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from our perspective:
exploring the strength and resilience of families
that include a parent with a disability

MARILYN RAFFENSPERGER, MISSY MORTON, JEFFREY GAGE, FRANCES CALDWELL,
CAROL PENFOLD-GREEN, REBECCA RAFFENSPERGER, KATA FÜLÖP

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Families Commission
Public Trust Building
Level 6, 117-125 Lambton Quay
PO Box 2839
Wellington 6140

Telephone: 04 917 7040
Email: enquiries@nzfamilies.org.nz
www.nzfamilies.org.nz

ISSN 1174-815X (Print)
ISSN 1174-8168 (Online)

ISBN 978-0-478-36918-2 (Print)
ISBN 978-0-478-36919-9 (Online)

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ACKNOWLEDGEMENTS

We express our deepest sympathy to those who have lost loved ones, homes and businesses as a result of Christchurch's devastating earthquakes of 4 September 2010, 22 February 2011 and 13 June 2011. Months of recurring aftershocks continued to challenge the physical and emotional resources of those living in Christchurch. We are grateful to the many people who shared their time and resources with us during this challenging time.

We would like to thank the mothers, fathers, children and family friends who participated in this project. After the earthquakes there were many extra demands

placed on families and we are grateful that these families chose to spend time conversing with us.

We would like to acknowledge the continued support from the University of Canterbury during a season when many individuals had damaged homes and/or damaged offices. We are also grateful to the other academic institutions that assisted Canterbury University to maintain an electronic library while the main library was being restored.

We would like to thank the Families Commission for making this research possible and for demonstrating kindness and support throughout the project.

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EXECUTIVE SUMMARY

This report examines the strength and resilience of families that include a parent with a disability. The purpose of this exploration is to learn how to tailor research and practice to better meet the needs of these families. Disabilities are often viewed from a deficit perspective, obscuring the strengths that co-exist alongside disabilities. In this report we aim to highlight the families' strengths without diminishing the challenges that they faced and resilience they demonstrated.

Walsh (2006) stated, "Resilience can be defined as the capacity to rebound from adversity strengthened and more resourceful" (p. 4). Resilience is often viewed as bouncing back to one's original state after a difficult circumstance. However, families face many kinds of challenges, which are often ongoing. Walsh has suggested that a more suitable metaphor for resilience is that of "bouncing forward" (p. 84). Resilient families adapt and change to move on with their lives amidst the challenges.

Parenting with a disability can pose a number of challenges. Many parents with disabilities face economic hardship and employment challenges. Some face prejudicial attitudes from professionals and community members. Disability support needs change over time, as do the needs of growing children. To gain a better understanding of how families bounce forward amidst such challenges and changing circumstances, we interviewed 20 New Zealand families that include a parent with a disability. More than 20 different disabilities were represented in this study. The following themes summarise the parents' experiences: (a) mobility difficulties; (b) mental health conditions; (c) chronic pain; (d) learning and processing differences; and (e) sensory impairments. Brief descriptions of the disabilities can be found in Appendix A.

We talked to 20 mothers, 10 fathers, 19 children and 11 family friends. By maintaining a strengths-based perspective we sought to gain a better understanding of how to promote the wellbeing of families and foster family resilience.

The research was conducted in the Canterbury region of New Zealand between 2009 and 2011. Eighteen of the families were recruited from Christchurch City. One

family was from the Waimakariri District and the other was from the Kaikoura District. The last census was done in 2006. At that time, the population of Christchurch City was 348,435 and the city had two major tertiary institutions, nine major hospital, and 164 schools (Christchurch City Council, 2007). Following major earthquakes¹ in 2010 and 2011 "Christchurch City's resident population decreased by 8,900 people (2.4 percent) in the June 2011 year" (Statistics New Zealand, 2011, para. 1).

The families in this study were diverse in their family structure, socio-economic status and the specific challenges of their different disabilities. In spite of this diversity, the strengths exhibited by these 20 families were remarkably similar. And though their specific challenges were different, the overarching themes of their challenges also bore remarkable similarity.

Walsh (2006) posed three keys to family resilience: (a) family belief systems; (b) family organisational patterns; and (c) family communication processes. The families in this study exhibited a number of strengths in these areas. They spoke of shared belief systems, maintaining optimistic outlooks and persevering. Their family organisational patterns included an ability to be flexible and adapt; closeness that included an awareness of the need for individuality; and support from extended family and friends. Within their communication processes there was openness, expressions of love and affection, humour and working together to solve problems.

These families faced a number of challenges, including the Christchurch earthquakes. Their flexibility and adaptability were evident as they balanced disability-related support needs and the needs of the rest of the family members. Their faith and optimism buoyed them in challenging times. Their sense of humour and family closeness stood them in good stead during the earthquakes. Their persistence was obvious in the face of employment and economic challenges, which all but two of the families faced.

When considering these findings in the light of existing research, it appeared that these families had considerable buoyancy in their family qualities, personal attributes and family communication processes. However, their resources ran low in their connectedness to the community and finances. Although their economic challenges were met with persistence, many remained in

¹ Starting with a 7.1 earthquake on 4 September 2010, Christchurch has been shaken by three major earthquakes. A 6.3 earthquake on 22 February 2011 claimed 181 lives and caused widespread damage to the city. On 13 June 2011, a 6.3 earthquake again shook the city. Between each of these earthquakes, the city rattled with thousands of aftershocks, which weakened the existing structures and took a physical and emotional toll on Christchurch residents.

low-income situations. Extended hospital stays, the cost of disability-related equipment and loss of former abilities posed substantial financial challenges to these families.

Some families were well connected in the community, but still found it difficult to find sufficient emotional support. Other families chose to be more insular. Being well connected to the wider community provides certain protective factors. For this reason, it would be useful to research what leads some families to choose a measure of isolation over connectedness to the wider community.

In addition to exploring the families' strengths and challenges, we asked for their ideas on how to improve support for their families. They would like others to know that one person's disability affects the whole family. They would like services to be holistic and family-centred. In particular, they would like more attention paid to fathers. They would like more avenues for talking about their struggles. They would like more clarity around support services and less paperwork. They also expressed satisfaction with many of the services they had received.

The findings from this study suggest five principles to bear in mind when engaging with families that include a parent with a disability:

- 1. Every family is unique.** While there are general principles that can be applied to many families, there is no 'one size fits all' model. Take time to get to know the specific family you are engaging with.
- 2. Disabilities co-exist with abilities and strengths.** When engaging with families, keep their abilities and strengths at the forefront because these will buoy them when they encounter challenges.
- 3. Spending time together having fun helps to build family resilience.** Appointments with professionals, time spent in hospitals, time spent in therapy and the ordinary demands of family life can crowd out

time for fun. When suggesting interventions for families, it is important that professionals safeguard families' downtime. Extended family, whānau and the wider community can play a vital role in providing opportunities for families to have fun together.

- 4. Families function as a unit.** In a family situation, a parent's disability is not theirs alone; family members adapt and work together to meet the demands of family life. Support and interventions targeted to individuals alone do not harness the strengths within the family unit. Some parents with a disability in this study expressed distress at having their partners excluded from meetings with professionals.
- 5. Poverty and social isolation are challenges in themselves.** When families that include a parent with a disability are facing numerous challenges, the root cause may be underlying poverty or social isolation, rather than the disability itself. When families are well resourced, financially and socially, they are better able to meet day-to-day challenges posed by the disability.

Resilience research began by focusing on individuals, seeking to learn what personal qualities fostered resilience. Over time it became apparent that resilience has a strong relational component. Children facing hardship are more resilient when they have support from at least one caring adult (eg, Walsh, 2006). Families are also more resilient when they are surrounded by caring communities (eg, Mirfin-Veitch, 2010). Resilience is not forged in isolation; it is forged by "interdependence with others" (Walsh, 2006, p. 5). It is our hope that the information contained in this report will enable community members and service agencies to be more "aware of and responsive to disabled people" (The New Zealand Disability Strategy, 2001, p. 12), so that together we can build more resilient communities.

