hand, so that I can always refer to it.

Frank also spoke of feelings of frustration about his experience of the 'expert' medical examination:

There have been a lot of visits, and without speech it's very difficult to gauge any reaction from Bruce. Eye tests at various distances comparing what he can see at a distance to what he's got in his hand can vary greatly and each time we go they seem to sort of come up with a different conclusion from eye tests. If he can't see he turns off very quickly ... there's no point in just gazing into the distance if you can't

see anything, and I can see nurses and eye specialists getting very frustrated when questions don't bring forth an answer. If he did have an answer he can't express it, and it's very difficult to know just which eye he can see out of, and the assessment of his vision is done by experts with minimal response from Bruce, which I guess is frustrating for them, with no idea what reaction Bruce would have, and most frustrating for parents as well, just knowing that your day gets interrupted to go to a medical examination, and when it's over you think well, that was another waste of petrol.

It is clearly not only the language of the medical encounter which is mystifying, but the reasons for appointments, and the expected outcomes, as well as actual outcomes, are all too often unclear to parents, who are left feeling confused and resentful about the waste of time involved when they can see no benefit for their child.

Negotiation of the Maze

In this chapter I have discussed some of the issues the parents in my study faced when finding their way through the maze of the medical world of institutions, terminology, technology, and professional people. In presenting their perspective, the parents have shown how parents of children with disabilities are doubly vulnerable in their dealings with medical professionals and systems. This vulnerability derives firstly from the disability and/or illness of their child, and secondly, less obviously but equally powerfully, from what Oliver Sacks, writing of his own experience as a doctor become patient, calls

the reduced stationless status of a patient, and, in particular, conflict with and surrender to 'them' - 'them' being the surgeon, the whole system, the institution - a conflict with hateful and even paranoid tones, which added to the severe, yet neutral physical affliction a far less tolerable, because irresolvable moral affliction. I had felt not only physically, but morally prostrate - unable to stand up, stand morally before 'them' ...

(Sacks, 1984, p. 122)

He goes on to describe how the failure of the medical personnel to listen to

him, and to believe his account of his own experience caused him to feel "morally helpless, paralysed, contracted, confined - and not just contracted, but contorted as well, into roles and postures of abjection". He tells how he had to play the role of "all-passive patient" to the surgeon's "all-wise consultant". This is interesting, and all too familiar to a good many parents of children with disabilities. The critical point in the story, however, the point at which Sacks' story diverges from the 'norm' is that he goes on to tell how he was able to have 'a good talk' with the surgeon "which took us both off the hook". This was because "I needed him less. I no longer felt critically (and resentfully) dependent. It was possible because my world had enlarged - and so he, the system, the institution, could shrink, shrink into a reasonable and proper perspective." (ibid, pp 122-123). Parents of children with disabilities are, by contrast, usually not able to have 'a good talk' to 'get them off the hook' because their roles as parents of patients prohibit it. As well, they continue to need, and to feel critically, (and often resentfully) dependent upon medical personnel and the system. Exit is not often an option for parents of children with disabilities. Negotiation is one way in which the "calm, unproblematic surface of the assessment process" and other 'small acts of cunning' may be "at least ruffled" (Withers and Lee, 1988, p. 188).

The stories in this chapter have followed the parents' sometimes slow and painful progress through the medical system. They have shown how 'technologies of power' such as discourse and language use function to shape reality for children with disabilities and their families through labelling, mystification, even intimidation. They demonstrate also, the power of the medical 'gaze' (Foucault, 1979), for example professional assessment, by means of which people's bodies are examined, defined and ranked against certain 'norms' (Munford, 1994). These stories have, quite literally, mapped out the terrain in which, and by which, the lives of children with disabilities and their families are constructed (Kondo, 1990).

The next chapter looks at the settings, the systems and the professionals that parents deal with in trying to obtain the most appropriate educational opportunities for their children.

Chapter Five

Education: Creating Opportunities or Life-long Disadvantages for Students with Disabilities?

The definition of special educational need which still dominates today is one that sees it as an individual problem. This individualization pervades the teaching process, the categorization and assessment of children, and the practice of the professionals, notably teachers, doctors and educational psychologists.

(Oliver, 1988, pp19-20)

Education, like health, has traditionally been regarded in New Zealand, and still is by the general population, as a public good and as something to which everyone should and does have a democratic right. Since the 1989 Education Act, all children have the right to attend their local school. The law guarantees an education system that provides for the needs of all students. However, this right is compromised in practice by an education system which, like the health system, is increasingly the site of struggles between a managerial and a professional ethos. One example is the struggle that has arisen between the teacher unions and the government over the Minister of Education's efforts to devolve management down to individual Boards of Trustees, while retaining absolute control of finite resources.

The administrative reorganisation which devolved management of schools to parent-driven Boards of Trustees also strengthened state powers of control at the expense of the professional autonomy of teachers. The Ministry of Education retains its responsibility for policy and curriculum, and the Education Review Office, whose reports are made available to the public and the media, is designed to maintain control of the teaching profession. Conditions of employment, such as the introduction of contract service for principals, the 1991 removal of the requirement for teacher registration, the ongoing debate over performance-related pay, bulk funding and more recently, direct funding can all be seen as a threat to professional security, and have found allies, as Roy Nash remarked of the reforms, in "localism, anti-bureaucratic populism, and even tribalism" (Nash, 1989, p. 126). Writing in

1993, he observed: "Schools have become increasingly responsive to parental needs, partly as a consequence of administrative reforms ... " (Nash, 1993, p. 207), and he commented also: "At the moment - and it seems an extended moment - government educational policy is driven by a neo-liberal economic doctrine that sees in the operation of market processes a powerful mechanism for efficiency." (ibid, p. 205). We have seen the effects of these struggles in Board of Trustee decisions to opt for bulk funding resulting in teacher strikes. The contradictory goals arise from the construction of parents on the one hand as managers of schools and employers of teachers, and their contradictory construction on the other hand as consumers of the professional services of teachers who teach their children.

The struggle continues, and in fact as I was writing this chapter Labour, United, New Zealand First and Alliance MPs combined in a bid to restore compulsory teacher registration. As a result, the government was defeated and The Teacher Registration Bill was referred to a select committee for consideration (*The Hawkes Bay Herald-Tribune*, Thursday, September 21, 1995, p. 2). This has been interpreted, by the editor of this newspaper at least, as having "more to do with giving power to the teacher unions to decide who schools can employ than keeping child molesters out of the classroom" (ibid). Similarly teachers have walked off the job in protest at Board decisions to opt for bulk funding (*The Dominion*, Friday, September 22, 1995, p. 2). What this means is that parents and children are effectively at the mercy of politicians, educational professionals and Boards of Trustees whose attitudes frequently have not kept pace with the law.

Parent groups have been advocating for an equal and inclusive education for their children for at least a decade. As Keith Ballard says "Success in school and community integration is well documented in New Zealand, as elsewhere. We do not need further research to support the idea of inclusion because inclusion is a moral imperative, not a matter of data." (Ballard, 1994, p. 305). The call for "inclusive education for New Zealand" was made in 1991 by the Interagency Group, which involved the New Zealand Society for the Intellectually Handicapped (Inc.), New Zealand CCS, the Royal New Zealand Foundation for the Blind, and the Government Special Education Service

(McKay, Rowlands, Ballard, Smith and Gleeson, 1995, p. 3). It is a position, as McKay et al argue, that is supported by many New Zealand parents of children with disabilities "who want their children to experience the same classrooms, curriculum and opportunities as every other child in their community" (ibid). As one parent writes:

The word 'special' sometimes permeates every aspect of children's daily lives, their educational programme, their teachers, transport, benefits, employment. Many parents view the word 'special' with loathing; it hangs around their child's neck like a dead albatross, signalling the separateness of their lives. For many parents 'special' translates to 'exclusion' and 'devalued'.

(Brown, 1994, p. 241)

The policy of the Minister of Education to support parent choice means that the Special Education system in New Zealand is still split, as are the resources, between two models: that is, children can attend their local school in what is commonly called mainstreaming, or they can be part of the special system, that is, special schools, special classes or special units. However, a failure to provide adequate training and resources sometimes leaves children and their parents with little real choice. They are forced to go to the option which is best resourced to cope with their child's needs. This means that the parent voice is split because some parents are having to struggle for resources to support their children in the mainstream, while others struggle to save their special school.

Boards of Trustees play the largest part in providing special education services, managing seventy per cent of total special education resources and employing special education class teachers and itinerant teachers, teachers' aides, and, in some cases, speech-language therapists, occupational therapists, and physiotherapists. The remaining thirty per cent is accounted for by the Special Education Service (23%), school transport (5%) and study awards (2%). The Special Education Service (SES) is a crown entity and provides specialist advice, guidance and support services under contract to the Minister of Education and a range of other purchasers (*The New Zealand*

Education Gazette, Vol. 74, Number 4, 15 March 1995).

While currently receiving most of its funding from its contract with the Minister of Education, the Special Education Service is "increasingly carrying out a wide range of other work" (ibid) and contracting to agencies other than schools. The environment is one in which market forces rule, and indeed the local SES has recently applied for and won a business management award. It is not surprising, then, that teachers and parents find it increasingly difficult to enlist the help of SES personnel "on the ground", that is, in schools and homes where children are. It is clear that while the government remains in control, the SES has a shrinking role in and commitment to the support of children in schools, and the overwhelming responsibility for managing this decentralised system rests with Boards of Trustees.

It is very difficult to ascertain from the small amount of literature available if the option of being elected or co-opted on to Boards is a course which has been taken up by parents of students with disabilities to any significant extent. Anecdotal evidence suggests that it may be, but the research suggests that the system has already moved a long way from its original conception (that anyone who can manage a child can manage a school), towards a more professionalised, managerial view which favours the election and co-option of 'experts' rather than representative parents; on to Boards of Trustees. A 1990 study found that 57 of the 85 parent representatives worked in occupations which placed them in the top three socio-economic categories of the Elley and Irving scales (Middleton and Oliver, 1990, p. 53). If this was the case in 1990, then Gordon's 1993 finding that "there has been a general shift from 'representation' to 'skills' as the basis for co-option (and election)" (Gordon, 1993, p. iv) may indicate a trend towards "professionalisation" of Boards of Trustees that may make it increasingly difficult for members of any minority or special interest group to influence school policy and practice at that level.

Given this situation, it is clear why the responsibility for making educational decisions and for gaining and maintaining resources to support children with disabilities often lies with the parents of those children. The issue of choice was a major theme for the parents in this research study.

Choices

Making choices presupposes a knowledge of the options and opportunities that exist, and being free to make a choice is meaningless to a parent who is struggling to get information. This was a problem for Violet when Shaun was little:

I know they kept saying, you need to introduce him to a lot of experiences, but **how** did you do that? How was I supposed to do that? Those were the little finer details, the practical things, like ... a lot of times when I did things for Shaun, I had to close my own eyes and try and figure out how would you teach this blind child? And he couldn't feel much on his right side. A lot of that type of stuff, you know the practicalities of things and how would you go about it because there wasn't that type of information. They gave me lots of things to read, but I think I would have preferred them to actually show me ... someone coming here on a daily basis would have been wonderful ...

I guess with normal children you take so much for granted of how they just wander round and play with things, but with the blind children, they don't **do** that. They don't **do** those things - to a point. The early childhood advisor for blind children was only here like once a term I think it was, and then it was like once every six months. But she was excellent. We just used to say to her, it's a pity you can't stay down here. And I guess that even in the kindergarten, I think that to have someone that had some of that specialised knowledge - because there wasn't anyone, and she was trying to establish early childhood at Homai at that time too. It was really important, because there wasn't a lot of input into preschoolers at that time - early intervention as it's called. So I guess that's why I got such a buzz and felt early that early intervention was so important.

Doreen's choice for Chelsea has been the local kindergarten, and she has found it works well for Chelsea and for her:

This is only Chelsea's first year at kindy. Even her teacher aide, and

you know the teacher, like they really are keen, keen people. One part there, someone suggested to put her in a room by herself, and I said no, I don't want that ... for a little while maybe, but not the whole session. Because they reckoned they had too much interference from the other children. I thought well that's ... you know, she's got to get social activity as well, and she's home most of the day by herself anyway. They actually, they always ask me how I feel about it.

Violet also found the early childhood staff interested and supportive. She said:

I was really thankful for the CCS kindergarten, because they took him in, and he went there until he was four ... or five I think he was.

However, at that stage she was forced to make another decision, and her story reflects the anguish of a family confronted by an excruciatingly difficult decision:

The only thing that seemed available to me at the time was the suggestion Shaun go to Homai because he was totally blind ... that would be the best place for him. And I think I was really ... like it didn't seem that the service here could cater to his blindness. They could cater to some of the other things, but not the blindness ... when Shaun went off to Homai it seemed like that was the only option we were given, because it comes back to being totally blind. You know, they kept saying, well he's going to have to learn braille, and things like that. But even though he was quite young, it seemed like they were saying it was the best place to go. He was five and a half. That was quite young. I remember feeling quite dis... and then I had to go to the assessment. It was done so differently in those days. You went to see a psychiatrist, and he did his observation up there, in the assessment room, and ... ah, I didn't particularly like ... and I mean as soon as you hear psychiatrist eh, it's like oh God, you're going to be named a ... a mad mother or whatever ... or a bad mother or ... and I was by myself, and that was the hardest ... I think it must have been the hardest thing I ever had to face. And like I was saying because things weren't going too well between my husband and I, I think that all added to the ... you

know, and having to make ... it seemed to me like having to make a major decision, and realising that I wasn't coping as well. That's when sort of I realised there were a lot of things I wasn't coping with. And I felt that that was all sort of put under a microscope, and I knew that there were pressures at home because our oldest daughter was coming into her teen years and she was playing up a bit. Nothing really major, but it **seemed** that way, you know, it just added to everything else that was going on. And I made the decision to allow Shaun to go there, because I felt I needed to give her time too. I felt I needed to give the eldest girl some time and help her, and I didn't feel like I could cope with both issues. And that was a really hard one. I always remember, I remember that day I rang after one particular assessment, because you're up there for several days. I think after the first day I was like, in tears, and I remember being on the phone to my sister, and I mean that's the first time I they had this image of me of being a very strong person, and so here I was howling on the phone! And of course my sister didn't know how to cope with that! ... [laughter] ... she kept saying oh are you alright Violet. At the same time that I was going through what I was going through, my husband was home with the children, going through his own hell - whatever it was - because he felt he needed to be there as well. But then he felt he should be here to look after the other children, and while I was up there I was fuming and getting more angry with him, and didn't realise that he was down here, wanting to be a part of that but didn't know what to do with the children. So it was a lot of miscommunication in a big way ... and the missed opportunities we had to be sharing in that time. Because when I reflected back, I didn't want to share, like what was happening for him and things like that. So the whole bit ... and it was really quite sad. I mean it wasn't until years later, like I say, that we actually got to talk about those things, and that was a lot of years of miscommunication. And I mean he was coping the best way he knew how.

Now he and I have sat together and talked about it, and as I said, I actually, if I had my time again, I would not have sent Shaun away that young, because I think for him that was quite traumatic, because he had

been so involved with the family.

There were many battles and difficulties for Shaun and his family, but as Violet explained:

We can't keep beating ourselves over the head ... we did the best that we could with whatever information we were given ... about the educational placement ... so I guess I had made a decision and I sort of stuck with it, and just got on with it. [...] It seemed like the only choice, because when we were looking for assistance, when he was going to the CCS kindergarten, and they were asking for a lot more help, they didn't seem to get that support ... I know [early childhood advisor] said that Shaun could go to his local school, but from my experience of what little support we got for kindergarten I didn't think it would be any better at school.

Violet talked about the "guilt trip" that went with the decision to send Shaun away to school, and the pain of not being there when he was ill or when there was a need or a crisis in his life. She told how the decision to bring Shaun home and try to find support within the community has been very difficult, putting pressure on the family and on the relationship between husband and wife, and limiting her own options because, as she said, she couldn't work. For a time Shaun attended the local intermediate school, where he was placed in the special unit. Violet felt he was coping well, and that the environment was good for Shaun, but that came to an end because, as she said, the curriculum was not appropriate and the staff were not coping because they were not getting enough support. So now Shaun is at a special school, where the staff are appropriately skilled and committed, and it seems, Violet says, to be okay for Shaun. The trouble is, as Violet says:

I guess the continual battle with systems is the hard part. I'm now at a different stage with Shaun and we're going in to the young adult stage, and that's a whole new lot of problems again, and then I guess when he becomes an adult that's going to be another stage.

Mary too, has had to make a series of decisions about Justin's education, based largely on the labels arising out of various psychological assessments. Things changed dramatically for Justin once his visual impairment was recognised and addressed:

That's really opened up a whole new world for him because he then started doing a lot of his learning by aural listening. He still kept on reading, he actually still kept on trying to read until ... but it was like a twelve year old learning what a pre-schooler would learn, and he found it really frustrating. But he persevered with that, and it wasn't until last year that he actually decided not to carry on with the very basic reading, and just to do it all aurally. Oh, it's just been wonderful. He sat School C English - got the same mark as me, thank God! Or else I would never have lived that down! I thought I got 64, and I had to go searching for the results, but thankfully I got the same as him, because I would never have lived it down! But, you know, it means, it just means that things have been put into place to allow him to do things. He does a lot of his learning in the classroom. He has a reader-writer who will write for him, but he has the tape in the classroom himself so that he can have control over what he hears, rather than what the ability is of the person to take it all down. So he's actually hearing word for word what's said, and if he chooses to retain it, that's what he does, and if he doesn't he can toss it out, rather than having to rely on somebody totally for his learning.

Justin's achievement was, and is, a major cause for celebration, as Mary says:

That was how he ended up doing his school work, before he sat School C English last year, was through his ears. Because he couldn't read or write, he did all of his learning through listening, revision through listening, through having somebody read his work to him. His achievement in the end was just an absolute tribute to the amount of work that he'd put in. It wasn't easy. I mean, he and I argued something dreadful at weekends, when it came to studying, because he wanted to give up, and I said to him you're not giving up when you've come so far ... you're not going to give up. Because he had it there, I

just knew that he just had to be kept encouraged to go ... because he couldn't read or write, he just found it terribly frustrating, because everything that he learnt in the end, he has learnt through memory. It's not been through reading and writing ... and when he got 67% for School C English, that was just the most **wonderful** achievement in the world. It was just unbelievable! So I would really like to pay tribute to Justin and say that he's just the most wonderful son.

