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RAISING A CHILD WITH HIGH CARE NEEDS

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

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

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CONTENTS

Acknowledgements	vii
Abstract	1
Preface	2
Chapter One: Introduction	4
Outline of thesis	5
Chapter Two: History, models of disability, and definitions	
Introduction	11
Family care, service development and disability	12
Societal beliefs about disability	17
Models of disability	19
Defining disability in New Zealand	25
Conclusion	30
Chapter Three: Parenting and family	
Introduction	31
Caregiving is gendered parenting	31
Parent and child bonds	32
Understandings of the role	33
Impact on the caregiving parent	34
Exclusion and isolation	36
The experience of grief	37
Family and community influences	39
Financial cost of care	42

Personal coping strategies	43
Support systems	43
Professional intervention	45
Conclusion	47
Chapter Four: Policy, services, and gaps	
Introduction	48
Service delivery and social policy	49
Parental experience in support sectors	51
Family policy	53
Children's rights	56
Support services and high care needs	58
Needs assessment, service co-ordination	59
Rights to services	61
Professional support	61
The caregiver role	63
Caregivers	63
Conclusion	64
Chapter Five: Theoretical lens	
Introduction	66
Systems theory	67
Feminist theory	71
Attachment theory	75
The research method	78
Conclusion	78

Chapter Six: Carrying out the research.

Introduction	79
Research question	79
Recruiting research participants	80
Process	81
Data management	85
Qualitative interviews	86
Analysis of data	87
Limitations of the research	87
Ethics	88
Bias	93
Conclusion	94

Chapter Seven: Parental experience

Introduction	96
Beginning a journey that is different	96
The research participants	97
Finding out	98
A glimpse of future pathways	101
Becoming involved	105
Getting someone to listen	107
Wanting to know why	108
Taking control	109
The ‘choice’ of surgery	111
Avoiding blame	113
Depression	114
Making new plans	115
Spending the time	117
Conclusion	118

Chapter Eight: Parental skills

Introduction	119
Family support	119
Family members	122
Siblings	124
Setting aside time	125
Advocacy	127
Agencies and services	128
Parent support groups	132
Conclusion	135

Chapter Nine: Discussion

Introduction	137
The family support system	138
Taking responsibility	141
Responsibility and attachment	142
Case manager	143
Parent support group	143
Professional support	144
Success	145
A first step to success	148
Negative imagines	149
Conclusion	150

Chapter Ten: Conclusion	
Summary	153
Recommendations	154
Conclusion	155
Bibliography	157
Appendix 1: Ecological social work practice and disability	166
Appendix 2: Notice of proposed research	167
Appendix 3: Letter to prospective interviewees	168
Appendix 4: Information sheet	169
Appendix 5: Consent form	171
Appendix 6: Confidentiality agreement	172
Appendix 7: Glossary	173

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Abstract

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

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

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

Preface

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

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

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

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

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

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