1. INTRODUCTION

Illness, disability, and death are universal experiences in families. The real question is not 'if' we will face these issues, but when in our lives, what kind of condition, how serious and for how long. (Rolland, 2003, p. 460)

This report is based on a research project conducted in the Canterbury region of New Zealand between 2009 and 2011. The project aimed to explore the experiences of families that include a parent with a disability. We wanted to learn how to tailor practice and research to better meet the needs of these families. To gain a broad perspective of family life, we interviewed parents with a disability, their partners, their children and (in some cases) family friends. Parenting with a disability can pose a range of challenges. We sought to understand these challenges while focusing on the strengths and resilience they were met with.

As the quote by Rolland (2003) suggests, none of us – neither readers nor researchers – are distant from the topic of this report. We have all been parented. We probably have friends who are parents, or we are parents ourselves. Each of us has been touched by illness, disability and/or death, either as a child, as a parent or as a family friend. Equally, we all have the capacity to be resilient in the face of life's challenges.

However, sometimes challenges arise that cannot easily be met by an individual's resources, no matter how resilient that individual is. According to Walsh (2006) "resilience is forged through openness to experiences and interdependence with others" (p. 5). In post-earthquake Christchurch, we have become acutely aware of our vulnerability as human beings. We have also experienced the strength that can be forged by actively engaging with the struggles and successes of those around us. We have seen what can be accomplished when strangers reach out to one another. We have been reminded that "the biological unit of survival for human beings is the clan... We are unavoidably interdependent on each other" (Perry, 2004, p. 2).

According to the 2006 Disability Survey, 17 percent of people in New Zealand are living with a disability (Statistics New Zealand, 2007). There are no data regarding the number of parents with disabilities.

Though the experience of living with a disability is relatively common, its impact on family life is not common knowledge. Qualitative research is one way of bringing lived experiences into the public arena while at the same time guarding the privacy of research participants. And, indeed, conversations between researchers and the public are an important part of social science research (eg, Kvale, 2007). In light of this, we have intentionally written this report in a more conversational style than is typical of research reports. This report seeks to share what life is like for 20 families that include a parent with a disability, so that we can consider how to better support family life and build resilient communities.

1.1. The rationale for this report

Despite the universality of disability, studies of parents with a disability are "relatively scarce" (Drew, 2009, p. 431) and parents with a disability are often viewed through a "pathologising lens" in research and practice (Kirshbaum & Olkin, 2002, p. 77). All too often one's disability is viewed more prominently than one's strengths and resilience. For example, an Australian study found a "significant over-representation of parents with psychiatric disability and of parents with intellectual disability in the NSW Children's Court" (Llewellyn, McConnell, & Ferronato, 2003, p. 248). Johnson, Henaghan and Mirfin-Veitch (2007) describe some of the difficulties that parents with an intellectual disability have faced in the New Zealand Court System.

Rather than viewing parents with a disability through a deficit perspective, this study seeks to explore family life by focusing on the strengths, abilities and resilience that lead to positive outcomes. In 2005 and 2006, the Families Commission explored what contributes to positive outcomes for New Zealand families with dependent children. Seth-Purdie, Cameron and Luketina (2006) identified "key factors that enhance family life to be: having time with the family, having good relationships with family members, having access to family and community support, and being able to live according to one's values" (p. 7). Being able to access appropriate family and community support is even more important for parents with disabilities, who often need ongoing support.

1.2. The starting point of this report

Like many research projects, this project traces its roots to professional and personal experiences.

In 2008, the project was conceived after a call for proposals from the Families Commission. One topic of interest was the experiences of parents with disabilities. In particular, the call for proposals sought to learn about “resilience and success factors from the perspective of disabled parents themselves” (K. Stewart, personal communication, 5 June 2008). This dovetailed nicely with our professional interests. In addition to research work, members of our team have worked in counselling, psychology, nursing, disability support services, teaching and health promotion. We are keenly interested in the wellbeing of families, prefer to work from a strengths-based perspective and desire to learn from those with whom we work.

This research report explores the following questions:

- > What factors contribute to the wellbeing and resilience of families that include a parent with a disability?
- > What challenges do these families face?
- > How can communities more effectively support families that include a parent with a disability?

When considering how to explore those questions, we decided to interview parents, children and family friends. From research and from personal experience, we knew that each vantage point tells a somewhat different story.

As researchers, we bring ourselves, both professionally and personally, to the interviews. Patton (2002) put it this way: “The researcher is the instrument in qualitative inquiry” (p. 433). According to Patton, providing information about the researcher is a ‘must’ in a qualitative report (p. 472). Knowing something of the researchers allows the reader to more accurately assess the credibility of the report. For this reason, we would like to briefly introduce our team and then share a personal position statement from the principal researcher.

Dr Marilyn Raffensperger is a counsellor and researcher with a special interest in the wellbeing of people with disabilities.

Dr Missy Morton is an associate professor in education at the University of Canterbury, Christchurch, New Zealand. Missy has worked for the National Offices

of IHC and for CCS Disability Action. Her research interests include inclusive education, the sociology of special education and disability studies in education.

Dr Jeffrey Gage is a senior lecturer in health sciences at the University of Canterbury, Christchurch, New Zealand. Jeffrey is a registered nurse with a clinical background in family and community health, health promotion and health education. He currently teaches in health promotion and men’s health and his primary research interests include fathering and family relationships.

Frances Caldwell currently works as a manager in mental health peer support in Christchurch and has previously worked in disability support and in university disability education. She has a Master of Education focused on social inclusion, as well as several theatre and performance degrees. She has personal experience of mental illness (which is essential to the peer aspect of her work role) and a specific learning disability, which has become increasingly less problematic as she has learned to work around it and utilise her strengths.

Carol Penfold-Green’s family holds connections to Ngati Porou/Ngati Kuri. Though of Irish descent, she has forever held a strong interest in other cultures and the disabled. Being involved in this project has enabled her to pull together her long-term experience in disability support, adult education and health promotion. She has a Bachelor of Arts in sociology, a Post-Graduate Certificate in Public Health, a Diploma of Adult Teaching and Learning and a Certificate in Kaupapa Māori Supervision.

Rebecca Raffensperger has a Bachelor of Arts with a major in linguistics and a minor in sociology. She has experience in linguistic anthropology. She was a research assistant on this project, transcribing interviews.

Kata Fülöp is a doctoral candidate at the University of Canterbury. She is specialising in performance and migration. She was a research assistant on this project, transcribing interviews.

1.3. Personal position statement from the principal researcher

I come from the United States of America, and for the past 13 years I have lived in Christchurch, New Zealand. Like many of us in the melting pot of America, I can trace my roots back to many places

including Sweden, England, Scotland, Ireland, Germany and to America itself. When my great-grandmother married my great-grandfather, being a Native American carried with it considerable stigma. She was able to pass herself off as a Caucasian and that part of my family heritage was kept under wraps for a few generations. My father was a scientist and my mother a homemaker. I am the fifth of six children. My husband and I have been married 29 years. We have two sons, one daughter and two daughters-in-law. My name is Marilyn Raffensperger.

As a youngster I knew that my mum had migraine headaches; a special crinkle in her brow let me know when a headache was present. However, the presence of headaches did not dominate my childhood. My childhood eyes beamed at the sight of homemade biscuits and special birthday cakes. I enjoyed fun times playing and learning. I snuggled down to bedtime stories. My mum's loving presence turned the tedious task of learning the times tables into a special memory for me. I remember one particularly enjoyable afternoon. My mum was lying in bed and I was sitting on a chair next to her bed chattering about my day and working on my times tables.

It was not until I had children myself that I looked back on that day with adult eyes. It dawned on me that my mother had probably been in bed because of an excruciating migraine. I wondered about that afternoon from my mother's point of view and appreciated once again the determination and resilience that featured frequently in the nurturing of her children. As I was raising my children, I became friends with a mother who had severe migraines. She has shared with me her experiences of parenting amidst migraines. I am well aware of the limitations that these headaches pose for her. I have also watched her children bloom and grow over our many years of friendship.

When my youngest child was 16, I was diagnosed with a medical condition called endolymphatic hydrops. A malfunctioning inner ear causes me to have episodic bouts with vertigo that last for 24 to 48 hours. During those bouts, moving my head or even looking around causes me to vomit. My vertigo does not respond to medication, but thankfully it is self-limiting. So when a bout of vertigo comes my way, I lie in bed without moving and wait many hours for the spinning sensation

to fade away. Parenting with a disability was a new experience for me. I wondered what our family life would have looked like had my children been younger. And once again, from another perspective, I thought of my mum, my times tables and her bedside parenting.