This achievement has, as Mary said, opened up more choices for Justin. It also must be acknowledged, though, that those choices have had to be earned, often against enormous odds, that they are by no means secure, and that they often involve compromise. When Justin changed schools, the physical environment changed for the better:

You know with Justin having been through high school, and particularly the hassles that he had at [previous high school]. And then I see what's happening in [new high school in different town], where they can't do enough. You know, they just ... they just **changed** ... he was upstairs for his history class and they just simply, the teacher just simply got his whole class and moved it downstairs - as simple as that! And yet when I think of the fight that we had getting Justin to be able to go into a pre-fab with just a couple of steps at [previous high school]. And in the end they made him go in the back door ... they were prepared to put a ramp in, but not at the front door. It had to be at the back door, and so he was the only one who entered by the back door. You know it's those sorts of things that actually, when you think back, you think, gosh, maybe what happened in his earlier life wasn't so bad, because at different ages you strike different things.

It was, however, a different story with the learning environment:

The issue of teacher's aide assistance at the school that Justin is presently at hasn't turned out to be quite as good as what I would have liked, because he has someone who is using a completely different system to what he's had for the past four years. He has always had a

reader-writer rather than a teacher's aide, and she has written down everything that has come out of the teacher's mouth or that's appeared on the blackboard, and that's been to enable anybody who's helping him with his homework to assist.

Unfortunately he's got a teacher's aide at the moment who really is not skilled in the ways of assisting a person with disabilities in the classroom, and I think there's been a bit of friction between her and Justin, because of her attitude and his attitude. He wants it done a particular way and she thinks it should be done another way. But I have been to the school, and I did explain to her that it's so important that everything is written down, so that someone can assist Justin with his work out of school hours. He's got everything down on tape, but that's of no value whatsoever to someone who is helping him. It's all on tape, but it needs to be in written form. So that sort of problem's had to be ironed out.

So you know, the personnel as well as having the teacher's aide hours granted and the resources made available ... having had two very good teacher aides who knew exactly what Justin needed to have done to enable him to study, and now having someone who thinks that it ought to be done differently, you can see that that's a really important issue as well, the actual personnel. So life there has not been like what we thought it was going to be.

Lack of information, or poor quality information, can mean that choices are made which seriously compromise educational opportunities for students with disabilities. As Mary says:

I mean I went along with it to a certain extent by allowing Justin to go to an IHC school, because that was what the psychologist had recommended that he ought to do, that he ought to go to an IHC school, so I allowed that to happen, and allowed him to stay in a Special Unit at the High School for so long. I mean Justin told me he didn't want to stay there, so, you know, even as a parent, even though you know

these things, you still allow them to happen sometimes, and you can look back and unfortunately you can't change the past. That's the shame about it, that you can't undo what you allow to happen.

There's so many things that I would have done different, now, heaps of things, particularly regarding his schooling. You know if I'd known, if I'd just realised, just the unhappiness that Justin was going through, which he kept telling me about. But you know, I was just afraid of how unhappy he would be if he got into the mainstream and couldn't cope. Instead of allowing him to go there sooner, instead of allowing him to go ... like I didn't make the change until the final term of his fourth year at High School. Now really I should have asked for him to go into the mainstream from the **third** form, and I didn't ... because I was afraid of whether he would be able to cope. Instead of actually just going ahead and letting it happen, and you know, seeing what was going to happen, I was protecting him, but to his detriment. Because once he got out into the mainstream, he just blossomed. So those are the sorts of things that I would change, with regards to schooling, just listen to him more.

These stories reflect a wide range of experiences of disability. McKay et al refer in their 1995 study of disability and tertiary education to "the diversity of experiences of disability, including disability as a valued part of personal identity, as requiring each day considerable physical effort and strong-willed commitment to study, and as involving the kinds of achievements and setbacks familiar to other, non-disabled students (p.1). They refer to Douglas Biklen's comment that people with disabilities are often "institutionalised, segregated and undereducated, socially rejected, physically excluded from public places and unemployed" (cited in McKay et al, 1995, p. 2). They argue that people with disabilities "do not need 'treatment', even 'special' treatment, but recognition of their human rights" (ibid, p. 3), which include the right to respect and recognition.

Effort and Recognition

Though children know, and their parents often do, and their teachers

sometimes do, the sheer effort that children with disabilities often have to put into their education is usually not even imagined by most people, and all too frequently goes unremarked, unappreciated and undervalued. As Oliver Sacks remarks of deaf children and their parents, that they have to be, in a sense, "super-children" and "super-parents" (Sacks, 1989, p. 118), so do children with other disabilities too often have to expend an extraordinary amount of effort just to be "normal". For Mary and others close to Justin his achievements have been a cause for intense joy and celebration. Sadly they have not been acknowledged by the school, and this is a source of pain for Mary, as she explains in the following story:

Just adding one thing more in here ... I'm not sure whether to put it in or not, but I'll just talk about it anyway. It's just really about probably the lowest point in recent years for me, has been when Justin left [High School] and wasn't recognised for his efforts that he had put in at school over the past four years. He was the only student who had been there for four years, and there's an award there, called the Rogers Cup, and because of Justin being the only student who'd been through the Special Needs Unit who had sat an academic subject, I don't know, I just naturally assumed that he would get it. But you know, because the teacher and I had not got on for a couple of years, he didn't get it ... I don't know that that's why, but anyway he didn't get it. It went to a student who hadn't been at the school for as long as Justin had, and I think for that school not to recognise his efforts was just a huge error, because the citation for that particular cup says "For perseverance and effort for a student with special needs", and I think Justin to have got to the point where he was, was really against the odds. He'd been given a label of "intellectual handicap" some years beforehand, and to have been even reaching a point where he was sitting School C - at that stage he hadn't got the results - was just amazing.

I mean that had been achieved through just sheer hard work and study and determination and gutsiness, and the majority of it was done while he was under enormous stress whilst he was in the Special Needs Unit. You know, he's never had the same formal schooling as his peers who

were in the same fifth form English class as he was. He'd spent his school life in either special schools or special units, and I think to even have got to the stage where he was sitting School C was just an outstanding credit to him. You know, I think it just speaks volumes for his courage and his ability to override extreme circumstances. And the fact that he couldn't read or write to any degree, and had to rely solely on his listening skills and his memory, I just think was a remarkable achievement, and I think he should have been recognised by [High School] for his perseverance and his effort, as it says for the citation for that cup. You know, that school should have been proud of Justin. They shouldn't have just ignored what he did. I guess I would find it more acceptable if the student who got it in the end had been at school for an equal number of years as Justin, but he hadn't, and that's ... you know, because I had a personality clash with the teacher, it wasn't awarded to him. That really was quite a low point for me.

Mary's points about the delicate relationship between her and the teacher, and about the school's devaluation of Justin's achievements are also reflected in the following comments by Colleen Brown:

... it is fair to say that the majority of parents find that they must continue to struggle to attain true equality in the parent/professional relationship, possibly getting labelled as radical in the process.

...

Assumptions made about children with special needs continue to confound and anger parents. [...] Parents need to arm themselves with a scrapbook of success stories to counter such assumptions. I tell people about the barriers broken by people with special needs in the fields of sport, art, television and education.

(Brown, 1994, p. 240)

Parents' stories, then, have a potentially powerful educative value ... if they are listened to.

Social Exclusion

Parents are often coping with intense feelings of fear, anguish, regret and anger, as they struggle to support their children in an environment that can be not just unappreciative, but overtly hostile at times. Theresa explains how she tried to help her daughter in a typical situation:

Carol's had a lot of problems in the last couple of years socially speaking. They go over one day a week for sport with the local primary school, and she's been teased unmercifully by some of the children there. So now, and I've been trying to teach her to be a bit assertive to put a stop to it, but also let her know that it's going to happen all the time - that's life Sunshine! Supporting **her** in doing that herself, and knowing that it's going on and keeping an eye on it and probably in some instances the teacher taking over so she doesn't have to deal with it all the time herself. Her teacher has spoken to the teacher over there and now always tries to make sure that the St [Mary]'s kids have got at least one person in their team there with them, so there's not just one St [Mary]'s School child in amongst a lot of Primary kids, that they've got buddies there.

Yeah. Trying to get her to know that with some kids it's curiosity, and with other kids it's just ignorance, stupidity - you know, how many fingers am I holding up, sort of thing. Trying for her to first of all answer, answer well, and if they carry on to just ignore it. Because I think for a long time Carol felt that she was on her own, that she was often in a team with the local primary kids and not really any St [Mary]'s ones. And I think sometimes whoever it was taking them didn't know how to deal with her, and even some of the St [Mary]'s kids when she got to the front of the line, you can't play cricket - go to the back! So she didn't get a turn. It just wrenched my heart out - she just wanted to go away and die.

Social acceptance is a major issue for children with disabilities, and their parents struggle to find ways to help. Mary explains how difficult that has been for Justin, and for her:

Lack of friends and friendships have been a big issue with Justin. When he was younger he had friends who would come round, you know six or seven or eight years old. When they realised what he wasn't able to do physically, that he wasn't able to go and play football and that sort of thing with them, they just didn't ever seem to want to come back again. He'd invite them, but they'd have some excuse as to why they didn't want to come and play with him. I mean, what he used to do when he was that age was play with his Lego and with blocks, a lot of Lego, and he'd play with his soldiers. And of course little kids of that age just didn't want to stay inside. I mean I compare him then to his brother who's now about that age, and [he] invites kids round and they come, and they're never inside. They're outside kicking the ball around and climbing up the tree out the front, and that's the sort of thing that Justin has missed out on and he has been very aware of it. And as he's got older, it hasn't changed. He's invited kids his own age around, and they've come once, but they've just not come back again. And it's because his ... what he wants to do is just sit round and talk, and listen to records, and ... I don't know what other young folk do, but when he's asked them back again, there's always been some reason why they can't come, and that's been a particularly sad part of it really, because he's always had the same desires as other kids.

Violet spoke of her sadness that Shaun's communication is still so limited, and her fears for his future:

One of the other things that we really wanted for him was ... after a few years, we got to see that there were lots of things he wasn't going to learn ... I don't know. There must be different ways of teaching communication, and we often want the children to fit in to our reality, or the norm of communication, and yet sometimes I think that we sort of have to look at the way that **they** communicate to help us communicate with them. I don't particularly think that was something that was done at the institution that he was in. It needed to happen more when he was young. But I often sit and watch him sometimes, and just some of the ways that we talk to him and things ... I don't know, I often wonder if

there was a way that we could have communicated slightly differently, I don't know. He never learned braille, so what was the use of him being there?

I mean as parents we were only looking at certain things, like ours was if he could communicate a little bit more clearly that was basically all we were looking at. And if it meant him learning braille that was a bonus, but of course he didn't learn it. There was one teacher there in particular, she felt that the way that they were teaching some of these children just wasn't appropriate, and she came up against brick walls when she tried to change ... tried to do different things. And for the time that she was there, it was about the best results we ever had with Shaun. I was really sad when she ... I think she had Shaun for a year, and the progress that he made! It was really ... oh you know she just had this thing about the children, but too many people were against her ideas. She left ... it was quite sad.

He actually at one stage like I was saying at Homai he was actually learning basic braille. He was learning, you know the ... the teacher that left up there was actually teaching him braille. But that stopped, and ... she felt you know that story books ... because he **loves** stories, he loved listening to stories, and you know the tactile books that they have to read. He had like you know ... okay repeat and repeat ... repetitive ... but he was getting to the stage where he was actually learning how to associate pictures and words. He was doing that, and he was learning that this is where the story came from - the braille. And he was actually beginning to learn that. And he didn't get to move to the next stage, and then it's all just been lost. And that's been the saddest part of all. How do you teach a totally blind person to communicate other than verbally now? Because he hasn't learnt braille ... unless, you know, we have like descriptive signs ... yeah. I often wonder about the communication. Because the only thing he has is, well, you know ... imagine if his hearing goes! And that's a likely thing - that could happen! Because he's, he's got less hearing in one ear. That could happen eventually, you know. And then what other things,

what is he going to get out of life? ... I don't think he would have progressed to a higher level of reading, but he could have, you know ... to some level.

Violet's questions about Shaun and his future are similar to the kinds of questions that, as Colleen Brown says,

are being asked by parents and professionals of schools, hospitals and communities about how do you value this child? Is the valuing of somebody who has different needs a community or individual responsibility? Or is it both?

(Brown, 1994, p. 241)

Many parents look to the community to value their child, as Colleen Brown says, and one tangible sign of valuing is the level of inclusion and resourcing the community is prepared to support.

Resources

Resources are a major issue for parents of children with disabilities, and it seems that their choices for their children are often guided by their perception of the availability of resources. As Violet explained:

But there seems to be clashes sometimes between the systems, like you've got the special school system and then you've got the ordinary education system, and they, these people here in the special schools can see what the children need out there, but getting it into the "norm" system is very difficult. And like a lot of times it wasn't seen as a need for children to have that particular support. They've still got an idea of trying to keep it as normal as possible ... but how can you do that without the right support?

Often opportunities are limited by of a lack of resources. As Mary says:

Some of the things that are really unfair, are the opportunities. Because some disabled people are not able to do things immediately, and because there may not be the resources in place to help them to

complete a task, what I've found from talking to other parents is that the disabled person is often given a menial task other than learning to do. For instance, playing in a sandbox, while others may be doing reading; using building blocks while others may be learning how to print. I don't always put that on to the school, because it's the government, it's the Ministry of Education who allow for disabled children to attend the school of their parents' wish, in most cases, but the resources are not in place to enable that to happen satisfactorily.

Frank talked about how Bruce spends some of his school day:

At the school currently they're using some of his wanderings to turn him into a message boy for the office staff, and the stationery department, and he does all the deliveries all around the school. He's now well versed in the lay-out of the school and can cope with directions, and so he's currently the delivery boy for a lot of messages.

Progress so often depends upon the amount of support children get, and as Mary says, this is a crucial issue for many parents:

As a parent I would never have wanted Justin in a class where he wasn't resourced properly, because (a) that's unfair to Justin, (b) it's unfair to the class, and (c) it's unfair to the teacher. And this is what parents feel - we don't want our children to be in there taking the time of the teacher, and this is why the teacher aide issue is such a big thing, where it seems every year, instead of children, because they've gone up a class and their learning is going to be more, by rights they should have more teacher aide hours, it's actually the opposite, where as you get further and further on in age, you lose maybe just a couple of hours [per week] a year, maybe half an hour [per week] a year, but the workload has increased on the child, it hasn't lessened. So this is quite a big issue for a lot of parents, and it has been for myself right throughout Justin's schooling, that he hasn't had the amount of hours that ... oh, he's got by okay, he's got by okay, but he's got by with frustration - frustration on the part of myself, and him, and the teacher

aide who's worked with him.

As Mary says, even when adequate resources are allocated in the form of teacher aide hours, they can be arbitrarily changed and may need to be strenuously defended, often by parents. Caroline's experience is not uncommon.

When she started school that started off the IEPs for discretionary teacher aide hours. She gets three and a half a week now. One year they went down quite drastically and I wrote away, to the Minister and MPs and everybody, and they got reviewed and put up again.

The following stories from Frank and Violet give some indication of parents' perceptions of the resourcing dilemma, and of the debates and difficulties within the system itself:

As a Special School Board we constantly coped with returning children that had been returned to the community, often without adequate backup or support ... and they have to be given their chance in life, and Special Schools have always been there, to pick up those ones that require an education. I guess part of the policy is that when they return to the community they join community activities which I guess is supposed to be normal schools, where a lot of these handicapped people have gone to and not been able to fit in. Often they are unaware that there are special schools available, and there's a special service run by the Ministry to cope with educating handicapped people, and these don't always work hand in hand, or have the funding to cope.

We've seen, we've heard of, and we've been involved with cases of children that have been sent to a kindergarten as their first starting point on an education, and kindergartens don't know that there is a school that they can go on to if necessary.

Often the parents are advised that their next step is to be mainstreamed into normal schools and often the people with the funds

to administer don't correct that idea, and hope the children get absorbed into a normal school. Their parents don't get the best advice available and they're often unaware of their rights ... who can offer them services, and these avenues are not always available and advised to parents.

These are problems that we dealt with as a board of a Special School almost on a daily basis - people uninformed, and existing often under terrible conditions where parents are one hundred per cent involved in caring for a child that could be helped in other directions ... don't know about any other of the services available to them.

We as a family have been better looked after than most, mainly because we've been capable of banging our fists on tables and demanding to be heard, and this often doesn't happen for people. But to see a parent that has had a child involved in a special school after a month or so and realize that a load that has been with them for many a long day has been partly relieved with access to a school for part of a day is just unbelievable. To see the almost joy on parents' faces when they realize there is some salvation in the world for their difficult times!

I'm aware of children in mainstream that are there because parents have insisted they be there, and are not coping. Teachers can't cope. Schools are looking for numbers to improve their funding, and children with handicaps and problems are being pushed into the background, being ignored in the classroom until they become problems in other directions ... when we see how well Bruce has coped with special schools .. to realize that without that he would have been a problem, a bigger problem to us and we are almost grateful now that we were in a position to jump up and down and demand better treatment for Bruce.

I think as parents we need to still have options, and to be made aware of the options, and what the options present, and to give you a clear picture of how the systems actually work. It took me a while to figure out how the unit actually worked with the ... like how it was still attached

to the Special School and things like that. It took me a while to figure all of that out, as a parent, how they actually worked together, because you still saw them as being a separate body, and then when you got to go into the meetings it was like you weren't sure whether they actually were working together, and it's ... getting better.

