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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.