As this report is being written, a dear friend's son is preparing for his wedding. My friend has cerebral palsy; her husband is legally blind. One of their sons has attention deficit disorder and the other son is deaf. Raising my children alongside this family, I was included in the joys and struggles of their daily life. In my growing up years and in my years of parenting children, disabilities were an ordinary part of life.

1.4. Our framework for viewing disability and family

Although disability and family are everyday words, they are fraught with meaning and assumptions.² Therefore, we wish to be candid about four key assumptions that have framed our outlook.

1.4.1. Disability is a part of life

Disability is often 'pathologised'. That is, it is seen as something that is wrong or unnatural. In contrast, we see disability as an ordinary part of life.

1.4.2. When children help their parents, it is not necessarily a problem

Many children of parents with disabilities take on caring tasks within their families (eg, Gaffney, 2009).³ This is often regarded as problematic. However, we do not consider that "caring tasks themselves deprive children of what would otherwise be a 'normal' childhood" (Olsen, 1996, p. 46). Clearly, while providing care can sometimes be detrimental to children, we do not assume that.

1.4.3. Families are diverse

We appreciate the diversity within New Zealand families. Families vary in structure, culture, socio-economic status, living arrangements and so forth (Ministry of Social Development, 2004). We are aware of "the many and varied contexts in which mothers and fathers find themselves parenting" (Gage, Everett, & Bullock, 2006, p. 61).

² A more detailed discussion of these concepts is found in Chapter 2.

³ Gaffney's work is discussed in Chapter 2.

1.4.4. Families will be viewed through a systems perspective

Families are made up of unique individuals. And as we have seen in the interviews, each family member brings a different perspective to family life. By taking a systems approach, we will also consider how these distinct individuals work together as a “functional unit” (Walsh, 2006, p. 15). Positive family outcomes are likely to be enhanced by responding to the family as a whole while maintaining an awareness of the needs of individual family members (eg, Newman, 2002; Thomas et al, 2003).

1.4.5. A strengths-based approach

While there is much to learn by exploring the deficits associated with disabilities and the risk factors that make resilience difficult, this report takes a strengths-based approach to disabilities and resilience. In the words of DeFrain and Asay (2007):

The family strengths perspective is a world-view or orientation toward life and families that is positive and optimistic, grounded in research conducted around the world. It does not ignore family problems but restores them to their proper place in life: as vehicles for testing our capacities as families and reaffirming our vital human connections with each other. (p. 3)

1.5. How this report is organised

This report is composed of an executive summary, six chapters, a reference list and appendices.

In the first chapter we introduce the report.

In the second chapter we review literature relevant to this report. We begin by discussing disability, family, wellbeing and resilience. Next we review studies that explore the experiences of families that include a parent with a disability, with a particular focus on New Zealand-based studies. In this review we highlight some significant gaps in research.

In the third chapter we describe how this project was designed and carried out. We have highlighted both the successes and the challenges of our work. In light of the gaps in research, it is critical for researchers to converse with one another and with the public. In particular it is important to learn what works and what does not work when designing and carrying out research that involves parents with disabilities. As Kvale (2007) has pointed out, “The relevance of conversations in social science goes beyond the use of conversations as an additional empirical method. It includes conversations between researchers and the public about the truth and value of the knowledge produced in interview conversations” (p. 144).

In the fourth chapter we explore the participants’ understanding of the word ‘disability’ and some of the differences that living with a disability brings. More than 20 different disabilities were represented in this study. Rather than discussing each disability in detail, we discuss five themes that summarise the parents’ experiences: (a) mobility difficulties; (b) mental health conditions; (c) chronic pain; (d) sensory impairments; and (e) learning and processing differences.

In the fifth chapter we begin by highlighting the families’ strengths. Next we discuss some of the challenges these families faced and how their strengths were used to meet the challenges. We close the chapter by highlighting the participants’ ideas for how support could be improved.

In the sixth chapter we discuss ways to incorporate these findings into our existing knowledge and common practices. We begin by discussing the research questions in light of the findings and the literature. We then describe the strengths and limitations of this study. We conclude with some suggestions for engaging with families that include a parent with a disability and offer some ideas for future research.

Documents relevant to this report can be found in the appendices.

2. LITERATURE REVIEW

We begin this chapter by discussing what is meant by the terms 'disability', 'family', 'wellbeing' and 'resilience'. We then explore what the literature has to say about bolstering family resilience and about the experiences of families that include a parent with a disability. We conclude the chapter by focusing on New Zealand-based studies that explore the experiences of families that include a parent with a disability. In reviewing those studies we have attended to the strengths that the families exhibited and the challenges they faced.

2.1. Disability

Writing about disabilities poses a variety of challenges. First of all, a writer hesitates to draw a sharp line between those with disabilities and those without, knowing that all humans have strengths and weaknesses. Drawing such distinctions can lead to discrimination and social exclusion. However, it is difficult to address the needs of those with a disability without such a differentiation. We have made the differentiation because we wish to promote the wellbeing of families by providing information that will help communities and service agencies to be "aware of and responsive to disabled people" (The New Zealand Disability Strategy, 2001, p. 12).

2.1.1. Terminology

Writers also encounter difficulty with terminology. We have chosen our terms with care, but in the disability field acceptable terminology varies considerably over time and from place to place. Even word order can suggest meaning. For example, some writers prefer to put the word disabled in front of the noun (eg, 'disabled parent'). By doing so, they emphasise that people are disabled by the barriers they encounter (eg, Olsen & Clarke, 2003, p. ix). Others prefer to use people-first language and say, 'parent with a disability'. This order emphasises that the person comes before the disability. We have chosen to say 'parent with a disability' because we wish to emphasise the humanness we all share. People-first language is the preferred choice of certain disability groups and cultural groups (eg, Self Advocates Becoming Empowered, n.d.; T. Rongonui, personal communication, 3 August 2009). (See Appendix D for the letter from T. Rongonui.)

2.1.2. What is meant by the term 'disability'?

Like many common but complex words, 'disability' has a number of definitions. For the purposes of this report we will use the World Health Organisation's definition:

Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.

Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives. (World Health Organisation, 2011, para. 1 – 2)

This definition of disabilities takes a wide variety of impairments and limitations into account, and acknowledges the interactions between individuals and their communities.

2.1.3. Ways of viewing disability

It is important to consider the way that one views disability, as it often frames one's response to people with impairments. One common model for viewing disability is the 'medical model'. This model considers that disability resides in the individual. When using this lens, one often attempts to measure or quantify the disability, and an attempt is made to cure or alleviate the disability. For example, a person who is short-sighted goes to an optometrist to have his or her eyes tested, in the hope of receiving glasses that will 'cure' the sight impairment. One weakness of the medical model is that it fails to consider the role that the wider community plays in the lives of people with disabilities. It also risks 'medical paternalism', which can limit health choices for people with disabilities and "injustices occur when disability is overmedicalised" (Shakespeare, Lezzoni, & Groce, 2009, p. 1815).

In contrast to the medical model, the 'social model' of disability sees disability as residing in society. This model focuses on identifying and reducing barriers and forging a more inclusive society. This quote from The New Zealand Disability Strategy (2001) is an example of how the social model lens frames a response to impairment:

The New Zealand Disability Strategy presents a long-term plan for changing New Zealand from a disabling to an inclusive society. ...

Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments. Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have.

Along with other New Zealanders, disabled people aspire to a good life. However, they also face huge barriers to achieving the life that so many take for granted. (p. 1)

The social model of disability has been instrumental in making positive changes in the wider community's response to people with disabilities. However, when viewed on its own it fails to account for the personal experience of disability. As Shakespeare et al (2009) have pointed out, the "dichotomy [between the medical model and the social model] can be overstated" as both models can benefit people with disabilities (p. 1815).

For this report we strove to use the strengths of each of these models. The medical model lens is useful for examining the details of the specific disabilities experienced by the participants in this study. In particular, when people are experiencing pain, either physical or emotional, many people welcome medical responses that alleviate such distress. The social model lens is useful for exploring wider social issues, such as poverty and social exclusion, which many people with disabilities experience (eg, Morris & Wates, 2006).