Though parents are divided over the issue of inclusion, it is clear from these comments from Frank and Violet that many parents are not well informed and are confused over what options are available for their children, so information, as well as resourcing, is an issue for them in deciding. Getting physical resources is often a major battle for parents as well, as Violet explains:

I find it very difficult when professionals say "cost-effective" ... for equipment. For blind children, you know, their equipment is very expensive, and then of course with Shaun's added disability ... um intellectually. One of the things I've always wanted him to try was a computer. But of course he's getting a lot older now, so whether we're going to ever get to do that I don't know. But constantly we got told, oh we don't think he's going to cope. Try all these other ways to see if he will ... and what's the use of having this expensive equipment around, if he can't work it. A lot of these things, a lot of the children that I saw at Homai and Shaun - unless something is actually there, they won't go on it. You know, it's got to be there when **they** want to go and tutu with it or ... that's what they'll do. But I guess you have to be practical ... to leave a \$4000 equipment sitting there just for this child, I mean ... but they have to learn to ... So but that was the one thing, "cost-effective" that bugs me ... So those type of things ... that we had to be cost-effective, and it might be a waste of time to be doing those things with him now, and we should be looking at these things, and ... I've given up on the computer. We've got a hand-organ instead ... so that'll teach him some basic stuff.

Violet's sense of frustration is shared by many parents who know that the technology exists which might provide a breakthrough in communication or learning for their children, yet they cannot access it. Sometimes the main

barrier is difficulty in accessing the information, either about the equipment or how to obtain it. Sometimes it is difficulty in persuading the professionals who act as gate-keepers for a restricted amount of funding. Either way, the process can often take so long, and be so exhausting, that it seems not worth the struggle, and parents give up. The sourcing of specialised equipment is a confused and confusing maze of different schemes, in which regional differences also play a part. It seems largely a matter of trial and error, and of stumbling upon a professional who is willing to help, and who has access to the relevant information.

Robyn Munford, Sara Georgeson and Janice Gordon, writing about these kinds of "social and environmental barriers" which may be put in the way of people with disabilities, make the following assertion:

In the 1990s in Aotearoa/New Zealand, people with disabilities are no longer going to accept the role of 'spectator', but will have something to say about social policy and service provision. They will continue to challenge society's notions of what constitutes worth and productivity and will make a contribution to the processes that determine how society allocates its scarce resources.

(Munford et al, 1994, p. 275)

They note the key role that social workers can play in this process, and this relates closely to another major theme for parents, that of people resources.

Training

Parents talked often and at length about the difference that a particular teacher or teacher aide can, and often does, make to their child's ability to manage school. As Mary said:

It depended on who the teacher was, and whether you could talk to them and ... but Justin has had teachers who have been excellent. All you've needed to do was to say, I think maybe this may be a way to go, and that's the way that they've gone with him. If it's been Justin's wish to do something, they've done it. If it's been my wish on behalf of

Justin, for something to happen, that's the way that it's gone. But unfortunately, to make life very unbearable, you've had teachers who have made life quite difficult, where you've got to have so much stamina, and so much ... determination, even just to have the guts to speak up to somebody.

Violet speaks for many parents when she talks about a lack of resources in the form of adequately trained and skilled educators:

But you definitely need to have more people resources, which is something that we're lacking in. But also I guess to make it look like a viable ... not business ... but a viable career prospect as well - for the teachers. I look at the special school Shaun's in and if it wasn't full of really dedicated people, you know, you wonder how it would survive, you know. I mean those people are quite dedicated to do that, and ... I shudder to think what would happen if they weren't dedicated to it, because there's not enough other people who are interested to do the work. It's **very**, it's very demanding ... and unstable ... and I believe it is important for teachers to have at least a year's training in special needs, and not six weeks as some of them do ... [laughter] ... maybe a six month intense part of their training, but that it has to be in special needs, because a lot of teachers find it very difficult.

Violet spoke about the many different teachers and teacher aides that have come and gone in Shaun's life, and about the situation at the time of the interview:

His two teacher aides that he has now are actually skilled people, and that makes a big difference. The new teacher aide that he has, she's come from Palmerston North. She actually did the Teaching People with Disabilities course down in Palmerson North. She actually was a tutor, so a lot of the things that she ... I mean within a few days that she actually was working with Shaun, she was coming up with ideas herself, about how they could approach certain things, and maybe if we did it this way rather than that. So that was really great - it was great for

the teacher too. He's got a new teacher now as well.

And the other girl who had worked with him, a Maori girl - wonderful person - is now doing the course on teaching people with disabilities, and oh she says it's been such an eye-opener for her, to actually do the course now, and come back and look at Shaun and the other children that she works with, and she's going, oh there's so much there, you know! And when she reflects back to the year that she had with Shaun when she wasn't, you know she was just new at it, there's so much that she's learnt. So it tells you a lot about - that was a really good insight into, you know ...

But the two that he has now, they cope really well, but then like I say, the Maori one who's learnt new skills, she was saying, gosh, we hovered over him too much ... we were around him too much, weren't we. And I lot of times I would say, there's lots of things he can do ... make him do them ... like you don't have to be around him all the time. And it wasn't until she actually went to do the course that she actually realised what I was talking about. She said that she could come back and see that oh yes, well! Because she said that the course helped her with her own attitudes to disabilities as well, and she said that was probably one of the biggest things for her, was really looking at her own attitudes to disabilities, and how she was dealing with it and why she was doing certain things. So she actually got those out of the way.

Colleen Brown asserts that

In education, many of the teachers at the forefront of inclusive teaching practices are simply fine teachers. They do not have any special training at all, but a belief that children with special needs have the same rights as all other children in their class.

(Brown, 1994, p. 243)

Perhaps indeed, effectiveness in teaching has as much to do with attitudes and beliefs as it does with specific training. Certainly it is the case, as McKay et al argue,

that change might more readily come, not just from exposure to numbers [statistical and survey data], but from exposure to the lived experience of people with disabilities. We believe that if the reader attends to the voice of people with disabilities and learns something about their experiences, then they may be better informed about the issues and may be better able to identify a personal position and role for themselves on disability in tertiary education.

(McKay et al, 1995, p. 5)

While these remarks relate specifically to the field of tertiary education, they are, I believe, equally relevant and applicable to people who may have a role in pre-school, primary or secondary education and will in due course encounter students with disabilities.

Surviving the System

In a system which can be very hard to handle, it can be argued that disabled children need opportunities to make links and share experiences and activities with others who have faced similar issues. Otherwise they may never see someone who has survived the system, or be able to talk at first hand about the issues or choices which may face them in adult life. Michael Oliver argues that "disabled adults must participate much more actively in the education of disabled children for it is only these people with direct experience of the special education system who can know just how disabling it can be" (Oliver, 1988, p. 28). This may in fact be disputed by parents such as the ones in my study, who have battled for their children, and who surely have 'direct experience' of the special education system and know how disabling it can be.

It seems clear, in any case, that getting an education can be very hard work for some people. For example, a Workbridge publication quotes a young man with cerebral palsy as saying "It seems a long hard road when you're at school, but if you can survive mainstreaming you can survive anything" (*Workbridge News*, Vol 1, Issue 5, 1993). A teacher in Jenny Neale's survey of parents of disabled Form Four students commented: "To get School Cert and possibly UE has involved a lot of very hard work and struggle, and very

few disabled pupils who get this far are prepared for the continued hassle and extra effort involved with going on to tertiary education" (Neale, 1984, p. 32). A more recent study of what a university education is like for people with disabilities suggests that the following remarks by students with disabilities sum up the way many students with a disability feel about their time at university:

I feel resentful that it should be so jolly difficult for me to do something you can't quantify the effort that has gone into it ... Also the extra costs ... it's a lot harder than it needs to be.

Although I feel I am a very capable student and could achieve in all areas ... and am doing everything possible to solve every problem I face, the weight and practicalities of it all still regularly have me near the point of giving up.

(Lang, 1993, pp 80-81)

The point of including these 'stories' is to listen to and try to learn from the voices of students who have themselves experienced the kinds of barriers to achievement that discriminate against them and limit their educational opportunities. As McKay et al argue:

... disability is not as well understood as it needs to be in an equitable society, and the need to advocate for access and for resources identifies disability with issues of policies and power.

(McKay et al, 1994, p. 1)

There is room, I believe, for more research which pays attention to the experiences of students with disabilities in the school system, from the point of view of the students themselves.

'When You Lack The Word'

Education plays such a big part in the hopes and dreams parents have for their children, and school has such a large and important place in the social and emotional development of children, as well as their learning, that

educational issues are a major theme for many parents. There are, however, a large number of families whose hopes for their children are limited by the restrictions of poverty, class and race, as well as by the limitations imposed by society's attitudes towards disability. This has to do with the fact that, as Roy Nash explains:

Families are differentially endowed with specific resources as a result of their structural location in a class system, and these resources are used strategically in the interests of obtaining for their offspring educational qualifications and an appropriate occupation. The effective causes of socially differentiated educational performance are thus material and symbolic resources along with the strategic practices they make possible.

(Nash, 1993, p. 36)

Violet talked about her experience of the effect that the lack of material resources has on families with children with disabilities, in terms of the "strategic practices" that are not possible for them:

... a lot of the parents that I actually worked with, their needs were more on survival. You know, to actually talk about educating a child that has a lot of disabilities is like - well, is that really a priority to what they're needing now? And so all those things come into it. And for the families I have worked for, to actually see them grow as parents, it's been really wonderful. It's taken a lot of alongside work. When I say survival, I mean survival as just living - like you know to get the food on the table, to get the roof over my head, and to try and keep your kids fed and things like that. That seemed to be a lot of their first priority. And of course here you come in with a piece of paper and say, hey look, we're going to have an IEP for this kid, that's like, whoa! Yeah, and for me that was a real eye-opener, because like my own agenda was, you know, these children are capable of learning and progressing, if given the opportunity, and the right support. But for a lot of parents, that was just too big a picture to see, and just that the kid was being fed and cared for was their first priority. And I know for fathers in particular that I

came in contact with - when I talked about these children - they, a lot of them have no experience to cope with it. But the whole thing that the children can learn is ... a lot of them don't think they could. That they were being cared for was enough, and the fact that you had to think about educating them was ... why? So a lot of times I found that really frustrating. For a child to go anywhere was good, in some of the cases I worked with, it was just a relief to have that child away, you know, to give the parent a break, and that's how they saw it. And I guess that's that whole thing of coming to terms with a lot of things themselves, emotionally, and a lot of them maybe not ... and that's the other thing.

The other part of the equation, the symbolic resources, consist most importantly in the "cultural capital or literate knowledge" that rests, as Nash says, mostly in the hands of the middle class (ibid). Again, Violet explained what it means to be lacking in this kind of capital:

... they had no idea of those stages that children went through. They would ask, but because they had no visual concept themselves, or understanding, when we went through an IEP process they had no idea what we were talking about ... and I'm talking about parents who had an average education to parents that didn't have much of an education. And I found that a lot of the parents who were more educated would actually go out and look for that information, and knew that they had rights to that, but the other parents didn't know that they had rights to a lot of information. Because I dealt mainly with Maori parents, and they in particular didn't realise that they had a lot of rights ... to information ...

It was interesting ... you know for Maori people to have the life skills is more important than some of the other skills that you may have in a piece of paper, as they say. And that's true - but having the piece of paper, working towards the piece of paper, I suppose, you learn a lot of things. And I believe that we do need to have certain skills, and with a lot of the things that I came across, I was just, you know, a lot of times felt over my head. So that made me appreciate more the people, the professionals that I actually, that were involved in my life. I got to appreciate the skills that they had, but until I actually was in that role

myself, I didn't really appreciate. I suppose because some of the experiences I had with them were not very good ones, but I think a lot of that had to do with my own ... what I ... I guess it has to do with my own inadequacy, or what I **felt**, you know, maybe a low self-esteem. That plays a big part, and until, I guess the experiences of walking with other parents and seeing it, and until you help them cope with that low self-esteem - very difficult to get past a lot of things. That's from my own personal experience as well. You know, with low self-esteem it's very difficult to progress, to learn to empower yourself and know that you have the rights too ... that makes a big difference ... the rights to information and ... and knowing that, okay you may step on people's toes! And even the parents that seem outspoken, a lot of times, and they may seem quite aggressive or, how would you put it ... a lot of times that's just a front for low self-esteem. And it's knowing how to approach that too. And until I learnt to be confident and .. I mean assertiveness never came into it 'til years later! [laughter] When you lack the word, you know - and that didn't come in until I actually was out working in the community. So you know, it was a real self-educating thing, to go out there and do things.

A lot of the parents I meet now like have the confidence. Even though they're young, they seem to be a little bit more aware, so whether that's ... I don't know, it's just change of times, I don't know, they just seem to be that much more aware. They at times may have a moment of low self-esteem and things. One of the mothers was saying - she's only young - that because she's had to go and find the information herself, because she hasn't trusted in what the professionals have told her, that's made her more aware and self-confident, you know and now she's gone to learn.

So education plays a big part, and low self-esteem. I still fall back into those old habits, you know, and I guess too the continual battle with systems is the hard part.

In this chapter I have identified the structural factors which impact on the lives

of children with disabilities and their families in terms of their access to and inclusion in educational institutions. The parents' narratives show how they experience restrictions on educational opportunities for their children, and they also suggest strategies they have found effective in resisting those limiting and disabling effects. The stories can be read in the light of Foucault's ideas about 'relations of power' and the way these are maintained in institutions like schools, to help us understand why parents find 'technologies of power' like the IEP meeting or the teacher interview so daunting, exhausting, and disempowering. Fairclough's theories about language and discourse and the way they can be used to shape experience can shed light on why even quite assertive parents can feel that their opinions are not respected and their children are not valued by the educational professionals they come in contact with. The theories of Henry Giroux about a critical approach to schooling link with those of Freire about 'conscientisation' to suggest how students and their parents might find opportunities to affirm their own experiences while critically examining the systems which form the background to those experiences. Freire's concept of a 'radical pedagogy' suggests ways in which parents might link with others; educational professionals or other parents on Boards of Trustees, or non-educational professionals, to listen to each other and to work together for change.

The stories give an indication of the extent to which the lives of the children are shaped by their experiences of schools and teachers. Dorinne Kondo's ideas about how our lives are created by the way we negotiate, co-operate with and resist 'relations of power' at various levels are helpful in understanding how children's experiences of school can open up educational opportunities for them, or cause them to be disadvantaged for the rest of their lives.

The next chapter will analyse the role professionals play in the lives of children with disabilities and their families in order to show how relations of power frequently work to disempower the families. This section will also highlight strategies of resistance, and point towards the construction of a framework for professional practice that would make possible a sharing of information and resources so as to restore the balance of power and redress injustices.

Chapter Six Professionals

Let us not, therefore, ask why certain people want to dominate, what they seek, what is their overall strategy. Let us ask, instead, how things work at the level of ongoing subjugation, at the level of those continuous and uninterrupted processes which subject our bodies, govern our gestures, dictate our behaviours etc. We should try to grasp subjection in its material instance as a constitution of subjects.

(Foucault, 1980, p. 97)

The previous three chapters have been devoted to the parents' perspectives on issues which impact on them and their children, in the family and in the medical and educational arenas. As parents have talked about relationships within and outside the family in relation to their child's disability, it has become evident that one of the major themes for parents, and probably the one which generates the most emotive response, usually of anger and frustration, is that of issues surrounding the professionals who are involved in their lives.

'Parents as partners', and the concept of parent-professional partnership are by no means new ideas. They have been around long enough to be commonly regarded as 'good practice' by a range of professionals who are involved with children with disabilities and their families, especially in the field of education. Often, however, partnership is invoked by professionals as a vague ideal or as an undefined description of some level of parental involvement in professional decision-making and treatment. These arrangements occur in a variety of situations, ranging from those where parents support the work of professionals by working on committees, fund-raising and attending social functions, to those where parents are involved at the level of planning and policy making. While there may be general agreement that some kind of sharing of power is involved, there is by no means any general understanding of what is meant by the term 'partnership' in this context.

Alongside the professional literature describing projects and approaches to

partnership, is a parallel body of literature, written by parents, expressing, largely, their dissatisfaction with the way they have been able to relate to professionals. For example Colleen Brown says:

The so-called parent-professional partnership has had a rather hollow ring to it for many parents. In reality it has involved a constant challenge to change professional attitudes, often at great personal cost.

(Brown, 1994, p. 237)

As Rod Wills says, professionals hold power because they control the resources that families need. He, too, is sceptical about the reality of partnership in practice:

In recent times there has been talk of power sharing through 'parent-professional partnership'. The much-vaunted parent-professional partnership runs the risk of becoming little more than a code used by the professionals to describe what they think they should do.

(Wills, 1994, p. 258)

Real partnership, as he says, is impossible when the relationship is based on inequality in terms of information, and financial and material resources. Parents frequently feel dismissed, ignored, patronised by professionals. Lack of choice in services for their children constrains complaint for fear of losing access to the system and thereby depriving their children of the knowledge and skills they expect the professionals to have. Stories parents tell about their experiences with professionals appear frequently in the literature, and there is plenty of published evidence to support these claims (Wood, 1988; Baxter, 1989; Ballard et al, 1992; Ballard, 1994). The stories are also told within families, and between families, and often to anyone who offers a listening ear; over and over again, the overwhelming impression, the most telling comment is about what a 'battle' everything is.

Rod Wills suggests that it is not partnership parents really need; it is

some of the financial resources, more of the information and all of the

decision-making and control.

(ibid)

If parents express disappointment, frustration and anger about the way they are treated by professionals, they also talk about the professionals they have found helpful. There were several important themes for the parents I spoke to.

Information

Information is one of the key themes, and it is very clear that parents expect to be given information, in a form which they can understand and remember. It was information that Theresa was referring to when she said that families want:

support from the doctor, the doctor answering your questions before you've asked them, being able to tell you what information is out there and where you can get it from, supporting you going to agencies like RNZFB, and knowing what those agencies do.

Information in writing was often mentioned as being especially helpful, as Violet said,

and in plain English, because I mean they tell you, you're told a lot of things verbally, but I mean a lot of it washes over you ...

Theresa mentioned educational professionals who came from Auckland about twice a year and she said:

the information they gave me was very helpful ... they used to bring booklists and photocopied bits of information.

Parents indicated that they expected information that was trustworthy, and explained so as to be useful. Both Mary and Violet mentioned this. Mary said:

I also think that professionals shouldn't, I'm going back to Justin's birth here, I think professionals shouldn't give out information they don't

know **anything** about, because when he was born, and he was nine weeks prem, and at ten months old we were told as a family that he had cerebral palsy, but at that stage it didn't mean anything to us, because we'd never experienced cerebral palsy before, and so it was just like being told the time of the day really. But I recall at the time the doctor saying to us, don't worry because by the time he's three he'll be up and walking, and you know that still sits in my mind today ... it was like being told something that really was just a pie in the sky thing. And of course when that doesn't eventuate, you feel quite disillusioned.