2.2. Family wellbeing

2.2.1. What is meant by the term 'family'?

Before talking about family wellbeing and family resilience we would like to clarify what we mean by the word 'family'. For the purposes of this report we will use the term 'family' to include "a group of people related by marriage, civil union, blood, or adoption, an extended family, two or more persons living together as a family, and a whānau or other culturally recognised family group" (Families Commission Act 2003, p. 8). When referring to 'parents' we are referring to the

women (mothers) and/or men (fathers) in a family group who are related to children "by marriage, civil union, blood, or adoption" or "are living together [with children] as family". These definitions acknowledge the diversity in New Zealand families.

2.2.2. What is meant by the term 'wellbeing'?

The literature on wellbeing is extensive (eg, Diener, Lucas, Schimmack, & Helliwell, 2009) and many constructs have been created to understand wellbeing. Because this study is based in New Zealand, we have chosen to use Mason Durie's model of Te Whare Tapa Whā, which translated means "the four sides of a house" (Durie, 1985). Te Whare Tapa Whā considers wellbeing in four dimensions: (a) te taha wairua (spiritual health); (b) te taha hinengaro (mental health); (c) te taha tinana (physical health); and (d) te taha whānau (family health). This multi-dimensional focus on wellbeing aligns with our desire to maintain a wellness and strengths-based focus and to avoid 'over-medicalising' disabilities.

In addition to "giving Māori a distinctive voice in healthcare services", this model has moved healthcare delivery towards a more personalised, holistic approach to care, which has benefited all New Zealanders (Durie, 2011, p. 30).

2.2.3. What are the characteristics of 'family wellbeing'?

In 2005, as part of the Families Commission's "What makes your family tick?" campaign, New Zealand families described what 'family wellbeing' meant to them. Seth-Purdie, et al (2006) reported on the 3,673 written submissions that were received and Stevens, Dickson and Poland (2005) reported on the 43 focus groups that were held. Similar themes were found in both reports. "Perhaps unsurprisingly, participants generally agreed that love or aroha is one of the most important characteristics of a strong family. The concept of love was linked closely with notions of commitment, affection, closeness and belonging" (Stevens et al, 2005, p. 26).

New Zealand families valued spending time together, and loving relationships with the immediate family and extended family were an important part of family life. However, relationships sometimes presented challenges to families. These included "disagreements between family members, separation/divorce, family violence/abuse, addictions and traumatic events such

as the death of a family member" (Seth-Purdie et al, 2006, p. 9). The families mentioned the importance of effective communication and positive parenting.

The families valued the support they received from their family, friends and the wider community. Most did not view a lack of support as a challenge for their family life. The families that said they lacked social support included single-parent families and immigrants.

Morals, values and beliefs were considered an important aspect of family life, but these varied considerably between families. Education and access to healthcare were also important parts of family life.

Although money was not a key contributor to a strong family, sufficient income and adequate housing did contribute to family wellbeing. Money was one of the families' key challenges. Families valued having time together, but many found it difficult to juggle work and family time. Achieving this balance was most difficult for single-parent families and families with low incomes.

2.3. Resilience

2.3.1. What is meant by the term 'resilience'?

There is a wealth of research exploring both individual resilience and family resilience. For example, Walsh (2006), Benzies and Mychasiuk (2009) and Kalil (2003) have extensively reviewed the literature on family resilience. For the purposes of this report we will use the definition of resilience provided by Walsh (2006):

Resilience can be defined as the capacity to rebound from adversity strengthened and more resourceful. It is an active process of endurance, self-righting, and growth in response to crisis and challenge. ...Resilience is commonly thought of as 'bouncing back', like a spring to our pre-crisis shape or norm. A more apt metaphor for resilience might be 'bouncing forward', rebounding and reorganising adaptively to fit new challenges or changed conditions. (pp. 4, 85)

The metaphor of 'bouncing forward' is well suited to the ongoing challenges of living with a disability.

2.3.2. Bolstering family resilience

When considering how to strengthen family resilience, Walsh (2006) has proposed "a conceptual framework comprising three domains: belief systems, organisational patterns, and communication processes"

(p. 25). She calls them "the three keys to family resilience" (p. 26).

The first 'key' that Walsh identified was 'belief systems'. This echoes what the New Zealand families in the "What makes your family tick?" project said about wellbeing: they, too, saw belief systems and spirituality as an integral part of family wellbeing. Other scholars also concur with Walsh regarding the relationship between belief systems and resilience (eg, Benzies & Mychasiuk, 2009). According to Walsh (2006), beliefs that foster family resilience include working together to make meaning out of difficulties, maintaining a positive attitude and transcendent beliefs (spirituality) (p. 55). Families work together to make meaning out of adversity; a crisis is seen as a shared experience. Maintaining a positive outlook often requires hope, initiative and perseverance. Walsh refers to spirituality as "an active investment in internalised beliefs that bring a sense of meaning and wholeness and a connection to others" (p. 73). Transcendent beliefs and spirituality also incorporate inspiration, innovation, creativity and a willingness to grow and change.

The second key that Walsh (2006) identified was 'organisational patterns'. Family patterns that foster resilience include: (a) the ability to be flexible yet still maintain stability; (b) the ability to establish closeness yet allow for individuality; and (c) having sufficient social and economic resources (p. 84). Similarly, Benzies and Mychasiuk (2009) highlighted the importance of family cohesion (closeness), supportive parent-child relationships, social support and adequate income and housing. New Zealand families also highlighted how economic and social resources impacted family wellbeing (Seth-Purdie et al, 2006; Stevens et al, 2005).

The third key that Walsh (2006) identified was 'communication processes'. As stated by Kalil (2003), "effective communication is especially critical at times of sudden crisis or prolonged stress, as these are the times when communication is most likely to fail" (p. 33). The three characteristics Walsh (2006) highlighted were "clarity, open emotional expression, [and] problem solving" (p. 26). Openly expressing a wide range of emotions and actively fostering positive interactions within the family helps to build resilience. Benzies and Mychasiuk (2009) highlighted that the ability to regulate emotional expression contributed to resilience. According to Patterson (2004), play and

imagination are essential tools for building resilience in children. A number of studies demonstrate the use of humour when coping with difficult situations (eg, O'Connor, 2010).

2.4. Exploring the strengths and resilience of families that include a parent with a disability

Caring for and rearing children safely and well is one of the most rewarding and challenging tasks of adulthood, with many personal and societal factors interacting to make this task easier, or to pose enormous barriers to successful parenting. (Mirfin-Veitch, 2010, p. 95)

In contrast to the wealth of studies about wellbeing and resilience, studies exploring the experiences of families that include a parent with a disability are relatively sparse. It is easier to find studies of families that include a child with a disability, than those that include a parent with a disability. But when considering the wellbeing and resilience of families that include a parent with a disability, the literature is clear about the challenges these parents may face.

Parenting with a disability is often accompanied by employment and economic challenges. Compared to their non-disabled peers, people with disabilities earn, on average, lower wages, and a larger percentage of people with disabilities are unemployed (Morris & Wates, 2006, p. 40). There are also financial costs associated with having a disability, which widen the financial gap between those with disabilities and those without disabilities (Disability Resource Centre, 2010; Saunders, 2007). In a United Kingdom study of 67 families that included a parent with a disability, "only 12 respondents were in regular paid employment of more than 10 hour per week" (Olsen & Clarke, 2003, p. 57). Inadequate income can lead to inadequate housing. The challenges associated with poverty are many and are not limited to those with disabilities.

Parents with a disability face another challenge: the lack of disability awareness of some people in the wider community:

Disabled people have had to mediate sustained contradiction in their daily lives. On the one hand, they have had their lives highly scrutinised, while on the other, they have often remained invisible and without a voice and the power to change

disruptive and harmful service systems and intervention practices. (Munford, Sanders, Mirfin-Veitch, & Conder, 2008, p. 339)

Many parents have experienced negative comments from both professionals and members of the community, questioning their choice to become parents and their ability to successfully parent (eg, Morris & Wates, 2006). Parents in the study by Olsen and Clarke (2003) reported that "social care professionals had told them that 'Disabled people shouldn't have children', or had asked, 'How can you possibly look after a baby when you can't even look after yourself?'" (p. 42). In a New Zealand study of five parents with bipolar disorder, the parents reported feeling stigmatised as a parent with a mental illness (Wilson & Crowe, 2009). Some parents with a disability reported being reluctant to seek help for their difficulties lest their children be removed from them (Morris & Wates, 2006). Such fear may be merited, because parents with a disability are over-represented in child protection services, particularly those with mental health issues or intellectual disabilities (eg, Llewellyn et al, 2003).