Violet indicated that there may be some particular difficulties for Maori parents around how the information was given:

I think being who we are, which is Maori, also - and I've spoken to different ones about this - we tend to take the professionals at their word, and so we have a tendency to really trust in their judgement, and yet it went against some of the things that we felt personally. This is my own personal experience with certain things with Shaun, and I don't think we ... like a lot of the things needed to be repeated and repeated until it actually sunk in. When you have to start at the beginning, then it has to be at the beginning, right? When Shaun was in the hospital we could have done with a lot of support then, emotionally.

Violet talked about how she would have liked information not just spoken, or written, but demonstrated:

I remember somebody saying to me, he's fourteen inches long, but you just don't have a, you know a picture of what fourteen inches is, like fourteen inches is about that long [using hands to indicate measurement]. But he weighed less - I think it was only 800 grammes - he was the second lightest baby they'd ever worked with. So I didn't have - I mean when he said 800 grammes - well what's that? If he'd held a piece of paper and said, look, your kid's only that big, then you would have got a better idea, you know?

Later on too, she would have liked the information in a format that was more useful to her:

I think that's the part that I often really notice, a lot of that type of input and **how** you do it. I know they kept saying, you need to introduce him to a lot of experiences, but **how** did you do that? How was I supposed to do that? Those were the little finer details, the practical things, like ... a lot of times when I did things for Shaun, I had to close my own eyes and try and figure out how would you teach this blind child? And he couldn't feel much on his right side. A lot of that type of stuff, you know the practicalities of things and how would you go about it because there wasn't that type of information. They gave me lots of things to read, but I think I would have preferred them to actually show me ...

The amount, and the timing, of information given was an important issue for Violet. In the beginning, talking about medical information, she said:

I think I would have preferred to have known and been given the whole picture.

Later though, she found that to be given too much information at once was daunting, for her and for other parents as well:

There were some of the IEPs that I have seen from health services in the old days ... used to be like six month ... this big fat paperback. I don't know, it just took too long to get through, and when you've got a thick piece of paper - well, you just didn't bother, you know, just sort of went oh yep, yep, because I said oh it's just a whole lot of stuff just written down. Say if you had one piece of paper, with the small steps, then you've got less to have to look at. I mean, like I said, as I get more educated it didn't see to be a problem, but in the beginning it was. It was like ... sh... ! and I mean a lot of the things, and even at Homai it used to be the same thing. I used to come back and just go aach! ... and then like when I felt up to it I would sort of get it out and read a page at a time and sort of try and take in what they were trying to say. So I

quite liked it when I got to be one of the staff, got to work with other parents personally, and I found that the one piece of paper was far better, because as soon as it started to go like this [indicates thick volume] it sort of put them off. And so yes, the one sheet seemed to be ... in the beginning, until they actually got more into the process of the IEPs and once they realised that they weren't paranoid about that piece of paper, they got confidence and ...

A crucial idea about information is that parents often don't know what questions to ask, so it is important for professionals not to assume that a lack of questions means parents have no desire for information. It needs to be a dialogue, with plenty of checking on the part of the professionals to see if they are being understood, and to see if they are meeting the current need for information.

Interest

A feature of the parents' narratives that struck me again and again was the way they used the pronoun 'they' to refer to the professionals 'out there' as if it was a matter of 'them' and 'us'. Professionals who attracted special mention were usually those who showed special interest, or who stood out through their apparent lack of interest in the child and family. Violet mentioned one particular professional:

My [public health] nurse was really helpful. She must have seen a need and she kept coming back a lot more frequently than ... yeah. And she actually saw that I needed help even though I didn't think I needed it. I remember one day she popped in, and she said to me, do you need help? Oh na na na. She goes, I can't get help for you unless you tell me I can do it, tell your doctor, organise for a counsellor ... so I said yeah, okay, so she got on the phone smartly, and it got done within a few days, you know, and we had a counsellor come out.

When interest was not shown, it was remarked upon unfavourably, as in the following story from Sarah:

They were really good in the ward. I mean, there was only one nurse I

didn't like, and I only had her for one duty, but she just had that couldn't care less attitude, she was just there doing her, earning her money, and she was very unhelpful, and wasn't interested and I asked her a couple of times for things, and then after that I just couldn't be bothered. I wasn't interested in her because she wasn't interested in David or me, whereas all the others were very very good who looked after him.

The family felt especially keenly the lack of interest shown by the original family GP who, they felt, might have been expected to take some responsibility for what had happened:

The GP made no contact at all with us, and of course that ... we were just so angry about that, that he had made no contact, I mean Mark had rung him once or twice while David was in Intensive Care and I think his nurse had rung once when he was in the children's ward, and that was it. But there was no contact at all when we got home, and that was just so appalling, you know, you can't believe that people could treat you that way. I mean he'd made a big mistake with David, but he could have tried to make amends and at least visited us or visited him and ... but he didn't. He never said anything or phoned us up or anything, and it was just terrible, so terrible. But we put him behind us and that's it.

Being interested related, for this family, to having a bigger picture of the child and family than just the immediate medical setting:

We saw the paediatrician and of course he was very uninterested in referring on to anybody for David, and upset us greatly. He was just, I think he just saw David as a particular medical picture, and that was it, he was just going to deal with that and these other things, oh they might get better, we'll just wait and see, but Mark and I didn't want to wait and see, we wanted to do things for him, and if by some miracle he became a hundred per cent right in a few months well that was just a bonus, but if he didn't we weren't going to waste nine to twelve months because [he] said it would be a nine to twelve month recovery for David.

This family adopted a range of strategies to resist this perceived lack of interest and unwillingness to refer. Sarah explains:

Even though it's a negative thing that's happened to him, you don't want to perpetuate that, you want to move on. Well, this is what's happened, now what can we do for him even though he's got this disability, and that's like getting positive people involved with him too, and then you sort out the other people that have to be involved, and like negative people, you work out how often you need to deal with them and things like that ... a little bit at a time's fine, and then you just go on. Like you have your appointment with the paediatrician and you know such and such is going to happen, and that's fine, and then you go on ... you don't worry about it, because they're not going to change, their attitude or whatever. You know they're like that, they have that opinion, and so they can keep it and we'll do what we need to do for David and deal with who we feel we need to deal with. You know, because he is very critical, and doesn't feel these people need to be involved with him, but that's just too bad, because David's not his son. It's disappointing, I'm sure it's just him, I'm sure there are other really good paediatricians around, it's just my luck that we've got him and he's just like he is, so we have to get out of him what we need to, and what he can't give us we don't worry about it, we go on to other people, you know because we've tried ... I always inform him about David's progress as far as his vision and going to the Sensory Resource Centre play group, and having [itinerant teacher] visit, and there's just that ... you know, not interested, but I'm going to tell him anyway, just to get up his nose. You know, he even had the audacity at the last appointment [to say] oh [itinerant teacher] surely didn't have to visit that often, and I said well, as David is progressing, the visits are being cut down, and I'm getting him more involved in play groups and things like that and she can do assessments there, and she can help him there. I thought, you know, what do **you** know? ... you don't know anything about that side of it, and then you feel you can comment on it, and that was a bit annoying! But I just, you have to let it go, and not carry it with you.

Doreen and her family felt uncomfortable at the particular way in which interest was shown by one professional:

I felt funny about this because soon as we turned up at [...] the Maori social worker, he come running up to me and said, oh we didn't realise you were a Maori family - you should be under me. And I thought, oh, what's the difference ... you both do the same job, sort of thing, and it wouldn't matter if I'm brown, green or blue. That's ... even Joe felt like that when we left that day. I felt really awkward, cause I felt torn ...

The parents' stories show that it is impossible to generalise about how professionals might interact with them. Robert Donmoyer (1990 cited in McKay, 1995, p. 4) claims that

... people actually use what they learn from many sources in order to interpret and understand a particular situation, and to make decisions about what might work for particular people in a particular setting. In this sense, and in practice, whatever the 'data' we may have, we behave as the intuitive, reflective and complex human beings that we are.

The stories parents have told about their encounters with some professionals, indicate, as McKay et al claim, that there is a pressing need "to understand disability from the perspectives of people with disabilities themselves, and the need for some specific resources and support systems" (1995, p.5).

Support

It was generally acknowledged that parents want, and expect to get, professional support. Mary spoke of professional support as something you can appeal to if all else fails, a last resort:

As well as support from other parents, you still need support from professional people. Maybe they don't understand exactly what you're going through, but they can advise on stuff that's available in the community, they can arrange for your child to go on camps, to give you

a break, they can arrange for the siblings to attend functions. I suppose you could do that without professionals, but ... it's really having them there so that if you run out of where to go, you always know that there's that door that you can knock on in the end. You know that in the end, if you can't do it yourself, or if you can't do it with other parents, you've always got that sort of support from professionals.

Violet said she had appreciated professionals who would just

pop in and see how you're doing ... I really appreciated [that], because a lot of times you were always at home and you needed to talk to somebody ... it was really good.

Sarah too, appreciated support that was available for her, when she needed it, and, like Violet, mentioned a particular professional who had been especially helpful:

She came over and she was wonderful to talk to. She was lovely, and she's had several visits. I haven't seen her this year, but she told me to get in touch with her if I need to. and you know just to have her to talk to, because I can talk to her about different things, and she's concerned about me as much as David, if you know what I mean, and that's really nice because you, you sort of get left out of it a lot too. Because you know everybody's dealing with David, but it's just really nice to know there are people out there that are concerned about you too ...

A key issue for parents in relation to support is not only the fact that it is available, but the way in which it is offered, and this relates back to ideas about discourse and the lived experiences of the professionals involved, as well as the parents.

Competence

Parents certainly expect services to be delivered by professionals who are competent in their own field, as Sarah explains:

Because you trust these people, or you put your trust in these people, and as we found out with our G.P. they're not all as competent as each other, and you've got to find out who's best for you, as a family, or as an individual, or who is best for your son, because if you have a special needs child, there are people out there who specifically deal with that area, and they are professionals in their own right in that area, and they know more about that condition or that vision loss or whatever, than that paediatrician or that G.P. The G.P. knows so much, so it's a matter of being able to combine these people. You have to do it. It shouldn't be that way, but it does, it falls on your shoulders, and you might have to change personality yourself just to get what you want. If you know what I mean, if people are not being helpful or forthcoming, or they're being negative about it. You're dealing with so much in your own life and your family's life you don't need that. You know, you only need people who are positive, and being supportive and helpful and caring, and that's who you need, and also professionals who know what they're talking about.

Access to services that are timely, appropriate, and competent is vitally important to families, as Violet explains:

I think that at that time this family could have done with a lot of that, because it was quite dysfunctional. That's a big word that I learnt! You know we were quite dysfunctional at that time ... when Shaun was in the hospital we could have done with a lot of support then, emotionally. Because when I think back to those times, I don't know how one copes, but obviously you do, you just get on with the job. That was my attitude - well, just get on with it.

...

But somewhere along the line you need to talk about those emotional things, and also talk about how ... the counsellor came to us. He was okay, but we felt he didn't have enough experience with disabilities, and so you felt like you couldn't really talk about it because you didn't think he would understand, so we didn't talk about those things you see ... we talked about surface stuff. He was with the hospital - a

psychologist, a family psychologist, and he came to the house once, and then we had to make appointments to go and see him, which didn't work at the time. It would have been nice to have appointments like for the times that you were already having to be at the hospital for Shaun, and then they could match up those times, and then maybe have someone to talk with you about how you're feeling about the whole ...

The notion of professional competence assumes certain essential knowledge and skills (Munford, 1994, p. 289), which are to be used in the service of the families. Parents want professionals 'who know what they're talking about' to inform them, to listen to them, and to support them.

Time

Time can be a crucial factor in determining how helpful a professional service is for parents. The time given is important, and, as Violet mentioned, so is the timing of visits or appointments. As Sarah said:

I'm at home with David all the time, and it's just nice to find that there are other people out there who come to see you and David, and talk to you about how everything's going and it's not just coming in, sort of weighing and checking David and that's it, out the door, you know? You feel you can talk. Because after a while you don't want to, I mean friends ask, but, you know, you just want to say quickly, oh David's fine, he's at this stage. You don't want to ... at the start you talk a lot, but now, all that's cut out, because people haven't got time to listen and all that sort of thing. It's just nice to know there are professionals out there that have still got time to listen to you, even though it's over a year down the track, if you know what I mean? You still ... the support doesn't suddenly stop, oh well, you've had your three months or you've had your six months, it's sort of ongoing, even though, at the start you have lots of appointments, so you have lots of visits, and it's a lot to deal with, but then as time goes on and David progresses you know those appointments get spread out more and more.

Time was also an important factor for Frank in his management of support for

Bruce, as he explained:

So prior to Audrey's death we had a lot of support from the hospital and other organizations. Bruce had a caregiver arrive at 7 a.m. every morning to shower him, wash him, dress him. I was getting his breakfast ready, and his lunch, and after Bruce went off to school the caregiver swept out, and then somebody arrived in time to meet Bruce when he arrived home from school. We had that sort of treatment for a period before Audrey's death, and it ceased instantly, two days after she was buried. So I sometimes think it was easier to have been on my own than answering doors and letting people in at all hours of the day. It helped with looking after Bruce, but it was sometimes much easier to do it yourself. It was - a kind of intrusion - but they were all trying to help. We had aids for Audrey to get round the house and help her shower herself. There were handholds put in the bathroom and the toilet, chairs were raised to allow her to sit down, and get out of chairs. Some of the aids in the bathroom and the toilet are still there, and they're more than useful, to young ones and us oldies as well, to help us up and down or in and out ... that was about the only good thing we got!

Professional support needs to be perceived by parents to be of some value to their child. If parents do not see how the support is helping, they may see it as a waste of their time. Violet talked about this in relation to the education system:

I guess in the IEP ... I think it needs to be an empowering thing, and I think that needs to be brought up a bit more in the meetings themselves for parents. There are a lot of parents that are really, like I say, they're really on to it, but there are also a lot of parents who say, like myself in the beginning, you know it's not until you go away with the I.E.P. that you sort of think hmmm, yeah but is that ... you know how is that going to be ... and I don't quite understand that ... and things like that. And like I say it wasn't until I actually got more educated and things that I actually saw how you learnt too. Because you don't really have an

understanding about how you really learn, and until I actually learnt and did papers on child development, that I actually got to see how we actually learn, and I often viewed the IEP as ... at times ... being a total waste of blinkin' time ... myself personally, and also some of the people, parents that I actually worked with.

Frank talked about this in relation to medical appointments:

There have been a lot of visits, and without speech it's very difficult to gauge any reaction from Bruce. Eye tests at various distances comparing what he can see at a distance to what he's got in his hand can vary greatly and each time we go they seem to sort of come up with a different conclusion from eye tests. If he can't see he turns off very quickly. There's no point in just gazing into the distance if you can't see anything, and I can see nurses and eye specialists getting very frustrated when questions don't bring forth an answer. If he did have an answer he can't express it, and it's very difficult to know just which eye he can see out of, and the assessment of his vision is done by experts with minimal response from Bruce, which I guess is frustrating for them, with no idea what reaction Bruce would have, and most frustrating for parents as well, just knowing that your day gets interrupted to go to a medical examination, and when it's over you think well, that was another waste of petrol.

This theme of professional support being interpreted or 'constructed' by parents as an intrusion into their lives or as a waste of time, is an indication of how it is not only the children's lives which become 'special' but the parents' lives as well.

Managing

Several parents spoke of professional support as something they had to manage. For example Sarah said:

you've got to deal with so many different people so you've got to make up your own mind about who's going to benefit you the most, and who needs to be sort of put aside really. Not in a horrible sense, and you

know some of these people are self-serving, but you've got to sort out who's really caring and who's not any important to him, and get the most out of those people, without you give a damn you not when you're dealing with all these people, do you know what I mean? So you've got to be able to say 'oh, I don't know'.

Parents have to learn to manage, and resist, not only individual professionals, but systems of professionals, as Violet explains:

Even the matron, when she was there, had often said to me, out of all the children that she had seen come through there, because Shaun used to fret a lot, and got sick a lot and things, she felt that that wasn't really a good placement for him. She used to try and say it, but it was the way she used to put it across ... she used to make you feel worse, you know, so you felt like you were being intimidated. As I got stronger, I actually asked for her not to be any part of the IEPs, and the same with the vice principal at that time. I felt that the people that actually worked with Shaun were a lot more comfortable without them there, because they could speak freely. And a lot of suggestions that they came up with were quite practical ones, but they couldn't do it when they were there, because you had to work with the system. You had to keep to the rules.

Professionals who had a lot to do with a family were frequently referred to by their first name, reflecting a degree of trust and intimacy that has to be built up again when professionals change, as Doreen explained:

... these people all left in the same year ... at that time I had every name to a face ... and then, and [speech language therapist], and then she changed to [name of her replacement]. I think that's all it is, it's just people changing, and you get so used to a name.

Parents often have to spend time and energy passing on information to new professionals, and one mother told me recently how she had refused to involve the school in administration of her child's medication, though requested to do so by the paediatrician, because, as she said, "My life is an

open book". There is a certain loss of normal privacy that often comes with having a child with a disability, that can make parents feel very vulnerable to the opinions of the professionals in their lives.

Parent-Blaming

Blaming of parents, and particularly of mothers, is deeply rooted in our society, and has been found to be prevalent in the professional literature: for example, a 1985 study by Caplan and Hall-McCorquodale (quoted in Ruffolo, Sugamele and Taylor-Brown, 1994) of clinical journal articles found that mothers were generally (in 82% of the articles reviewed) perceived to be responsible for their child's psychopathology and were often described in negative terms. A further study, completed in 1992, analysed case studies in social work textbooks published between 1989 and 1992, and found that "mother-blaming" was very much present and that there had been little improvement since the earlier study. The authors also noted that the same emphasis is also prevalent in the current family therapy literature (Ruffolo et al, 1994). Parents are probably unlikely to be directly confronted with these negative attitudes towards them, unless they intercept a referral letter, as Mary did when she discovered she was being described by the paediatrician as "neurotic". What is probably more common is the feeling parents often get of being indirectly criticised or blamed, as Violet experienced:

The other thing too, that used to happen there was that when he did get sick, we were often ... like if he got sick, with asthma and things like that, it was like it was our fault if he got sick because we often heard complaints about having to keep staff, get in another staff member just to be there with Shaun during the day, and so then we felt responsible for them having to have someone there. So those types of pressures were also added, you know.

Often in IEP meetings parents feel the tension of unspoken but thinly veiled criticism. Violet talked about her experience of this:

I like the idea of being set small goals for short periods of time, because then that gave you - you know it was more ... what would you say? I

think the short term goals, and the shorter IEPs were a lot better, because then you had something to work ... you know if you say something like a year down the track, or six months ahead, that's too far ... like, you know, if you say in three weeks or six weeks' time, if this hasn't happened, and we feel it should. review it, and like, set small steps, like he needs to be doing this and this and this. And until that's happened, well, you know you need to **change** the steps, not necessarily change the goal, but change the steps to get to that goal. And I think the more of that type of IEP, for some of the parents I worked with as well, that seemed to be the better one. I know for teachers it was a real hassle, you know, and then they saw that the pressure was on to achieve it, yeah, and that meant more input from them and things like that, and for some teachers, not all, it was like, well, we know that they're not going to get to that point, within that time, and yet the parents, they could see that it made just a little step.

Parents blaming professionals

Sometimes parents blame the professionals for things that happen, as in Doreen's story:

But like when I, when I held her after having, you know giving birth to her, her skin was fine ... her skin was as smooth as, clear as mine, and the next day they rolled her in with all these ... measles-like thing ... rash, a measles-like rash ... that's when I blamed the doctor.

As I have already mentioned above, there is a greater demand for accountability by a better informed public than ever before. People are asking more questions, more frequently and more aggressively, and demanding answers. This could be constitutive of an environment where there is excellent communication and consultation, and where professionals are responsive to the needs of those to whom they are giving service. However, it could also contribute to the building of an environment which is increasingly retributive, looking to blame and punish when things do not go well. Some medical professionals are already finding the practice environment in New Zealand to be increasingly harsh: it seems that they are being judged not on the quality of

care they have administered, but on the outcome. Of course when things do go wrong it puts great pressure on parents as well as professionals. Another issue that puts pressure on parents is the difficulty they often experience in trying to access services for their children.

Access

One reason for this difficulty can be that services are not readily available for geographical reasons, as Mary explains:

I think one of the things that I really regret though, is living in a small town in north Auckland for the first four years of Justin's life, from ten months until he was almost five, because we didn't have any paediatric services, we didn't have any visiting therapist, we didn't have any of the services that are available in cities. And that's something that I will always ... but you can't change that, you know you can't change the fact that he never got it, but I look at littlies who get these sorts of services from birth, and that is what allows them to just be ... you know, have more abilities later in life, the fact that they've been given help so early, and yet we ... we were living a nice life, up in north Auckland, you know, in a small, very, very small farming community up there. Justin's Dad was the sole policeman, so it was a lovely life, but for Justin, as it turns out, we should have moved back to a big city. But we didn't know - we didn't know! He was such a lovely looking child. He didn't **look** as if he had any disabilities. It was just that at four he still couldn't, you know, sit up by himself, and those are things that I really regret that you just can't bring back. You can't bring back the fact that he spent his early life in a town where no services were available.

The nature of the service systems, and their interrelatedness, not least in terms of the fact that doctors are frequently the gate-keepers through which other services are accessed, can also constitute barriers for parents, as Violet found:

But, yeah, I think education and health need to get together a lot more, and not in competition, which is how I sense a lot of it is now. Like you know, sounds like health services have become more involved in

intervention. And for a lot of parents too, that's where they get confused with the health providing information and education coming in, and how does that fit, because people ... when you talk to some parents, they see education as reading and writing, and a lot of the things that we [early intervention teachers] provide are also the same things like the child development things, like cognitive development and fine motor skills and all those sort of things - it's all part of education, but a lot of parents don't see that.

In September 1995 the National Advisory Committee on Core Health and Disability Support Services presented its fourth annual report to the Minister of Health. In this document the committee acknowledged these difficulties under the heading of "Intersectoral Issues" which, it said:

... occur between health and disability services, between disability services and special education services, and between disability services and non-accident and accident related services.

Providers have difficulties with discharge planning - the release into the community from secondary health services of children with disabilities - because some of the necessary services are not available or are delivered in an unsuitable way. This particularly affects people living in rural communities.

There are intersectoral issues between special education services and disability support services provided for children with disabilities, which parents and families find confusing. These services are funded from different sources, although both kinds of services may be delivered to children in schools, in particular special schools and schools which have special units.

(NACCHDSS, October 1995, p. 38)

Informal consultation, the report says, has indicated that the major concerns of young people with disabilities and their families are: lack of information; need for co-ordination between diagnosis and development teams; more flexibility

in family support services; need for social support counselling, and better co-ordination between different agencies. The committee is committed to further consultation, and this is a positive sign for families. Questions still need to be asked, however, about the nature of the consultation, about how and where it is being carried out. One also needs to ask what is meant by "informal" and whether that is sufficient for an area which the report says is "one of New Zealand's nominated health gain priority areas" (ibid).

One issue which is an ongoing struggle for parents trying to access services is the way that access to disability services depends upon medical assessment. This medicalisation of disability springs from the definition of disability currently used by the Ministry of Health, and adopted by other agencies. It says:

A person with a disability is a person who has been assessed as having a physical, psychiatric, sensory or age related disability (or a combination of these) which is likely to continue for a minimum of six months and result in a reduction of independent function to the extent that ongoing support is required.

The report acknowledges that the definition has limitations because it does not take into account factors like transport, housing and employment which keep people from full participation in their communities (ibid, p. 37). This is encouraging, though there is no real indication of whether forthcoming definitions and parameters for disability support services will address issues like the ones Mary's experiences raise:

I'll just have a talk about the Social Welfare and the absolutely ridiculous stuff that some parents have to go through. If you've got a child with, I don't know, maybe it's with any disability, but I'll talk about cerebral palsy, if they're born with it, it's never going to go away. It may improve, their abilities may improve, but the fact that they've got cerebral palsy is never going to go away, but what you have to justify to Social Welfare each year is the fact that they've still got it, and that is a very frustrating thing. Justin was thirteen when I finally got a letter from

Social Welfare saying that we didn't have to go through this yearly review, that they accepted that he had a permanent disability. And he has very obvious disabilities, someone who's never walked in his life. Thirteen! I have the letter, quite close to hand, so that I can always refer to it. So those are the sorts of things that parents have to put up with. When he went from the Handicapped Child Allowance on to the Invalid's Benefit, it was a similar thing. He had to go through the whole process of seeing an independent doctor. We walked in to his room, and we just laughed. He laughed at us and we laughed at the whole situation. You know it's such an obvious, obvious thing, and yet we had to go through this process. So he just signed the form without asking Justin any questions, and then we talked about life in general. It's those sorts of things that you get very frustrated with, you know the obvious, and you have to justify it. I felt really frustrated; Justin used to feel really frustrated, and say, why do we have to do this, year after year, because at that stage to get the Handicapped Child Allowance, until he was thirteen, I had to take him in every year and have a medical examination done and the form signed. I don't know whether it's any different these days. I don't know if other parents are thinking about that sort of thing, but that was four years ago, when he got that letter.

While I'm here, I'll talk about something else as well, and this is the sort of discrimination I'm talking about when I said that I realised that some people with disabilities are discriminated against, and that is the things that they have to do that non-disabled people [don't] have to do. When Justin went to Australia last year, he had to get a medical certificate. He's not a sick person. He's not ill. His physical disabilities will not cause his death. I thought, that's fine, to go to Australia, everyone must have to have a medical certificate. I had no problem with that. But when his caregiver, who went with him, fronted up to have her medical test done, because I said to her, you've both got to have a medical certificate to go to Australia, she fronted up to have hers done as well, to be told that she didn't need one. Now I went to the Travel Agent and queried why a person with a disability had to have one, and yet a person without a disability didn't have to have one, and that's just the

way it is. This is the sort of discrimination that you put up with, if you're a person with a disability. What is the difference? I mean, his caregiver could have had a bad heart, and could have had a heart attack on the plane on the way over, but she was not required to have a medical certificate. Justin, because he had a disability, as with the others who travelled with him, all had to have medical certificates. So that's just one little instance, you know. How can Social Welfare justify that?

The changing health environment poses problems for both parents and professionals, as is evidenced by the resignation of eight CHE chief executives in eighteen months. If the changes are difficult for the professionals to cope with, they are strikingly difficult and confusing for most parents, as Violet explains:

... now that things are getting ... systems are changing ... I guess ... I don't know if it's a good thing ... I have to I guess wait and see ... where people now can approach funders themselves and privatise things. So I don't know. It's all a new venture, so ... I guess only time will tell whether that's been a good move or not. That's not something that's been in our system before, is it? Or not to the extent that it is now. So it's new, so I'm not sure whether it's a good thing. A group of parents that were at the conference, they've actually applied for funding for their children, up in Auckland, that's only a small group - but if you look at the group, they're professionals, and they knew how to get into the system, and work it. Maoris are doing more of that now. We've got our own whares and communities for like, the mentally ill, and ... I guess there's going to be more of those, but then again, we don't have enough skilled people on the ground to do the work. I mean it's good to have these new ventures, but then you have to keep up with the skills.

Professionals as Gatekeepers

There is, as many of the parents' remarks demonstrate, widespread parental disillusionment with their efforts to form partnerships with professionals. It is true that the remarks of the parents in the present study did not generally reflect the level of antagonism or intensity reflected in the following remarks

from the editor of the *Braille Monitor* (1989):

It is no exaggeration to say that the term 'professional', which should be positive and complimentary when applied to employees of programmes that are designed to give service to people, has become to the blind of this country [United States] a virtual swear word - a bitter term of mockery and disillusionment.

(quoted in Vaughan, 1991, p. 207)

There is, though, a widespread sense of 'them' and 'us', and there are some who consider that the public agenda of partnership contrasts with a hidden rationale that justifies working with parents in a way that prevents them from organizing themselves too well into a separate political force, and effectively extends the professional role (Wood, 1988, p. 196). This does not mean, of course, that every professional works, either consciously or unconsciously, in this way. As Ballard points out,

The most significant difficulties are associated with the idea that disability is a personal problem, disorder or affliction that requires professional intervention and management.

(Ballard, 1994, p. 18)

This medical model, which defines disability as a personal tragedy (Oliver, 1990) places people in the 'sick' role, as Mary's stories about Justin clearly show. It is, according to John McKnight, an economic need for "need" which creates a demand for redefining conditions as deficiencies which need to be serviced (McKnight, 1991/1992, pp 20-21). Access to those services is through professionals who assess the needs and control scarce resources. As has been noted recently of social workers in the New Zealand context,

They are having to face more and more issues of social control with respect to families and resources. It is as if the social services pretend to be caring for families. Take health social workers, they control very scarce resources for people. They always were gatekeepers for resources, but it is even more so now.

It has been suggested that conflict is therefore an integral part of the relationships between parents, professionals and children; that it is "embedded in assumptions about disability itself and relationships are necessarily oppressive" (Wood, 1988, p. 196). As Ivan Illich has said:

Besides doing technical things to body and mind, professionalism is also a powerful ritual which generates credence in the thing it does.

(Illich, 1977, p. 28)

It is this credence that contributes to and reinforces a world view in which it is the norm for professionals to exercise power, and for consumers to be passive recipients, as in Elva Sonntag's description of the "stereotyped image of women who care for children with disabilities: self-effacing, subjective, pliant, passive and co-operative towards those who make decisions on their behalf" (Sonntag, 1994, p. 185).

In the context of a discussion on consumer participation in the voluntary sector, Robert Drake has proposed three pre-conditions which must be met to some extent if the idea of participation is to mean more than tokenism or manipulation. These are:

- (a) that consumers must have the capacity actually to exercise power;
- (b) that consumers must occupy roles in which power can be exercised: they must have authority;
- (c) that the role must be situated within links and networks such that the exercise of power is effective: that it achieves its purpose.

(Drake, 1992, p. 271)

In the context of the present discussion, the extent to which these three pre-conditions are met will determine the extent to which parents as consumers can exercise power in terms of decision-making and control over the services their children receive. In Illich's terms, this means challenging professional dominance "by the questions they ask and the style of life which they

consciously create" (Illich, 1977, p. 39). Part (a) above means that parents must have the information they need in order to ask the questions. As Violet said:

For me personally, I think I would have preferred having someone alongside in the beginning, a professional, like a social worker, simply because presumably they should have some skills about communication, and be getting to know the family history as well and help them make their list ... about their needs. Because as a first-time parent of a disabled child you don't really know what your needs are, and having a professional around that may sort of start pointing out the sort of things to you and give you some idea how you ... I think I would have liked to have someone from the beginning instead of having to come to it myself.

Part (b) means they must have the authority to ask the questions. Violet talked about what this means in practice:

Yeah, so I just think that, for me anyway, I feel that I would like to have had someone there, like a social worker, maybe finding the information for me that in some areas I didn't have confidence. It's one of the things I've learnt I guess over the years of being in the other position of the teacher is that the more educated you are, the more confident you are to ask. In the beginning I didn't feel ... you know we, well, got through some high school years. But I have found in my work that the less educated parent finds it very difficult and is not as confident to ask. It's not that they don't want to - it's just that they're not as confident. And I guess also I think in the beginning because I didn't feel confident I would have liked to have that person alongside.

Mary also talked about what it means to exercise authority:

... you've got to have so much stamina, and so much ... determination, even just to have the guts to speak up to somebody. You know to have the courage, is what I mean, to have the courage to question

something.

One reason why this exercise of power is so difficult for parents to achieve relates to the individual model of disability and the way parents are perceived as being in need of professional help to overcome their 'problem', and the way that

... parents learn to become acceptable to professionals through learning the role of parent of a handicapped child, and the consequent rules of interaction and what they are supposed to feel. This process is clearly thrust upon them by the professionals since they start out as 'normal' parents with the view that their child is a person in their own right and they relate together in a 'normal' way.

(Freeman, 1988, p. 84)

For part (c) to be realised in practice, for families to be able to pick and choose and evaluate professional performance in a way which gives them opportunities to control their own lives, parents have to be listened to in a way which is still all too uncommon. Certainly individual families often build up successful relationships with individual professionals, teaming up to overcome problems for their child. This may be very successful, or it may in fact seem less so to the parents, for whom it is much more difficult to express dissatisfaction with professional performance if the professional is also viewed as a friend. This problem derives again from the inherent power imbalance between parents and professionals (ibid, p. 79). A few parents may be in positions of power at the level of management, policy making, planning and development of services, because they have demanded them, but these parents may in fact be the exceptions which prove the rule (Wood, 1988). As Wood says:

The concept of 'parents as consumers', and therefore ideas concerning their rights to information, records and files, involvement and participation in decision making, are secondary to the recognized need of the professionals for parent collaboration and thus the interventionist and preventative purpose.

Referring to the area of special education, Wood suggests that the basic conception of partnership has merely served to extend the professionals' sphere of influence, "helping parents to be better parents for the sake of the child" (ibid). The home, the domain of the family, is one area where the social pathology model of individual needs offers professionals the legitimate authority to implement intervention, reinforced by the ideology as necessarily helpful. As Wood points out, "parents are frequently so grateful for someone visiting at home rather than having yet another appointment to attend, that they may actively encourage this taken-for-grantedness" (ibid, p. 200). However, as Andrea Freeman, a former educational psychologist, points out,

... we can never be sure that a home visit is likely to make the parents feel more comfortable, but we do know that some parents are never in when we visit them. Some visits may be very threatening and seen as a sort of inspection thus enhancing the power of the professional, whilst other visits may enable the parents to gain power through personalisation and moral pressure.

(Freeman, 1988, p. 81)

Freeman goes on to suggest that "in addition to expansion, parents can be used by professionals for many different purposes, including entertainment, reassurance, support, tea breaks, experiment, research, practice, and evidence." (ibid, p. 82). While it is not suggested that professionals deliberately go about using parents, or exercising power at the expense of parents, in order to increase their own authority, influence and job security, it is important to recognise the disabling effects as unintended consequences of professional practice, in order to understand "the divide between rhetoric and practice, and professional intentions and parents' experiences" (Wood, 1988, p. 202).

Families are, in this context, "perpetually vulnerable", because there is a permanent imbalance in need between parents and professionals: "lifelong needs, wants and hopes drives one of the parties in this relationship" (Wills,

1994, p. 258). Lack of choice for parents exacerbates this vulnerability, and ironically, the current trend in New Zealand towards 'deprofessionalisation' in the social services may serve to limit parent choices even further:

There is a trend toward deprofessionalising not just social workers, but also people like occupational therapists and physiotherapists. [...] We see the deprofessionalisation of jobs as being a way of introducing cheaper generic positions. The market reflects the element of truth in the notion that social workers, occupational therapists, psychologists and physiotherapists often have a common core of knowledge about counselling or resource information, but it is also exploitative in the long run.

(Thompson and Stenton, 1994, p. 432)

Anne Opie has also identified this trend as indicating a possible shrinking of services in response to "the organisational action culture and ... current political priorities" (Opie, 1993, p. 176). She suggests that:

In times of fiscal tightness, Regional Health Authorities may well question the value of employing trained social workers if their role is defined primarily in terms of information-giving because it would be easy to argue that less expensive workers could do the work as effectively.