While not all parents with disabilities are subjected to discrimination, prejudicial attitudes are fertile breeding ground for social isolation. Families are at risk when they lack strong social networks and a sense of community belonging. Mirfin-Veitch (2010) described two case studies that highlight the difference that strong social support and community belonging can make for parents with disabilities. These case studies were taken from a three-year study that involved 19 New Zealand parents with intellectual disabilities.

One mother, Nicky, was surrounded by a supportive extended family and was actively involved in community life. She retained custody of her child, in spite of "intense scrutiny ... as hospital staff reacted to the idea of a young woman with intellectual disabilities having a child" (Mirfin-Veitch, 2010, p. 100). By contrast, Suzanne's experience of social support and community life was at the other end of the spectrum. She experienced sexual abuse as a teenager and lacked ongoing support from her family. Her child was removed from her custody when he was five years old. She "experienced difficulty in developing and sustaining supportive relationships with men" and had "an impoverished informal support network" (p. 101). In spite of these challenges she maintained

a “mutually loving” relationship with her son (p. 101). Although she did what she could to try and regain custody of him, during the three years of the study her visitation time with her son was reduced. Mirfin-Veitch (2010) closed by reiterating, “Parenting in isolation is detrimental to both parents and children, making it critical that parents are supported to create positive, meaningful and self-sustaining relationships within these communities” (p. 105).

As Thomson, Chapman and Carter (2010) have noted, assisting families to gain appropriate support is likely to be time-consuming initially. However, as illustrated in the cases they presented, positive outcomes are likely to occur when social workers develop “engaging relationships” with families, by “demonstrating respect, reinforcing positive qualities and highlighting the family’s strengths” (p. 26).

Another ongoing challenge that parents with a disability will likely face is determining what, if any, extra assistance they might need to enable them to successfully look after their children. A barrier that is commonly referred to in the literature is difficulty accessing appropriate services (eg, Morris & Wates, 2006; Olsen & Clarke, 2003). Sometimes disability services are not equipped to support parenting needs; sometimes information is difficult to access. In New Zealand “a key issue for families is the **lack of coherence** between those government agencies providing services for disabled people, and the present **inequities across government-funded** supports for disabled people” [original author’s emphasis] (Ministry of Social Development, 2004, p. 100).

Another consideration for families is that children’s needs change over time, as do the needs arising from disabilities (eg, Morris & Wates, 2006). As children grow older, they may take on caring responsibilities within the family. There is a body of literature exploring the experiences of these ‘young carers’. Sometimes young carers are providing care for parents and sometimes for siblings or other family members, thus the term ‘young carer’ does not necessarily mean that the family includes a parent with a disability.

According to Newman (2002) and Olsen and Clarke (2003) the category of young carers emerged in the late 1980s or early 1990s. Research and service provision were driven by concern for children who were seen as taking on “inappropriate roles” (Olsen & Clarke, 2003, p. 14). After the initial trend of focusing on individual

children’s rights – which, inadvertently, took the focus off of the family as a whole – young carer research is becoming more family focused (Newman, 2002).

Many people assume that caregiving is inappropriate for children. Such an assumption can have unintended negative consequences for children. Some children have ended up feeling isolated or misunderstood because of their caregiving role in their family. For example, “one female young carer commented that some adults ‘looked down’ on young carers, thinking, ‘you don’t want to do that, you just want to be a child’” (Earley, Cushway, & Cassidy, 2007, p. 74). In New Zealand young carer research and young carer services are relatively new. Gaffney (2007, 2009) has developed an assessment tool for identifying young carers and a young carer’s group had their inaugural meeting in 2005 (Young Carers New Zealand, 2005).

The literature is clear that families that include a parent with a disability are likely to face challenges in the areas of financial resources, social stigma and the need to balance their needs with the needs of their children. What is much less obvious in the literature are the strengths with which families approach these challenges. By putting strengths in the limelight, along with the challenges, we can better recognise and foster strengths in ourselves and in those around us.

The remainder of this literature review will highlight family strengths that are exhibited in the handful of New Zealand-based studies, which have explored the experiences of families that include a parent with a disability.

As seen by New Zealand families, “love or aroha is one of the most important characteristics of a strong family” (Stevens et al, 2005, p. 26). The Office for Disability Issues (2005) collected the stories of 25 New Zealanders with disabilities. Of those 25 people, eight were parents with disabilities and one was a father to-be. Their stories give testament to the love or aroha that exists in their families. For example, Kathy said, “My family is very important to me. With them I know that I can achieve anything. My children and partner continue to support me to reach my potential. I love them very much” (p. 9). In the case studies presented by Mirfin-Veitch (2010), Suzanne’s ability to maintain “a mutually loving relationship” with her son in the face of many challenging circumstances is another example of the presence of resilient love (p. 101).

Also running through their stories is the theme of 'initiative and persistence', a key element of resilience. This theme also comes through in the study of 19 parents with intellectual disabilities:

Carla had deliberately chosen to repeatedly seek out parenting training programmes because she told us that she had not learned from her own parents how to parent well. ...Her struggle and determination to find the resources she needed had taken her through many agencies as she sought the type of information and support relationships that allowed her the space to learn. She had been subject to nearly a decade of challenge from state welfare agencies concerning her competence as a parent and, at the time of our interviews, had had her children removed. (Munford et al, 2008, p. 343)

Another quality found in resilient families is the ability to adapt and change yet retain stability. Achieving this sense of balance can be a challenge because the needs associated with disabilities ebb and flow, and the needs of children change as they grow. Payne, McPherson and Crerar (2007) interviewed nine mothers with multiple sclerosis. A key theme in this study was that their symptoms varied in type and severity. The mothers sought to maintain stability by anticipating their changing needs and organising extra support.

McDonald (2008) explored the experiences of nine families that included a young carer. Of those nine families, four included a parent with a disability. A key aspect of family resilience is the ability to adapt and change. In addition to detailing the families' caregiving experiences, McDonald used the data to formulate a theory of adaptation and change. According to McDonald, "in this study, life seemed to be relatively balanced for most of the young carers, and the effects on their lives did not seem as marked as had been noted in the literature" (p. 76). McDonald pointed

to another study, Eley (2004), where families had achieved a similar balance.

Benzies and Mychasiuk (2009) considered that emotional regulation contributed to families' resilience. In their study of parents with bipolar disorder, Wilson and Crowe (2009) noted that the parents employed high levels of 'self-surveillance' to regulate their emotional responses. While this constant self-surveillance was driven by a desire to be good parents it caused them to focus on their perceived weaknesses. However, the fact that the parents understood the importance of modelling emotional regulation for their children can be viewed as a strength. The parents felt guilty about their perceived inability to regulate their emotions. One parent said: "I feel guilty a lot of the time because I get irritable with them, I get impatient and I don't know whether that is my illness or whether that is normal at times, it is hard to work out" (p. 880). This study shows that families need to be supported to find an appropriate balance between emotional regulation and open expressions of a range of emotions, because both are aspects of strong and resilient families.

2.5. Gaps in research

Existing literature is rich with studies on wellbeing and resilience, but there is little research exploring the experiences of families that include a parent with a disability. And, in particular, there is a need for research that highlights families' strengths and resilience. Although researchers are moving away from a deficit-focused view of disabilities, descriptions of the challenges that families face are far more prevalent in the literature than descriptions of the strengths they possess. To move to a more strengths-based approach to families, it is necessary we hold the families' strengths in our mind's eye as clearly as we see their challenges.

3. METHOD

3.1. Introduction

Conducting qualitative research on family life is akin to inviting oneself over for dinner and then publishing the dinner table conversation for public scrutiny. Research reports must be transparent enough to entice the reader, yet opaque enough to protect the confidentiality of the participants. We begin this chapter by describing the study design and discussing the values and ethical considerations that guided our work. Next we detail the consultation process and the ethical approval process. We then describe how we recruited participants, and briefly describe them. We conclude the chapter by outlining the steps we followed when gathering, analysing and presenting the data.

This chapter and the relevant pages in the appendices provide sufficient detail for others should they wish to do a similar project. However, it is important to bear in mind that no two qualitative projects can be identical because each researcher brings his or her unique flavour to the 'dinner table' conversations.