(ibid, p. 182)

The problems are inherent in the system, because "professional training is a socialisation process where professionals learn how to be professionals and how to exercise power" (Freeman, 1988, p. 84). The solutions do not lie in blurring roles or changing labels, because parents acknowledge that they value and are reassured by the body of knowledge and the code of practice denoted by the term 'professional'. The Otago Family Network, a project whose value base was the empowerment of parents to become active partners with those professionals involved with their child (Ballard et al, 1992) set up support and advocacy services for children with disabilities and their families, and initiated schemes for parent involvement in the training of education and

health professionals. They noted that while the concept of 'partnership' between parents and professionals had been widely promoted over recent years, implications of such a model have been poorly defined for professionals, and it has been assumed that all parents wish to be equal partners all of the time (ibid, p. 340). They suggested that professionals need to gain a greater awareness of how they use power in their relationships with parents if parents are to be accorded respect and treated as adults rather than as children who need help and guidance (ibid p. 341). They conclude that there needs to be mutual respect, and that all parents wish to be kept fully informed, though they may not be interested in a relationship based on negotiation and equality in decision making all of the time. They acknowledge that neither parents nor professionals can ever share the others' experience completely, but they suggest that

... professionals need pre-service and in-service training in self-awareness regarding the models of professional-client relationships they work from and the need to be understanding of values different from their own. From experience in the Network we suggest that it may also be helpful for parents to reflect on professional value systems, including ethical responsibilities which in some instances (for example, child abuse) might appear to override parent wishes.

(ibid, p. 342)

In the area of education, Wood suggests that in addition to making themselves more aware of the systems and processes they are involved in and the consequences for themselves, and for children and parents, they also need

to alter structures to make room for parental choice, control and evaluation. They will have to be able to work within more open situations which involve sharing with and supporting other professionals, as well as parents. They will have to be prepared to critically examine their own practice themselves, and accept such from parents. They will have to be more open about what they are doing and why, to question their own motives, stances and the principles as well as the rhetoric upon which special educational provision is based.

The last, ultimately hopeful, comment is the following from Violet, who speaks for herself, and for many other parents, when she says:

It means that parents have to be more involved, and that's definitely what I've learnt from Shaun as far as the education system goes, is that as a parent you have to be more involved, and a lot more involved than you would have been ... like we would be with our normal children. But I also learnt that I could have been that much more involved with my other children as well, but I never did, you know? Because you think oh, those people at school know what they're doing. Now I've got involved in the system ... and it's not so! [laughter] They don't know everything, you know! And even with the normal children, as we say, I believe now that I've been involved in the system, in the education system, that parents have a really important role to play and it's a pity that some teachers feel threatened by it. I mean a lot of parents that I have met in my work only want to help as much as they can. But they often feel put off simply because the teachers feel threatened in some way, and yes, there are a lot of parents out there who think they know it all, and they do ... I mean, for me personally I don't mind being put in my place, if it's needed. But that's an issue I think - it would be really good if the systems could cater for people working alongside each other. It's a lot better than it used to be. I have to admit it's a lot better than it ever used to be. But I guess like everything else, there's always room for improvement.

Violet's remarks are so apt: things are certainly frequently much better than they used to be. A number of schools have written and implemented policies on inclusion for their students, and as McKay et al report on the tertiary sector, "institutional policies and practices, and the work of staff and of students themselves, have moved towards ensuring that disability is not a barrier to educational achievement" (McKay, 1995, p. 1).

However, while improvement is heartening, it is not to be taken for granted,

and as Colleen Brown says in relation to her own family:

Even now the children know that Travers' future is uncertain. They have some understanding of the energy we have to invest in making sure he remains as much a part of the community as they are.

(Brown, 1994, p. 244)

In the following section I outline some strategies for the sharing of power which I think are indicated by the research. I have been guided by what the parents have said they wanted, and by the stories of parents in the literature, like Colleen Brown, who says:

Parents do not need their visions for their child with special needs shattered by short-sighted restrictive practices. Parents need to have a vision based on what they really want, not what they think they can get.

(Brown, 1994, p. 241)

Chapter Seven

Strategies for Sharing Power

In order to sustain the effort which both client and workers invest in a relationship, and to ensure that the resulting intervention is an effective and empowering experience, it is imperative that a vision is articulated.

(Shaw, 1994, p. 419)

Advocacy though demands a wider vision. It begins from a picture of a world in which some people are included and some excluded. The advocate says to her partner:

I'll stand with you. If I'm with you then you're with me. If they exclude you they'll have to exclude us both.

What stops them both being excluded of course, are the people who will stand with her, and the ones who will stand with them, and so on.

(Tyne, 1994, p.253)

The 'technologies of power' (Foucault, 1979) to which I have referred throughout the text, are often, as Robyn Munford comments, "subtle and hard to detect" (Munford, 1995b, p. 38). Nevertheless, they can exert a powerful influence on what happens for children with disabilities, even the extent to which they are included in or excluded from the main stream of the life of their community. For this reason, it is important to examine in detail how this influence is exerted. It is important, too, to pay attention to what Dorinne Kondo calls "the simultaneously creative and distressing effects of the interplay of meaning and power" (Kondo, 1990, p. 24) in order to avoid characterising the 'relations of power' as unilaterally 'oppressive' (Oliver, 1990). It has been my aim in this text to emphasise the agency, the ability to 'craft' identities for themselves, of parents, and their children with disabilities.

It has been my intention to celebrate the successes, the alliances which have worked well, the joys and triumphs. At the same time, because one of the parents' most consistently and firmly stated aims was that other parents should

learn from and be empowered by these stories, it is necessary to articulate as well, the difficulties and regrets, and the anguish of lost hopes. The parents in this research study have done that with an extraordinary degree of courage and candour. It is also part of my task to make explicit the links between the parents' and children's experiences and the 'relations of power' that operate at both the micro or personal, and the macro or policy, level.

It is to this latter task that I now turn, looking in detail at a topic which is of major concern and interest to parents of children with disabilities - that is, caregiver support to families - from three different perspectives, through discourse analysis.

I shall then discuss various strategies for resistance and change from the literature, and show how the theoretical ideas introduced in Chapter Two contribute to an understanding of the experiences described in the narratives of the parents who took part in the research project, and their identification of strategies which have worked for them.

Discourse Analysis - A Strategy for Change

The Official Story

The following text appears as the centrefold of the Ministry of Health booklet entitled *Who gets Disability Support Services and when do you pay?* The booklet is not dated, but was produced by the Ministry of Health to explain the situation from 1 July 1995. The information is set out in columns, in table form. The headings in bold print are the column headings across the page. The services are listed in the first, left-hand, column. 'Caregiver Support' is the third service listed:

Service

Caregiver Support

What it does

Provides a number of days relief care each year so that the full-time caregiver can take a break.

Has been known as *Aid to Families, Alternative Care, and Respite Care*.

What happens if you already use the service

People who used the *Aid to Families* service, or had their applications approved between July 1994 and June 1995 will get a new allocation of 28 days relief care. Some people may not have used their number of days relief care but they will still get another 28 days.

From 1 July 1995 this group of people may have a simple review or assessment to work out how much relief care is essential. It may be more or less than 28 days, depending on individual need.

Who pays

The RHA pays a subsidy for caregiver relief. For most people the subsidy covers that cost of the service. However some of the agencies which provide relief care charge an amount over and above the amount of the subsidy. You should ask your RHA which of the services do not have the additional charge.

There is no income and asset test on the RHA subsidy, but the charges required by agencies will remain.

Texts, as Anne Opie observes, "do not occur in a vacuum, but are socially constructed" (1993, p. 172). They are the products, not only of the person who writes or speaks them, but also of the "historical, organisational, political and economic contexts" (ibid) in which they are produced. Texts respond and add to past texts, and anticipate and contribute to future texts: this "inherent historicity" enables texts to "take on the major roles they have in contemporary society at the leading edge of social and cultural change" (Fairclough, 1992, p. 102). Certainly the text before us is situated in a context of government acknowledgement that families need some relief from the constancy of caring for a loved one with a disability, and refers back to similar schemes which have preceded this one. The language of this excerpt is informal, as in "take a break", and as Fairclough says "if the voices of powerful people and groups in politics, industry, etc. are represented in a version of everyday speech ... then social identities, relationships and distances are collapsed. Powerful groups are represented as speaking in a language which readers themselves might have used, which makes it so much easier to go along with their meanings" (Fairclough, 1992, p. 110). The language is that of consumerism, in that it assumes a choice of services, for which a subsidy will be paid. The text thus contributes to the ideological constitution of powerful subjects who need only

"ask your RHA" for the necessary information with which to make an informed choice. The service itself is presented as conditional only upon "individual need" and this is determined by a "simple review or assessment". The language also reflects the discourse of 'commodification' (ibid, p. 207) in which services and service providers are organised and conceptualised in terms of production and consumption. In this text the impersonal terms "caregiver support", "relief care", "alternative care", "respite care" and "caregiver relief" all work to obscure the fact that it is people who do the caring. The text presupposes a consumer who buys the service, a government agency which pays for it, and "the agencies" which provide it, but makes no mention of the carers who do it.

Foucault's analysis of the 'technologies of power' can be applied to this text in several ways. What Fairclough calls "discourse technologies" (1992, p. 216) such as the simulation of power symmetry and informality can be used by institutionalised power-holders to obscure a real power imbalance: for example, the use of the word "simple" to refer to the review or assessment which decides how much relief care is essential, is a strategic device which obscures the real nature of the really quite involved, time-consuming, bureaucratic, medicalised procedure to which it refers. In the same way the phrase "ask your RHA" obscures the fact that asking your RHA is no simple matter for those New Zealanders who do not live in the same city as an RHA office, that the RHA is not listed in the phone book, and that an attempt to "ask the RHA" for information can become, as it did for me when I attempted it, an exercise in frustration and disappointment, yielding no useful information. The use of the word "essential" is another such strategy, but this is a more risky one, in that while it is not made clear who decides what is essential, the informality and the negotiative style earlier in the document (e.g. "This means that you and the people who know you best, help to decide what support you need") could offer an opportunity for a struggle over its interpretation, and resistance to a unilateral decision.

On the front cover of this booklet there is a statement that says: "This booklet talks about who gets disability support services and who pays for them from 1 July 1995". The text "talks" but with whose voice is unclear: at times it seems

to represent a universal perspective in its use of the simple present tense "provides", "pays", "covers", and "is", the use of this "objective modality" (ibid, p. 159) implying some form of power. The use of "will" as in "will get" and "will still get" gives a meaning of categorical prediction, and suggests that the text producer is writing from a position of insider knowledge (ibid, p. 173). Similarly with "may not", "may have", "may be" which imply permission from the expert, and "you should" which offers expert advice.

The booklet in which this text appears looks like an official document purporting to give answers to specific questions: who gets disability support services and when do you pay? The language used is informal, and the reader is addressed as "you", but there is no indication of what sort of people "you" might refer to: the terms "people" and "people with disabilities" are used to construct a knowledgeable, powerful social subject, as in "people with disabilities found ..." and "people get most of the disability support services they use ..." Nowhere is there any answer to the question "Who gets disability support services" and it took me four telephone calls to reach the local agency which is under contract to the RHA to administer the relief care service, and to be told that entry is through a GP referral to the service. The service is offered to "the full-time caregiver", but there is no definition of what that means, and no mention of the person who is to receive the care. This text is more remarkable for what it does not say than for the information it does supply. It does not say, for example, who may supply care, how or what they will be paid, or where the care will be given and received.

I have given this text an explicitly resistant, rather than a compliant interpretation, and I have augmented the information it contains with a telephone call, or rather four telephone calls. By using my capacity for a critical reading of this text, I have entered into a struggle over its interpretation and what it could mean for me as a potential user of the service, or as a professional working alongside such a person. I turn next to a different perspective, and a different reading of the scheme described in the text.

The Perspective of a Caregiver and Researcher

The following paragraph provides a critical commentary on the Aid to Families,

or Relief Care scheme. Written by Robyn Munford out of her experiences as a caregiver and a researcher, these comments appear in her chapter on caregiving in *Disability, Family, Whanau and Society*.

An illustration of how the needs of families can be ignored relates to the way the Aid to Families programme operates in New Zealand. The Aid to Families programme is seen as essential for families in that it acknowledges the importance of the caregiving role by allowing individuals to have access to respite care. Changes to this programme have meant that family members who provide the respite care are no longer eligible for a daily allowance. They can be reimbursed for expenses, but the onus is on them to document these expenses. Maori and Pacific Island Families have been disadvantaged as they may have a preference for family-based respite care. This is just one example of how services that have been effective for families can very easily be eroded by new policy directions.

(Munford, 1994, p. 288)

These comments make explicit what the text itself did not, that there have been some crucial changes made to the policy, and that these changes impact on families in a way that further limits their already meagre options. Robyn Munford comments further: "We have yet to make a commitment to providing appropriate high-quality services. How will people with disabilities be included in the 'mainstream'?" (ibid). In the absence of such a policy commitment, the answer lies at present with individual families, and depends to a large extent upon various, and variable, factors coming together in such a way as to make real choices available to people. For this to happen, it is usually necessary for family members to exert huge amounts of energy, and this is reflected in the stories of the parents in my research project, and in the following excerpt from a participant in another such project.

A Service User's Perspective

Analyses can assist and augment our understanding, but it is a primary tenet of this research project that it is the actual experiences, the "stories" of the families themselves that have the vividness, and the power to convince. The

following excerpt is from Elva Sonntag's chapter on women who care for children with disabilities in *Disability, Family, Whanau and Society*:

At the time of her interview Betty was becoming acutely aware that she could no longer expect her now ageing parents to continue to be respite caregivers. They had helped very readily in the past, but the problems associated with lifting their grandson could only increase, and already he was too heavy. He needs total 24-hour care:

I know that nobody would ever ring me up and ask 'Can I have Andrew for the day' [and] you feel you use people all the time and I still find that very difficult to cope with. I feel *guilty* a lot of the time because I ask people to pick my son up and I try to do as much as I can because I feel he is my - our responsibility. Though people are very good, they only do it up to a point.

Finding a way to access respite care has always proved difficult.

(Sonntag, 1994, p. 200)

It is Betty's words that unpack the full impact of those elements of the policy that are obscured in the initial text: the guilt, the daily responsibility of care, and the difficulty of finding the people to do the caring, people who have the training, the skills and the will to do the job of caring.

In this section I have shown how discourse analysis and critical language awareness can be of strategic value in resisting the technologies of power of dominant ideologies. As Pauline Boyles comments:

Language is one powerful method of exclusion whether that be in a verbal, ideological or a cultural context.

(Boyles, 1995, p. 153)

Other Strategies of Resistance

Analysis of language practice and critical use of language is one of a range of

strategies which may be employed to encourage resistance to practices, language and attitudes that restrict choices for people with disabilities or exclude them from the mainstream of education, employment or community life.

In the following section I discuss various action strategies that have been suggested by a range of writers and researchers to support the process of social change.

Education and Training of Professionals

The researchers in the Otago Family Network (Ballard et al, 1992) worked with parents as allies in the development of a programme in which parents contributed to the training of educational and health professionals. They were motivated by the idea that "professional involvement with parents can be seen as potentially changing the professional "world view" - the way events are perceived and defined - toward a perspective that has greater understanding of the reality and diversity of family experiences of disability" (ibid, p. 173). The researchers acknowledge, however, that "professionals' behaviour ... is the result of the interaction of many factors, including the powerful effects of the organisations and systems in which they work". They conclude that these efforts by parents and professionals to influence systems and the interactions between systems "do have some effects on professionals in training" but that "it is not possible .. to be sure of the effect or durability of this effect on systems of service delivery and modes of professional behaviour" (ibid, pp 222-223).

Professionals as Allies

Recognising the disempowering nature of the professional hierarchy, Hilary Brown and Helen Smith (1992) suggest an agenda for the 90s in which they propose that professionals support, empower, encourage and facilitate 'meaningful association' between people with disabilities, in and through self-help groups, consciousness-raising groups, user management of services and visible political activity and campaigning by people with disabilities for the resources which they decide are most important to them.

They acknowledge that "the mixed economy of care may prove exploitative of

users, carers and workers as the slender protection offered by national agreements and policy guidelines are dismantled and the new mechanisms of contracting and local employment negotiations are introduced" (ibid). Although Brown and Smith write about the situation in the U.K. we have seen how the situation in New Zealand is also one in which the ideology and priorities of those in power, together with legislation and employment practices favour the powerful. Without the personal commitment of non-disabled citizens, people with disabilities are increasingly at risk. If the oppression of people with disabilities is to be taken into the political arena, professional and cultural values which stand in the way must be challenged, and the conflicts of interest which lie at the heart of services to people with disabilities must be exposed.

Analysing Structures of Power

In her analysis of social policy in Britain today, Fiona Williams has developed a model which is helpful for understanding the divisions through which people's lives are constituted. At a simple level it is a series of axes which represent different social relations of power. Axes of power which are currently important in New Zealand are those of gender, race, class, sexuality, disability and age. This model is a way of highlighting the dynamic relationship between the individual, power and structure. It shows how the individual consumer of welfare is not a person who is free to choose, but a person whose needs and choices are constituted, articulated and structured by a variety of divisions and differences. This model goes beyond identity politics and acknowledges the impact of structures of power, recognising not just the moment, but the pattern and the structure too.

Translating this into policy terms means moving in the direction of universal services which are capable of meeting diverse and different needs. In political terms this means being able to identify and articulate the needs which people have in common. Such a strategy centres around issues of empowerment, representation, and access to quality, accountable user-centred provision.

Naming the Moment

Deborah Barndt suggests four phases in the process of political analysis for

action or "naming the moment" (Barndt, 1991, p. 27). These are: identifying ourselves and our interests, our history and our constituency; naming the issues or struggles; assessing the forces; planning for action. Stuart Rees adds some important aspects in his steps to empowerment, such as; developing the notion of choice, experiencing solidarity with others, and acquiring and using language (Rees, 1991, p. 89). Rees also suggests "biography" as an important strategy for empowerment, in that "[t]he story which unmask choices made in the past can suggest opportunities for the freedom to choose in the future".

Developing a Critical Practice

Robyn Munford, Sara Georgeson and Janice Gordon have brought together some guiding principles which together form the basis for a coherent framework for a critical way of working with people with disabilities and their families (Munford, 1994, pp.276-277). This framework was designed to guide sound social work practice, and as Anne Thompson and Geoff Stenton point out in their interview with Robyn Munford and Mary Nash (Thompson and Stenton, 1994, pp 433), there are elements, such as advocacy for example, which social workers may share with other professionals. By grounding these principles in the realities of his or her own everyday professional practice, each worker contextualises them anew and opens up new sites for intervention and change. Thus the process of building a healthy way of working with people is cumulative and collaborative, and above all, respectful.

The framework begins with a structural analysis of disability, in which private troubles are linked to public policies. This account recognises the extent to which the problems for which people seek help are the outcome of "certain practices of relationship and practices of the self, many of which are actually informed by modern notions of 'individualism'" (White, 1995, p. 115) and structures of inequality pertaining to gender, class, culture, age and economics, as well as disability. This analysis is done through "the asking of perceptive questions, the listening to and telling of the life histories and stories of clients, and by entering into a critical dialogue" (Shaw, 1994, p. 420).

The next principle is a critique of the worker's role in relation to the person or

family he or she is coming alongside, with particular attention to its social control tendencies. Workers need, as well, to be very clear about constraints on their practice, because, as Anne Thompson and Geoff Stenton say, "if one works for an organisation one cannot pretend to the consumer that one can always advocate for them" (1994, p. 433). Advocates cannot afford to be too closely allied with the service system, because "compromised interests weaken the capacity to speak out with commitment" (Tyne, 1994, p. 250).

The third principle involves a critique of existing structures, with the aim of understanding social policy and how it impacts on the lives of people and families in terms of resource allocation and real choices. An understanding of the part discourse and language practices play in shaping social reality, and a critical language awareness are useful tools for the appraisal of current policies and practices.

The fourth principle is one that is commonly identified by parents as important: that is, commitment to working alongside families and individuals as they build strategic alliances and make important choices. The worker functions as an ally of the person and family, rather than as an expert, or even as a partner. Beginning at the beginning, where the family is at, she or he works to understand their story with a view to "resurrecting the subjugated knowledges" (White and Epston, 1989, p. 34) in a way which creates space for them to celebrate their own successes and also links them to other people and groups.

The fifth principle, another one which parents identified as critically important, involves the skill, knowledge and competence of the worker to be able to "manoeuvre through bureaucracies, to unlock resources, and to advocate on the part of clients" (Shaw, 1994, p. 422) in order to meet their immediate needs. It also involves the ongoing process of action and reflection which Shaw calls "the linchpin of the radical working relationship that both worker and client engage in" (ibid, p. 419). This strategy links Michael White's ideas about therapeutic work as primary research (White, 1995) with Freire's (1992) notions of the way in which people are enabled to effect both personal growth and social change by developing an awareness of the connections between their own lives and the oppressive social and political structures within which

they live.

In this review of various strategies for social change, I have briefly outlined some suggestions for ways in which professionals might work towards the creation of an inclusive community. In the next section, I will show how the parents in the study have developed various strategies for change, and how those strategies link back to the ideas and theories in Chapter Two.

'Conscientisation'

Because language plays such a major role in the construction of our selves as social subjects and of our social relationships, a critical awareness, and use, of language can go some way towards redressing imbalances of power. There is a sense in which power, residing in innumerable small acts of saying and doing, can be cumulative and self-perpetuating (Drake, 1992, p. 269) and while it is usually not in favour of those whose voices have been silenced by the voice of authority, there are ways in which it can be. Violet's story shows how strategies of resistance are developed over time, through the conscientisation of individuals, and through the building of strategic alliances:

A lot of the parents I meet now like have the confidence. Even though they're young, they seem to be a little bit more aware, so whether that's ... I don't know, it's just change of times, I don't know, they just seem to be that much more aware. They at times may have a moment of low self-esteem and things. One of the mothers was saying - she's only young - that because she's had to go and find the information herself, because she hasn't trusted in what the professionals have told her, that's made her more aware and self-confident, you know and now she's gone to learn. ... And so my idea became that we need to have really good social workers working alongside of families, and particularly when parents have to really push on the system. And to be a good support for people particularly when they're dealing with professionals.

Speaking Out

Freire talks about "speaking the word" as an act which is "at the same time

associated with the right of self-expression and world-expression, of creating and re-creating, of deciding and choosing and ultimately participating in society's historical process." (1985, p. 50). In her story Violet explains the profound significance of language by contrasting her present confidence and assertiveness with the impoverishment of her former wordlessness:

And until I learnt to be confident and ... I mean assertiveness never came into it 'til years later! [laughter] ... when you lack the word, you know ... and that didn't come in until I actually was out working in the community. So you know, it was a real self-educating thing, to go out there and do things.

Sharing Information

One of the things Violet 'went out there and did' was to offer information to other, especially young Maori, parents:

The majority of them I spoke to didn't realise they could access that. They saw the piece of paper that the doctors gave, but no-one actually said to them, you have the right to actually see it. And even when they got told, they still didn't trust it. So I actually went along with them to actually ask if they could have their file, and it wasn't until they actually got it in their hand, and it was like ooh, we do, we do have this right, you know, this is fine. And I used to see this in young Maori people, and they were sort of like, am I really allowed to open this damn thing? ... and I would say to them, some of the medical terms might be ... you know, so we're allowed to ask.

Being allowed, or being given permission, to ask, to question, to speak, is a crucial step for many parents, and may come through peer or professional support, or just the sudden realisation that no permission is necessary.

Asking Questions

Freire talks about the "culture of silence" in which "the masses are mute, that is, they are prohibited from creatively taking part in the transformation of their society and therefore prohibited from being" (1985, p. 50). The "elites", amongst whom are included the doctors who inscribe the medical case notes

that create children with disabilities in their own (medical) image, "are anxious to maintain the status quo by allowing only superficial transformations designed to prevent any real change in their power of prescription." (ibid, p. 78).

Choosing Identities

Violet's actions in resisting this 'power of prescription' effectively begin the process of 'conscientisation' for the parents, through which they are enabled to begin to re-create their children in their own (family) image:

And so when they got to work at it, and got to ask questions about some of the medical terms, the empowerment that actually occurred was absolutely incredible you know. Then after that, to know that they could ask questions and they were going to get answered ... you know, they may not be the answers they were wanting, but that they were going to get some answers anyway, and the fact that they could keep asking questions ...

Like Foucault, Freire recognises that "domination is never so complete that power is experienced exclusively as a negative force" and stresses "that there are always cracks, tensions and contradictions in various social spheres such as schools where power is often exercised as a positive force in the name of resistance." (Freire, 1985, p. xix). Violet's story shows how sometimes people find those cracks and things change for the better:

... they felt that they weren't coping, they weren't getting enough support ... and you could hear it, in the IEPs, like the head teacher was saying, no no that's fine, I'm coping, but ... and they had problems keeping their teacher aides ... and the teacher aide Shaun had was a young man. I felt personally he was excellent, in actual fact he was, he was good with Shaun. He actually left the job, but a lot of it was because he was really frustrated with certain persons, and he couldn't ... there were a lot of ideas that he had that weren't getting listened to. He didn't even get invited to a lot of the IEPs, so of course he was left feeling very ... and of course he gave it up. But he came back to the special school and the difference was ... he was given more freedom to

work with Shaun and it was really good, and it was you know, like a male role for Shaun. So he was really good for Shaun.

Violet's story also shows how pain accompanies conscientisation; how with the idea that it is possible to change things comes the grief and pain of not always being able to:

And again it was because of the lack of people support ... so now he's at a special school. If we were able to have moved to Auckland, we would have moved to Auckland and left him in Homai because we felt for his disability, the blindness in particular, it was a better place for him. But the fact that he lived away from home, and we couldn't be there a lot of the times, and particularly when he was ill ... so on a daily basis, if we were there on a daily basis, yes I would have kept him at Homai, but because we were away and we had to travel up there and things like that, at times of crises or need, his needs, we weren't there, so there's a whole guilt trip that goes with it too. And so the decision was, because all of these behaviours were manifesting, somehow we got the message that they weren't coping. So I just thought, oh I'm not going to go putting myself through this again. So I said, well I'll have a look what is in the community, and maybe we could find support within the community ... which has really, it's been quite difficult.

Mary's story also speaks of ongoing resistance and ongoing pain, and shows how the 'power of prescription' categorizes Justin, attaches a certain identity to him and imposes a particular subjectivity on him, a subjectivity which he struggles to resist, with varied success:

... another issue that arose at the school was that a physiotherapist turned up at school. It was something that obviously the school had arranged, because nobody else did. She turned up from Wellington, and went into the classroom and she must have had a walking frame because Justin hasn't got one there, unless he was using someone else's. But he had a really unhappy session with her, and actually spoke about it afterward, so that's how unhappy he was, but she tried to

make him walk. She went in there, without reading any of his case notes, without knowing anything of his background, and said to him,, when he said, I can't walk, she said yes, you can, because Matthew can. This is another student in the school. This has been one of Jason's problems there, that he's being compared to someone who has cerebral palsy, but who is actually able to 'weight bear'. What this woman failed to realize is that Justin's not able to "weight bear", and he tried to tell her on this particular day that he was not able to stand, that he can stand on the walker, but it's using the top part of his arms to support himself. So he actually wasn't able to do it, and she growled him and told him that he ought to be able to do it, because, you know look, Matthew can do it, so you should be able to too. And that for Justin is really undermining. He really feels that, if he says he can't do it and then someone says yes, you can, especially someone who really doesn't even know him, who has never read anything about him. I found out later on that she actually has not read any of his background notes. She would have realised that the only reason that he stands on a walking frame is for postural drainage. It's nothing to do with walking. It's just to get his body in an upright position.

This is not an isolated incident: the struggle over Justin's body, the battle to define his identity for him, has been going on for years:

Unfortunately over the years he's had physiotherapists, and very well-meaning people in his life who have just encouraged him to carry on trying to walk. But the reality is that, because of the way that Justin's body is, he won't walk. And I think it wasn't until about three years ago that Jason finally accepted that that was the situation. Prior to that he would spend a whole weekend out of the chair. He would just pull himself along the floor, rather than get in the chair, because he'd had to spend the whole week in the chair at school. He got very, very anti-wheelchair, and it wasn't until he had a new young physiotherapist come into his life who really got stuck into him, and told him that there wasn't any point in carrying on trying to use the walking frame, because he would never walk. And for about three months after that Justin

would have nothing to do with her, and never spoke about it, but what she said to him was, instead of focusing on this - because of the way your body is you won't walk - you're better to just forget about walking and focus on the positive things in your life. You know, forget the walking and just accept that you're going to be in a chair for the rest of your life, and find something positive to do.

'Crafting Selves'

Justin's task, as Foucault's work (1982) suggests, is to refuse that kind of subjectivity that is imposed on him by others, and to choose his own. Justin's way of doing this illustrates Dorinne Kondo's point about how people "consent, cope and resist" at different levels, taking advantage of "multiple, mobile points of potential resistance" (1992, p. 224). His mother describes the choices he has made:

That was a really, really hard message to take. I found it really difficult to take too, particularly because she was just a new person come into town, but what she was doing was not giving Justin false hopes, and that was really the turnaround I guess, because since then, he doesn't have an attitude towards his chair now, but he's not at all happy that he lives his life in it, and nobody would be, I guess. But what he's done is then found things that ... rather than concentrate on that, he's just found things that he really likes doing. I mean, he just **loves** music, any sort of music.

Celebrating Successes

The celebration of success is another powerful strategy for resisting the labels and the low expectations that can be attached to children, and adults, with disabilities. This is a powerful strategy in several ways: first of all, it challenges low expectations, restrictive labels and exclusionary attitudes and practices; secondly it contributes to the building of personal confidence and self-esteem; thirdly it helps to broaden the base of acceptance and inclusion for people with disabilities by showing others that they are capable of both ordinary and extraordinary achievements, like everyone else. Justin's mother goes on to talk about his achievements:

... everything that he learnt in the end, he has learnt through memory. It's not been through reading and writing. And when he got 67% for School C English, that was just the most **wonderful** achievement in the world. It was just unbelievable! So I would really like to pay tribute to Justin and say that he's just the most wonderful son. He has a wonderful personality. His personality is what really endears him to everyone that he meets, and he's got the most wicked sense of humour at times. I mean at times he has had us in stitches, just through something that he's said, and has just had us laughing and laughing and laughing. And those are the sorts of things, with all the lows that he's had in his life, that have shone through; his personality, and his wit, and his humour and his courage and his determination. Those are the sorts of things that have made him the person that he is today, and he's a really really neat young man, and I'm really really proud of him.

Both Mary and Violet strongly acknowledge the pain involved in the processes of conscientisation and ongoing resistance, and the need for support and encouragement from allies in the system who are willing to struggle alongside them in a "politics of difference" such as that suggested by Jana Sawicki (1991, p. 28).

Finding Allies

Violet's story about one of the 'professionals' who works with her son shows too, the way in which discourse, including experiences, ideas, language and learning, shapes perceptions and practice:

But the two that he has now, they cope really well, but then, like I say, the Maori one who's learnt new skills, she was saying, gosh, we hovered over him too much, we were around him too much, weren't we? And I lot of times I would say, there's lots of things he can do. Make him do them ... like, you don't have to be around him all the time. And it wasn't until she actually went to do the course that she actually realised what I was talking about. She said that she could come back and see that oh yes, well! Because she said that the course helped her

with her own attitudes to disabilities as well, and she said that was probably one of the biggest things for her, was really looking at her own attitudes to disabilities, and how she was dealing with it and why she was doing certain things. So she actually got those out of the way.

Analysing Structures and Advocating for Change

This story of Violet's shows also the critical importance of appropriate training for people who work with children with disabilities and their families. Along with other parents, Violet advocates strongly for the recruitment of people with skills and commitment. She also refers to

professionals [who] knew how to get into the system and work it

In this section I have paid particular attention, and tribute, to the resourcefulness, stamina and determination of parents and their children, who have employed a range of strategies of resistance. These strategies include a critical and emancipatory use of language and discourse, which is consistent with the ideas and suggestions of Norman Fairclough (1992). A very powerful strategy employed by parents is described in the work of Paolo Freire (1972) as 'conscientisation': this works through a process which involves people in educating themselves, sharing information, speaking out and asking questions. Taking the power to make choices that work for a particular family and a particular situation at a particular time is a strategy that is very much an extension and an outworking of the concepts of Michel Foucault on relations and technologies of power, and on resistance. Dorinne Kondo's ideas about how identities are constructed are given explanatory power by her creative use of metaphor in the image she uses of 'crafting selves' (Kondo, 1990). This image of something special created over time fits well with the strategies of parents and children in the research as they continue to work away at realising their dreams, sometimes stopping to lament a loss, or make another attempt at something difficult, or admire the progress. Rejoicing over a successful outcome is very much a part of the constructive process of creating identities, and celebration is an important strategy. Finding professional and parent allies, analysing the structures of our society in order to identify and resist constraining practices and structures, and advocating for change are all

strategic struggles in which parents engage in some form or other on an almost continuous basis.

In this section I have outlined a series of strategies for both professionals and parents. From the parents' stories I have shown the kinds of things families find helpful in their efforts to get lives that suit them, and to effect changes in the systems so that families in the future will not have to struggle so hard to get what they need.

I conclude by reflecting on this research project and suggesting possible directions for future research.

Conclusion

'Stories can conquer fear, you know. They can make the heart bigger.'

(Okri, 1993, p.46)

It is my aim in this chapter to bring together the stories in the preceding chapters in a way which shows how language, discourse and the small strategies of power that are exercised daily and in a largely unexamined way, function to 'construct' (Kondo,1990) the lives of children with disabilities and their families.

I make no claim for the qualitative and interpretive research processes I have used in this project to produce "direct, unmediated truth" (Beatson, 1995, p.224). At the same time I do not subscribe to Beatson's idea that such an approach can be characterised as "gossipy" (ibid). Like researchers McKay et al, I share the view that such a research design reflects "the idea that people actively construct and reconstruct the meanings that their life experiences have for them" (McKay et al,1995, p. 3). I also agree with their idea that disability is "a social construction of multiple experiences waiting to be recognised" (ibid, p. 4). I understand that my responsibility, as the researcher who initiated and controlled this project, is to recognise the experiences of the research participants, and report on them in such a way as to make them accessible to others who may wish to learn from them.

This final section contains reflections on the research process, suggestions for possible directions for further research, and some implications for practice.

The research study I have described in these pages was undertaken with the modest intention of giving a voice to a small number of parents of children with visual impairment and other disabilities, and creating a space for them to tell their stories. As a qualitative rather than a quantitative research project, its intention was to provide a listening ear rather than a clipboard with a set of questions to answer. My intention was to do the kind of research which will add new stories about disability to those which have already been told, in such a way as to swell the volume of voices so that eventually they must be heard

by those who make policy and carry out practice.

Research is, as Len Barton notes, "a profoundly social act" (Barton, 1988, p. 79). As a researcher I was engaged in the 'power relations', the social negotiations that go on between people, at the same time as I was involved in studying them. My identification of myself as a parent working with parents, and as a social worker interested in hearing what sort of services parents want, was crucial to the study in several ways. My identity as a parent of children with visual impairment gave the parents I spoke to an assurance that I would listen with an ear that was attuned to the kinds of experiences parents of children with disabilities have. My identity as a social worker meant that the parents could expect that the suggestions and strategies that came out of their stories would be put into practice; my own practice, which would directly affect them, and the practice of others whom I could influence either directly or indirectly. As a researcher, it is my responsibility towards the families who took part in the research, to make sure that what they said reaches as many parents and professionals in the field as possible. One way to do that is to write and to speak out about the issues, and co-presentation of the paper mentioned earlier at an international conference certainly involved conscious power-sharing.

Interviews with parents were structured as opportunities for them to tell their stories, to which I was invited, occasionally, to contribute. Choosing the narrative method helped, I believe, to guard against misrepresentation, by giving people the time and space to build up a picture of their lives in their complexity and uncertainty, and to show, especially, the contradictions that cannot be reduced to generalisations.

We all tell stories as part of the job of making sense of our lives, or 'creating coherence' (Linde, 1993). Story-telling as research can provide people with a way of "weaving personal experiences into their social fabric" (Graham, 1984, p. 119), and where they have experienced inequality, it provides an opportunity for describing and dealing with that in a therapeutic way. It can therefore be seen as a resource by means of which research participants can go some way towards redressing the imbalance of power. It is a way of

bringing under control what has happened. As Lois Keith, writing as a woman with a disability, explains:

... it's a kind of survival strategy. We tell each other stories about the ridiculous things strangers in the supermarket say, we moan about doctors, employers, inaccessible buildings, our illness or impairments, and what society and the world in general does to us. This 'grumbling' is a private matter; through it we work things out and we carry on.