3.2. Study design

This study was designed as a multiple case study exploring the experiences of families that include a parent with a disability. We chose this research strategy because we were exploring "a contemporary phenomenon within a real-life context" (Yin, 2003, p. 13). Each case was bounded by geography (located within the province of Canterbury), activity (family life) and participant group (families that include a parent with a disability). We intended to view each case from more than one viewpoint; that is, through the eyes of parents, children and family friends. All but two of the 20 cases include more than one viewpoint.

3.3. Ethical considerations

3.3.1. Our motivation

The first step in embarking on an ethically sound project is to have a good reason for conducting the research. It is not ethical to collect personal information from families simply for the sake of collecting information; the project must be of benefit to families. The purpose of this study is to highlight family strengths

and to gain new information on the resiliency processes and factors of these families. Information gathered in this study is intended to be used to inform stakeholders about how they might work more effectively to make a difference to families that include a parent with a disability. Our motivation for doing this project was to promote the wellbeing of families and to work towards positive social change.

3.3.2. Our role as researchers

We saw ourselves as the learners and the research participants as the experts. We chose an interviewing style called "responsive interviewing" (Rubin & Rubin, 2005, p. 30). This style aims to obtain "interviewees' interpretations of their experiences and their understanding of the world in which they live and work" (p. 36). We sought to establish "conversational partnerships" with the research participants, which were reciprocal in nature rather than hierarchical (p. 79). We took time for the "give and take of social interactions" (Harrison, MacGibbon, & Morton, 2001, p. 323). We shared cups of tea, admired children's artwork, commiserated at the devastation of our city and rejoiced that we were all unharmed.

We endeavoured to "act with care and respect for individual and cultural differences and the diversity of human experience" (New Zealand Association of Counsellors, 2002, p. 26). Treating others with respect and valuing diversity is not only a core value of counselling ethics, but is also a part of the Health and Disability Code of Consumer Rights (Health and Disability Commissioner, n.d.), and the guidelines from Health and Disability Ethics Committees (Health and Disability Ethics Committees, 2007).

3.3.3. Supporting participants' communication and needs

According to the Code of Health and Disability Services Consumers' Rights (Health and Disability Commissioner, n.d.), research participants have a number of rights, including the right to effective communication, appropriate support and independence. In order to include participants with a variety of abilities we needed to consider how to address a broad range of possible communication and support needs.

For example, we considered the particular vulnerabilities of people with intellectual disabilities.

They often have fewer opportunities to acquire ordinary knowledge. They may have difficulty with abstract concepts and may have limited vocabulary (Bray, 1998; Finlay & Lyons, 2001). Therefore, we were careful to check participants' understanding of concepts such as confidentiality and anonymity. We also took time to explain research in general as well as the specific research at hand. Many people with intellectual disabilities tend to comply with the wishes of those perceived to be in authority over them (Bray, 1998).⁴ Thus, we chose to use an informal conversational style during the interviews. This style of interviewing also put the other participants at ease, and was in keeping with our value of establishing reciprocity rather than hierarchy in our research relationships.

We were aware that literacy levels would vary from participant to participant, so we presented information both verbally and in writing. When necessary, we read the information sheet and consent forms to the participants. Some versions of the information sheets included pictures. When participants were unable to read, pictures were used alongside the written information. Information sheets can be found in Appendix B. Consent forms can be found in Appendix C.

3.3.4. Obtaining informed consent from parents and children

Because this project involved parents and children, informed consent was a two-step process. First we approached parents with information about this project. If they were interested in participating and gave permission for their children to participate, then the children were invited to participate. We gave information to the children, and, from our perspective, they were free to participate or not, as they wished.

Pressure to participate or simply good manners?

On a few occasions, the children's participation in this project was constrained by the parents' notions of 'good manners'. For example, part-way through a family interview, one child wanted to leave the interview to go and play. The researcher told the parent that as far as the project was concerned, the child was free to leave the discussion. However, the parent told the child to remain present for the duration of the interview. It seemed the parent's goal was to teach their child how to be polite to the researcher who was a guest in their home. One of our overarching values was an appreciation of the unique

culture of each family. Therefore, we deferred to the parent's wishes and continued interviewing that child. The child complied with the parent's wishes and continued to participate in the interview.

3.3.5. Obtaining informed consent from family friends

As with the children, the consent process for family friends began first with the parents. If a parent was interested in participating and had given permission for a family friend to participate, then the family friend was invited to participate. We gave information to the family friend, and the family friend was free to participate or not, as they wished.

3.3.6. Confidentiality

Another important concept was 'confidentiality', which we explained to participants. We explained that they were free to talk to anyone else about their involvement in this project, but we would keep their information confidential. We then explained the limits of that confidentiality. That is, we may break confidentiality if we learned that someone was in danger. We also explained how we planned to guard their privacy when we disseminated the findings from this project.

3.3.7. 'Do no harm'

The issue of safety, that is, 'doing no harm' and 'protecting from harm', is of particular relevance to research involving children. As researchers we are "temporary visitors" (Munford & Sanders, 2001, p. 106) in their lives, but may well run into complex situations where a child's safety may be in question. It was important that we were equipped with contingency plans that included knowledge of support services for families as well as a range of responses that may be appropriate in such situations.

Interviewing both children and their parents requires special sensitivity to family wellbeing. Although we did not anticipate any physical or psychological risks to participants, we were aware of the sensitive nature of this project. The primary interviewer is a counsellor and has experience in sensitive interviewing. She attended to the content and direction of the interviews as they were taking place and, when appropriate, shared information about support services for families and people with disabilities.

⁴ For a more in-depth discussion of ethical considerations when interviewing people with intellectual disability, please refer to Raffensperger (2010, pp. 80 – 84).

3.3.8. The ongoing nature of ethical considerations

Conducting group or one-on-one interviews in a family setting is fraught with ongoing ethical issues. The presence of parents and children produces possibilities for a range of interests that problematise the key ethical issues of informed consent, 'do no harm' and confidentiality [sic]. (Munford & Sanders, 2001, p. 99)

The issues of informed consent, 'do no harm' and confidentiality are important to consider not only during the face-to-face interviews, but also throughout the design phase of a project, during the recruitment and consent process and during the data analysis, presentation and dissemination (Bray & Mirfin-Veitch, 2003; Munford & Sanders, 2001, 2004).

3.4. Cultural considerations

Although none of our team members identify as Māori, our values and principles align with the Māori ethical framework presented by Hudson, Milne, Reynolds, Russell and Smith (n.d.). This framework is constructed around four tikanga-based principles: (a) whakapapa; (b) tika; (c) manākitanga; and (d) mana (p. 4).

Important aspects of whakapapa include cultural consultation and establishing respectful and caring relationships with research participants and with the Māori community. Early on in the research process we sought cultural consultation with the Research Consultant – Māori at the Research and Innovation Office, University of Canterbury. A letter acknowledging this consultation process can be found in Appendix D.

According to Hudson et al, it is important that researchers "protect the rights and interests of Māori" throughout the project (p. 9). As the principal investigator is an American, we were well aware of our need for ongoing cultural consultation. So before recruiting Māori participants we began looking for someone who could act as a cultural advisor. Finding someone who had available time and the necessary expertise proved to be challenging. The Research and Innovation Office suggested a number of possible avenues for us. Unfortunately it took us several months to find someone to fill this role. Once we had a cultural advisor on board, she was able to assist us with recruiting Māori families and she provided ongoing cultural consultation throughout the project. Three

of the 20 families in this study identified as Māori (15 percent of the families). While this is only a small number of Māori families, it is a larger percentage than the population distribution in the Canterbury region where, in 2006, less than 7 percent of the population identified as Māori (Statistics New Zealand, 2006).

Manākātanga includes the concepts of care, respect, cultural sensitivity, privacy and confidentiality. "Manākātanga is fully realised in the context of relationships. Here mana akiaki (empowerment) empowers partnerships whose quality is enhanced by the level of the parties' faith and trust in each other (whakapono)" (Hudson et al, n.d., p. 12). Our desire "to act with care and respect" (New Zealand Association of Counsellors, 2002, p. 26) and our value of developing reciprocal partnerships with our research participants bears some similarity to manākitanga.

The care we took to ensure voluntary informed consent aligns with the concept of "mana tangata (autonomous individual) [that] in the context of this framework refers to individuals that choose to participate in research and their right to be appropriately informed of risks to their individual or collective mana" (Hudson et al, n.d., p. 13).

3.5. Ethical approval process

Because this project came under the umbrella of the University of Canterbury, it was appropriate to obtain ethics approval from the University of Canterbury Human Ethics Committee. Because this study involved interviewing people with disabilities, it was also appropriate to obtain ethics approval from the Upper South Health and Disability Ethics Committee. Letters of approval from these two ethics committees can be found in Appendix D.

3.6. Recruitment process

Potential participants included: (a) parents with a range of disabilities, that is, mental illness, physical impairment, intellectual disability, specific learning disability and sensory impairment; (b) their families; and (c) selected family friends. Potential participants were identified through the researchers' personal contacts and through agencies that worked with people with disabilities.

Members of the research team and their colleagues gave information sheets to potential participants. The principal investigator also contacted several community agencies. Information about the project was passed on to potential participants according to the agencies' preferences. Some agencies included a paragraph about this project in their newsletter. Other agencies emailed the entire information sheet to the potential participants. Interested participants then made contact with the principal investigator, either directly or via the person who had made initial contact with them.

"Most disabled people have more than one impairment, with physical impairment the most common, affecting two-thirds of disabled people" (Human Rights Commission, 2004, Section 4, para. 2). Because it is common for a person to have more than one type of disability; we did not wish to limit our recruitment to a particular number of parents with one particular disability, that is, four parents with a mental illness only, four parents with physical impairments only, four parents with sensory impairments only and so forth. We focused instead on obtaining a purposive sample which included at least two instances of each of the five types of disabilities mentioned in the previous paragraph.

3.7. Inclusion criteria

This project had four different participant groups: parents with a disability; their partners (who may or may not have a disability themselves); their children; and family friends.

The inclusion criteria for a parent with a disability were: they have a disability and have at least one child that is 16 years of age or younger.

The inclusion criteria for a partner were: they are nominated as a partner by the parent with the disability and the parent with the disability gave permission for them to participate.

The inclusion criteria for children were: they are children of the parent with the disability and the parent has given permission for them to be invited to participate.

The inclusion criteria for family friends were: they are chosen by the parent with a disability and the parent has given permission for them to be invited to participate.

3.8. Participant descriptions

Twenty families participated in this study. The study was designed to include the perspectives of parents with a disability and their partners, children and family friends. However, we were aware that each family situation was different. Therefore, the parent with a disability could first decide who to include in the interviews. Then the other participants were free to participate or not as they wished. For example, Family 7 has three children who were invited to participate, but only one child chose to be interviewed. The Upper South A Ethics Committee set the guideline that only children over the age of eight could participate in individual interviews. As it turned out, only one child was interviewed without a parent present.

We recruited 20 parents with a disability. We conducted semi-structured interviews with 20 mothers, 10 fathers, 19 children and 11 family friends. Table 1 shows a list of the research participants, the disabilities represented in each family, and other members of the family. As noted in the table, some of those parents opted not to include partners, children and/or family friends. The ages listed are at the time of recruitment. Except when noted, the parents and children were living in the same household.

Brief descriptions of each of the disabilities can be found in Appendix A.

Table 1: List of research participants

Family	Research participants	Disabilities	Other children in the family	Employment status	Notes
1	Mother, age 44, European Father, age 43, NZ European	Bipolar, post-natal depression	Son, age 4, European/NZ European	Mother: Domestic Purposes Benefit Father: employed	In this family, the mother and father were in a committed relationship, but chose to live in separate households. The son lived with the mother. They chose not to include a family friend.
2	Mother, age 21, NZ European Father, age 29, NZ European	Post-natal depression, post-traumatic stress disorder	Daughter, age 1, NZ European	Mother: not employed Father: recently re-employed. He stopped working for several months while the mother was unwell.	This family chose to include a family friend, but due to the extra demands of the earthquake the friend was unable to participate.
3	Mother, age 42, NZ European Father, age 42, NZ European Daughter, age 8, NZ European Family friend	Intellectual disability Intellectual disability, hearing impairment Global developmental delay, hyperactive disorder and possible hearing loss		Mother: employed part-time and receiving a government benefit Father: employed part-time and receiving a government benefit	
4	Mother, age 38, NZ European Father, age 31, NZ European Family friend, age "nearing 40"	Multiple sclerosis	Son, age 18 months, NZ European Son, age 4, NZ European	Mother: not employed Father: employed full-time	
5	Mother, age 36, NZ European Daughter, age 8, NZ European Son, age 11, NZ European Family friend, age 61	Glandular fever, chronic fatigue syndrome		Mother: Domestic Purposes Benefit	The children in this family lived primarily with their mother, but also spent time living in their biological father's household.

Family	Research participants	Disabilities	Other children in the family	Employment status	Notes
6	Mother, age 39, NZ European Daughter, age 12, NZ European Family friend, age 34 Family friend, age 28	Deaf with cochlear implant, bipolar, OCD, borderline personality disorder Dyslexia	Son, age 2, NZ European	Mother: Domestic Purposes Benefit	The son in this family lived primarily with his mother but also spent time living in his biological father's household. This family chose to include two family friends, a married couple.
7	Mother, age ?, NZ European Son, age 12, NZ European Family friend, age 64, NZ European	Dyslexia, Irlen syndrome Dyslexia	Son, age 15, anxiety, NZ European Son, age 14, NZ European	Mother: student	The children in this family live primarily with their mother but also spend time in their father's household.
8	Mother, age 43, NZ European Father, age 47, NZ European Daughter, age 10, NZ European Daughter, age 13, NZ European Family friend, age 43, NZ European	Ménière's disease, Trigeminal neuralgia		Mother: employed part-time Father: employed full-time	
9	Mother, age 43, NZ European Father, age 47	Blindness, anxiety	Daughter, age 8 Daughter, age 7	Mother: student Father: employed	The mother and father live in separate households and the children are in the care of CYF. They opted not to include a family friend.
10	Mother, age 45, NZ European Daughter, age 16, NZ European	Brain injury, depression	Daughter, age 14, NZ European	Mother: employed part-time and receives the Domestic Purposes Benefit	The 16-year-old daughter lives with her father, but visits her mother regularly. The 14-year-old lives with her mother and visits her father's household. The mother chose to include a friend, but the friend declined to participate as she was too busy.

Family	Research participants	Disabilities	Other children in the family	Employment status	Notes
11	Mother, age 41, NZ European	Post-natal depression, post-traumatic stress disorder	Daughter, age 14 Son, age 3		The father and daughter were interested in participating; however, this family moved away from Christchurch. So only the mother was interviewed.
12	Mother, age 43, NZ European Daughter, age 15, NZ European Family friend, age 50, NZ European	Mental illness, pancreatitis	Daughter, age 18, NZ European Son, age 17, NZ European Son, age 13, NZ European	Mother: employed	
13	Father, age 43, NZ European Mother, age 39, NZ European Son, age 13, NZ European Son, age 10, NZ European Son, age 5, NZ European Family friend, age 43, NZ European	Charcot-Marie-Tooth disease (peroneal muscular atrophy) Charcot-Marie-Tooth disease (peroneal muscular atrophy)		Father: student and employed full-time Mother: not employed	
14	Mother, age 37, NZ European Father, age 38	Paraplegia	Daughter, age 5 Daughter, age 2	Mother: employed part-time Father: employed	The mother declined to involve other family members and a friend because of the busyness of their family life.

Family	Research participants	Disabilities	Other children in the family	Employment status	Notes
15	Father, age 40, NZ European Mother, age 40, NZ European Daughter, age 8, NZ European Son, age 7 Daughter age 5, NZ European	Motor neurone disease		Father: before acquiring MND, he was employed full-time. His disability has "drastically reduced" his "capacity to earn income and support [his] family". This family has maintained their standard of living by receiving donations from friends and family and from government benefits. Mother: not employed	
16	Mother, age 40, NZ Māori Son, age 8, NZ Māori	Asperger's syndrome, diabetes, macular degeneration		Mother: student	The mother chose to include a family friend, and the friend was interested in participating. However, due to earthquake-related demands the friend did not end up participating.
17	Mother, age 33, European/Māori Father, NZ Māori Daughter, age 9 Family friend, age 41, New Zealander	Nerve damage in her leg and foot which causes difficulty walking	Son, age 3 Daughter, age 2 Baby on the way	Mother and father: not employed, receiving benefits Two years before the interviews, the mother became ill, fell into a coma and subsequently suffered permanent nerve damage. The mother described their financial decline as follows: "When I fell sick, [my partner] lost his job because he came from [city] to be with me. So that sort of started a snowball effect. We lost our house. We lost our rental property. We've got bad references now."	At the time of the interview, the children were in the care of CYF under a temporary custody order. The parents had daily access and were working towards regaining custody.