(Keith, 1994, p. 8)

Taking story-telling into the public domain then, in this case by using it as a research method, adds another, political, dimension to the story: it builds on and adds to, the growing body of literature which seeks to reflect the experiences people have of disability, from the inside out. It becomes more than working things out and carrying on. It becomes an opportunity for the voices of people with disabilities and those who love and care for them to be heard. It may promote reflection which can lead to action and the creation of alliances if the stories are heard by those who recognise in them something of their own experience. It may create opportunities for communication, dialogue and the building of alliances if the stories are heard by professionals who are willing to be educated about what it feels like to have a disability or to be the parent of a child who has a disability.

The actual process of research, because it is a social activity, involves difficulties, which can not always be satisfactorily resolved, and uncertainties, for which there is not always an answer. I have tried to reflect this aspect of the research process, by telling what actually happened, as well as what was supposed to happen. I have tried to show how in trying to understand the perspectives and the knowledge of others, I experienced the tension of being immersed in the group as an insider, while at the same time wanting to position myself strategically 'at the edge of the frame' (Opie, 1992, p. 58) in order to minimise appropriation of the narrators and their stories. This can be a difficult and stressful position to maintain, as Hammersley and Atkinson (1983) note:

The ethnographer must be intellectually poised between 'familiarity' and 'strangeness', while socially he or she is poised between 'stranger' and 'friend'.

(cited in Barton, 1988, p. 88)

I found, like this student teacher describing research in schools, that "the dilemmas of my identity had almost contradictory effects upon my role" (Rogers, cited in Barton, 1988, p. 88). Sometimes, for example, my identity as a parent and a sense of shared experience and emotion drew me in, and I became absorbed in the story. On the other hand, sometimes when I heard about things from a parent that I had seen or colluded with as a professional, I felt that my position of trust was compromised and my poise 'at the edge of the frame' jeopardised. At times the balance felt precarious, and I was reminded of the researchers in the Otago Family Network, who wrote:

This was not a symmetrical dialogue and at times some of the researchers reflected on feeling "totally powerless" - this occurred occasionally when a professional held an opinion that opposed that advanced by a parent. Sometimes this became an issue of "whose side are you on?" If we did not agree with a parent view then we were just like those other professionals who hold the power to deny parents their wishes. This created role conflict for the researchers. If they continued to advance a viewpoint against a particular parent position then possibly they risked the friendship and partnership of a parent.

(Ballard, 1992, p. 228)

Len Barton, writing about teachers as researchers, quotes Woods (1985), who maintains that research of this type

... deals with *teachers'* problems, reflecting a concern not to 'take but to make problems', that is, not to pre-define the problem to be examined, but rather to find out the concerns of the people within.

(cited in Barton, 1988, p. 89)

It seems to me that the best way to find out the concerns of people is to ask

them. This idea opens up possibilities for research as practice that are consistent with Michael White's ideas about therapeutic work as "ongoing private research" (White, 1995, p. 80), which includes consulting families about their experiences of therapy in a constant spirit of investigation. He describes his work in this way:

I cry with the people who consult me, and I also laugh with them. I join them in outrage, and also in joy. We experience sadness together, and also hope. As I walk for a while with these people, I experience all of the emotions that one experiences in bearing witness to testimony. As well, there are contexts in which I find myself celebrating with people - contexts in which the alternative stories of their lives are being honoured, when the other accounts of their identity are being powerfully authenticated. And I experience inspiration from the steps that people take to dispossess perpetrators of their authority, the steps that people take in reclaiming the territories of their lives, in the refashioning of their lives, in having the "last say" about who they are.

(ibid, p. 86)

This kind of research, and this kind of practice, demands an awareness of the power differential that exists within the research context, and the therapeutic context. It also means taking responsibility for addressing the contexts of people's lives and for recognising and working against the structures of inequality that are associated with those contexts. This kind of therapy, or this kind of social work, means joining with people in "challenging those relations of power that inform the subject/object dualism" (White, 1995, p. 122). White suggests that one way of doing this relates to the idea of "returning the "gaze", or turning the gaze back on itself". This is an important idea for research participants, who give out so much of themselves with no very tangible return. In this respect, I have been careful to keep the participants in my study informed of progress and to make sure they know what is happening to their material. For people who are the recipients of assessments too, to carry out their own research on those assessments could be empowering. White suggests that this

might engage them in a study of who can speak, under what circumstances they can speak, which ways of speaking are acknowledged, which ways of speaking are disqualified, whose authority is privileged, the effects of the privileging of this voice, and so on.

(ibid)

The introduction of this idea has a positive effect, White says, even if it is not acted upon formally. He suggests that this is because "even to think the unthinkable goes some way towards undoing the effects of the marginalisations to which people have been subject" (ibid). This study has been all about giving people opportunities to think the unthinkable, to speak out, to break the culture of silence, and to engage in the small everyday acts of resistance which work towards the re-creation of themselves and their children as people in control of their own lives. As Mary says:

It's a learning thing really, to get people to understand that people with disabilities ought to be treated the same way as people without disabilities, regardless of whether they're severe or not, and I always ask the question, for whatever happens, would I like that to be happening to me? Would I like to be called 'handicapped'? Would I like to be ... whatever? And if the answer is 'no' then it is not appropriate, and it's as simple as that. If I wouldn't like it to happen to myself, then it's not ... to me, it doesn't happen for people with disabilities either. But what you've got to do then is change people's attitudes. You've got to change parents' attitudes; you've got to change professionals' attitudes, and you've got to change the attitude of people who are at the top of services.

Directions for Further Research

Taking into account the current New Zealand literature, there are three particular areas that stand out for me as being worthy of further investigation and reporting. The first is the current experiences of students with disabilities in the pre-school, primary and secondary educational systems. My idea is that we need to know much more about what it feels like to be a student in the

system, so that we can do more to support such students. The second is the experiences and attitudes of professionals working in the health and education fields particularly, in relation to people with disabilities. I have learnt from my research study, from personal experience and from anecdotal evidence, that professional attitudes have a major impact on the lives of people with disabilities, and I contend that we need to know more about what those attitudes are, how they are constructed, and what goes into making some professionals good allies.

The third suggestion for further research is really Violet's. She wants to see some research done on the kinds of things that happen when professionals are fighting to keep a newborn baby alive. Her concerns centre around the spiritual needs of the child and of the family, and around how they could be acknowledged and honoured within the present health system.

In conclusion I draw on Henry Giroux's critique of Paulo Freire, who, he says, has created "a language of possibility" that is rooted in a "permanent prophetic vision". By combining the discourses of critique and possibility, Freire lays down the theoretical basis for a radical approach that combines hope, critical reflection and collective struggle (Freire, 1985, pp xvii-xviii). In doing this research project, and in my practice of social work, I have tried to build on this foundation to celebrate the small victories that make the struggle worth the effort, and to speak the language of possibility in a way that encourages and supports people as they act to create and re-create their own unique identities, and to have the last say about who they are. Violet has expressed this in relation to building up or 'constructing' her Maori identity, a process which has similarities with the way that Justin, for example, is engaged in 'constructing' his own identity. Violet describes the process like this:

I actually want to share my experience because I don't have too many oldies or kaumatuas left in my line to go back and sort of share it with them. So I ... have been starting out with me and my family to do that. And I have been privileged to go back to my aunty and talk about different things ... and share with her some of the old stories if you like that belong to our whanau, and that's been a real learning curve for me,

because I'm still learning also about a part of me that wasn't permitted. And so it's ... it's all so new to me as well, and the friends that I have now as well ... several of my Maori friends, women friends that I have, have been lucky in the sense that they were actually brought up on the marae, and so to talk with them, we're totally ... we're different, simply because of the way we were brought up and how we view things, and I'm still learning to respect that as well ... that other part.

Appendix 1**Application to the Human Ethics Committee
Massey University**

Name of applicant: Alison Kerr

Department: Social Policy and Social Work, Massey University

Current Employment: Child and Family Social Worker/Counsellor, Royal New Zealand Foundation for the Blind

Project Status: Project to fulfil requirements for MPhil (Social Policy and Social Work)

Funding Sources: Application to Graduate Research Fund, Massey University

Supervisors: Mary Nash
Martin Sullivan

Title of Project: Parents, Power and Partnership: a proposal for action research which aims to empower disabled children and their families, and to enhance partnership between parents and professionals

Description of the project:**(a) Justification:**

The research will explore the experiences of five children with visual impairment and their families. It is intended that the research should take its direction from the participants, and the aim of the resulting action research is to create a forum for power sharing, group reflection and problem solving. A central justification in terms of the importance of the knowledge gained, is that the participants have an opportunity to speak with their own voices, about their own experiences. This is seen as a strategy which will lead to consciousness raising and empowerment in the interests of getting the needs of disabled children and their families recognized and met.

(b) Objectives

(i) To develop a theoretical and practical approach to partnership between parents of children with disabilities and the professionals who are involved in the children's lives.

(ii) To explore the way in which children and families experience service systems.

(iii) To bring families together in an environment that will foster mutual support, encouragement and empowerment in terms of getting what they need from professionals.

(iv) To record and publish the stories of the participants, children and parents, so that their voices can be heard.

(v) To contribute to the formulation and implementation of better professional practice.

(c) Procedure for recruiting participants and obtaining informed consent.

Participants will be recruited from an informal network of parents of children with visual impairment, of which the researcher is a member. The sample will include children in the primary to secondary school age range, their mothers, fathers, siblings and other family members who wish to be involved. Selected families will be approached and invited to participate in the research project. The focus, procedures and implications of the project will be explained to them. If they are interested in taking part, the attached information sheet will be given to them and they will be asked to sign the accompanying consent form.

(d) Procedures in which the research participants will be involved

The three families in the Hawkes Bay area and the two families in the Gisborne area would be asked to participate in group discussions, one at each location. At these recorded meetings the research questions would be introduced and an agenda set for the remainder of the research project. After these meetings, the agreed agendas would be circulated to all the families in each group.

At this point the researcher would proceed to conduct one unstructured in-depth interview with each of three families, one in one location, two in the other. The group would then meet again, at least once, to focus on the research questions on the agreed agenda.

Upon completion of the data analysis phase of the project, a summary of the group proceedings at each location, including all direct quotations intended for inclusion in the final report, will be circulated to the families involved. A further meeting may be held at each location if participants desire an opportunity to respond to what has been included and to suggest anything else they may wish to see included in the final report.

(e) Procedures for handling information and materials produced in the course of the research.

During the participant observation phase of the research, recording of data would be by tape recorder and written notes. Data collection would also include written material such as letters, government documents, submissions and teaching material. In-depth interviews and personal interactions with children and families would be tape-recorded where they were planned, with supplementary field-notes to provide relevant information on, for example, facial expression and gesture, and recorded in the form of field notes where they were observed spontaneously.

Embedded in the proposed research process is its function as a collaborative, negotiated social construction. Accordingly, data production and collection will be effected through a process of negotiation at all stages of the research.

The research is designed to generate qualitative data, the written or spoken words and observable actions of the participants, which once recorded, will be analysed, interpreted and organized according to themes and patterns. This process will necessarily be highly selective, but will be carefully monitored in order to avoid the suppression of elements which are paradoxical, contradictory or marginal.

Upon completion of the project, interview tapes will be returned to the families or deposited securely, with a proviso that they won't be used for a negotiated period of time. Tapes of group sessions will be similarly secured.

The researcher undertakes, as part of the empowerment process, to write up the material and the final report in such a way that it is accessible to the participants and to others of the community of interest which it involves.

Ethical Concerns

(a) Access to participants

The researcher has access to participants because she is part of the same community of interest, an informal network of parents of children with visual impairment. These children are also all members of the Royal New Zealand Foundation for the Blind, and the proposal is also being submitted to that organization for approval.

(b) Informed consent

It is possible a conflict could arise between individual and group consent, both in the family interviews, and in the group discussions. This will be dealt with by asking all members of the families who wish to participate to sign the form,

and by a process of ongoing negotiation. There will be no coercion, and the entire project will be a negotiated process, with a negotiated outcome.

(c) Confidentiality

Where families provide in-depth interviews for personal stories, the written account prepared by the researcher will be shown to the participants, who may indicate passages they do not wish to have quoted. This will ensure accurate presentation of family perspectives, and will protect privacy.

Data from group discussions will be treated similarly to protect the confidentiality of the participants.

(d) Potential harm to participants

(i) From the research process

It is possible that participants may find talking about some of their experiences painful and distressing, and could become upset during the course of an interview or a group discussion. They will, however, be aware of their right to withdraw at any time from the research or any part of it.

A further safeguard for participants would be the location by the researcher of a counsellor skilled in individual and family therapy who would be prepared to act as a standby in this area.

(ii) From the final report

There will be ample opportunity for participants to share concerns and negotiate with the researcher during the course of the project. The final report, like the whole project, will be produced by negotiation between participants and researcher, and it is anticipated that research participants will own the final report as reflecting something they themselves have contributed to, participated in, and lived for a specific time, and which therefore belongs, in a very real sense, to them.

(e) Participants' right to decline

Participants' right to decline, and their right to withdraw at any time, or for any part of the project, will be made clear to them initially, both verbally and in writing.

(f) Arrangements for participants to receive information

The research design ensures that participants will receive written notes from each session in which they participate and they will have access to all written or published documents which arise out of the research project.

(g) Use of the information

Participants will be asked on the consent form, to give Alison Kerr written permission to use the information that arises out of the group and family sessions, in both published and unpublished documents.

(h) Conflicts of interest

The role of the researcher in this project is envisaged as one of partnership with the participants. The research process will encourage the parents to assume the role of experts on their children. For the duration of this project the researcher will be involved in the research community as both parent and professional, as well as researcher. While at times this will need to be carefully and sensitively managed, and clearly articulated in order to avoid confusion, it is vital to the theoretical aspect of the research in its concern with themes of identity, discourse and language, that this be so. Further, it is envisaged that this will prove to be an advantage in terms of credibility and trust.

(i) Other ethical concerns relevant to the research

There is the possibility, indeed the intention, that if parents are encouraged to assume the role of experts on their children, and to see professionals involved with their children as needing to receive as well as impart knowledge, those parents may be empowered to make assertions and requests, for information and/or service, that they have not previously been accustomed to make. This may well lead to a change in the way they relate to the professionals involved with their children, and here there is potential for conflict with professionals who feel threatened in their status or autonomy. This will be discussed with parents.

Legal Issues**(a) Copyright**

Copyright of papers produced from the research will rest with Alison Kerr

(b) Ownership of data or materials produced

Any written material produced will be owned by the researcher, Alison Kerr.



Appendix 2

PARENTS of VISUALLY HANDICAPPED

SUPPORTED BY R.N.Z.F.B.

This letter is being sent to you as a family which includes a child or young person with a visual impairment. The purpose of the letter is to inform you about a research project which will be taking place in your area during the next few months, and to give you an opportunity to find out more about it and to take part in the project if you wish.

Research Aims

The research, undertaken with the approval and support of Massey University and the Royal New Zealand Foundation for the Blind, involves a study of families of children who are visually impaired. The aim of the study is to describe the experiences families have with educational, medical and other services, and to talk with families about ways in which such services may be improved and possibly developed.

The families will help decide what is important to study and record. There will be opportunities to talk within families and with other families about those issues that have been identified as important, and it is hoped that networks will be established that will help all those involved to learn from and to support one another.

The Researcher

The researcher is Alison Kerr, who can be contacted during the day at 25 Bower St, Napier, on telephone 06 8353777, or on 06 8796160 in the evenings or at weekends. When completed, the study will be written up in a report, which will be submitted to Massey University as a thesis in partial fulfilment for the degree of Master of Philosophy in Social Work and Social Policy.

If you are interested in taking part in the study, or if you would like to know more about it, please telephone me, and I will be pleased to answer any questions. If you wish to be a part of this research project, you will be sent an information sheet setting out the details of the research. If, having discussed this with other members of your family, you decide to be involved in the study, I will send you a consent form to sign, and the study will begin.

Alison Kerr

Appendix 3

PARENTS, POWER AND PARTNERSHIP

Research Project

The researcher in this project is Alison Kerr, who can be contacted at:
25 Bower St, Napier, on telephone 06 8353777 during the day;
Twyford Rd, R.D.5, Hastings, telephone 06 8796160 evenings or weekends.

This is a research project which aims to involve parents and families of children with visual impairment in talking, with the researcher and with each other. Interviews will involve participants both in reflection - on their needs and concerns and ideas for possible solutions - and in action, by way of group discussion, and the actions arising out of it, which aim at solving the problems and getting the needs met. This will be followed in turn by reflection on what works well, and on what strategies people find most successful.

The research will be conducted over a six-month period, from July to November 1994, and each family will be involved in no more than two interviews, and no more than three group discussions. Each session will be no more than two hours long and times will be scheduled to suit the participants.

Because the researcher is herself a parent of two children with visual impairment, the participants can expect to be part of a shared community of interest, to be listened to and encouraged in their hopes and dreams for their children, and to be actively supported in any advocacy or action they may wish to undertake on behalf of their children.

If you take part in this project, you have the right: to withdraw from the study, or from any part of it, at any time; to ask any further questions about the study that occur to you during your participation; to provide information on the understanding that it is confidential, and that it will not be possible to identify you in any reports that are prepared from the study.

Interviews and group discussions will focus on your experiences as members of a family which includes a child with a visual impairment, and your experiences of medical, social and educational service systems. Sessions will be taped and transcribed by the researcher. You will have the right to check and comment on the transcript, and the tapes, once transcribed, will be securely stored.

This project is being supervised by Mary Nash and Martin Sullivan, of the Department of Social Policy and Social Work, of Massey University, and is undertaken with the approval of the Massey University Human Ethics Committee.

Appendix 4**Parents, Power and Partnership
Consent Form**

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

I also understand that I am free to withdraw from the study, or from any part of it, at any time. I agree to provide information on the understanding that it is completely confidential.

I wish to participate in this study under the conditions set out on the Information sheet.

Signed (all participating members of the family)

Date _____

Appendix 5**Parents, Professionals and Partnership****Research Group Feedback**

What were your reasons for becoming part of the research group?

Were the research questions appropriate for you?

Do you have things that in retrospect you would like to add or alter?

How did you find the research process, i.e. the arrangements, the interview, the follow-up?

What would you like to happen next?

What would you like to see happen to the research findings?

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