18	Mother, age 42, NZ Māori	Neurosarcoidosis	Daughter, age 4, NZ Māori/New Zealander	Mother: not employed	The mother also has two grown children from a previous relationship, ages 22 and 19. They live on their own, but support this family. They opted not to include a family friend.
	Father, age 39, New Zealander		The father has a son and a daughter, ages 14 and 11 from a previous relationship, who live in this household on alternate weekends.	Father: employed full-time	
19	Mother, age 48, NZ Māori	Ruptured Achilles tendon (still in the healing process at the time of the interviews)		This mother had been working full-time but lost her job due to the earthquake and her injury. When her ACC benefit ended she applied for the Domestic Purposes Benefit.	The mother has five older children who live separately, but provide lots of support: son, age 26; son, age 24; daughter, age 22; daughter, age 20; son, age 18.
	Son, age 8, NZ Māori				
	Family friend, age 59, NZ European				
20	Mother, age 37, Fijian Indian	Diabetes, cataracts, depression, nerve damage on feet		Mother: Domestic Purposes Benefit. A few months before being interviewed she was a student; however, due to her loss of vision she was unable to continue her studies. She was hopeful that she could pick up her studies after receiving surgery for her cataracts.	This family opted not to include a family friend.
	Daughter, age 12, Fijian Indian				

Family structures varied. Eight mothers were solo-parenting; the remaining families in this study included both a mother and father. Of the eight families where the mother was solo-parenting, the children of five of the families also spent time living in the household of their father. Of the 12 families that included a mother and a father, 10 couples were living in the same household and two couples lived separately. Of the two couples that live separately, one couple was committed to each other and actively parented together on a daily basis, but chose not to

live together. The other couple had separated, but both remained involved in their children's lives. At the time of the interviews, two of the families had all of their children under the care of Child, Youth and Family.

The parents chose family friends whom they knew and trusted. There were 11 in total. One mother chose to select her mother as the family friend. Another chose a teacher and one family chose a paid disability support worker. The remaining families chose friends; that is, people not related to their family nor working with them in a professional capacity.

3.9. Collecting, analysing and presenting the data

Our research questions and interview topics provided a framework for the structure of the data collection and analysis.

The data were collected primarily through recorded interviews. Interview topics can be found in Appendix E. Some of the children drew pictures; two of these have been used as illustrations in the findings chapters. One participant who had difficulty speaking also gave permission for us to use some written information. All the interviews were conducted by the principal investigator. One team member was also present during one of the interviews.

We estimated that a typical interview would last about an hour, but some were shorter and others longer. Typically, there would be a short amount of conversation before turning on the recorder, and after turning it off. We also had an initial unrecorded conversation with the parent with a disability discussing the project and answering any questions they had. A table showing the length of the recorded interviews can be found in Appendix E.

The recorded interviews were transcribed by the principal investigator and three other members of our research team. The team members made notes about the topics they noticed when they were transcribing the interviews and discussed those topics with the principal investigator. The transcripts were then checked by the principal investigator.

Preparing the transcripts and discussing the topics allowed us to immerse ourselves in the data. This

is often identified as the first step in data analysis (McLeod, 2003, pp. 84–85). Our next steps in data analysis resembled the stages of content analysis as described by Graneheim and Lundman (2004) and thematic analysis as described by Braun and Clarke (2006). We identified content areas and then organised the data accordingly. The content areas included: participants' descriptions of the concept of disability; descriptions of the disabilities present in their family; challenges posed by their disabilities; family strengths; factors that hindered wellbeing; and factors that enhanced wellbeing.

The next step was to look for "meaning units" (Graneheim & Lundman, 2004, p. 106) in each content area which were then condensed into themes. According to Braun and Clarke (2006), "a theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set" (p. 82). We explored the themes looking for commonality, difference and relationships (Gibson & Brown, 2009, pp. 128–129). An interesting finding was that in spite of the diversity of the specific experiences of each of the families in this study, common themes ran through their stories. So although we gathered demographic data on ethnicity, age and family structures, we looked at the families as a whole rather than subdividing them according to demographic data.

The final stage of data analysis is telling "the complicated story of your data" (Braun & Clarke, 2006, p. 93). In this stage, we have chosen excerpts from the data which illustrate the themes.

4. LIVING WITH A DISABILITY

4.1. Introduction

For this project we distinguished between parents with disabilities and parents without disabilities. The parents in this study also made this distinction, by identifying themselves as a parent with a disability. Making this distinction implies that the presence of a disability brings with it some kind of difference. The purpose of this chapter is to explore some of the differences.

More than 20 different disabilities are represented in this study, as some parents had more than one disability (and in some families both parents had disabilities). Some disabilities have been present since birth, while others were acquired later in life. Some disabilities are ever-present and the symptoms of others only appear episodically. Some are extremely painful; others are pain-free. Some disabilities get progressively worse over time, some stay the same and others may improve or go away altogether; for example, a ruptured tendon. Rather than discussing each of the disabilities in detail, we discuss five themes that were woven throughout their descriptions: (a) living with mobility difficulties; (b) living with mental health conditions; (c) living with chronic pain; (d) living with sensory impairments; and (e) living with learning and processing differences.

4.2. What is a disability?

Central to this study is the participants' understanding of the term 'disability'. Some of the children did not know what the word disability meant, but all the other participants provided very similar descriptions. A disability posed some kind of limitation to the person and made it more difficult for them to do things that other people could do. Disability was generally viewed in contrast to 'normal':

Child, age 12: When you have a disability it means that you can't do as much things as you want to do. Like some people have, like Mum they are deaf, or blind. ...It means that when you're a normal person and you have nothing wrong with you, you have no disability; it means you can do more than a person with a disability.

For some participants, the notion of disability included a need for support:

Partner of a mother with a disability: Being unable to partake of the daily motions without assistance from other people.

Many participants acknowledged the wide variety of disabilities that existed:

Child, age 17: Different to other people for a certain reason. ...Heaps of different kinds of disabilities.

Mother with a disability: A whole range of stuff. It can be an invisible disability. ...Something is wrong with your mental health, to something that's very physical like being paraplegic, having significant medical needs.

Some participants discussed how the recognition of a disability depended on one's point of view:

Partner of a mother with a disability: One person might see it as a disability; another person might not. So it can be very personal to the person or the subject of conversation. They might not feel they have disability but according to ACC or health some criteria they do have. ...That can be quite tricky because they walk around with the label and they may not think they have a label.

Some participants referred to disabilities as being congenital or acquired:

Family friend: Disability to me means that you're not able to do something as well as say somebody with [pause] all their faculties ... for want of a better word. Someone who basically is either born, or through some kind of accident, has had something that has meant they find it tricky to do things that we'd see as just everyday ways of doing things. ... It's something that sort of impinges upon them so that they can't do things as fast or as quick or as well as someone fully able to.

When discussing disabilities, some participants did not like using the word 'disability' but lacked 'better words', so conceded to using the current vocabulary.

Mother with a disability: I don't particularly like the word 'disability'. ...Because at some fundamental level I think you could say we all have disabilities. So how do you define what is a disability and what

isn't? And sometimes disabilities can become strengths and abilities. I think they become opportunities to develop other skills. So that's why I don't particularly like the term. But I guess, probably for want of a better word it's somebody who ... has some long-term condition; something that makes some aspect of living hard.

A number of participants talked about the positive gains that they had experienced because of living with a disability, either their own or that of a family member. Participants spoke of gaining more compassion for others and a deeper understanding of themselves. Some mentioned that their experience with disability had helped them grow stronger within themselves and that their relationships grew stronger also.

Partner of a mother with a disability: If people are serious about staying with someone with a disability they [partners of people with disabilities] have to access their own disability, and embrace it. ... Or recognise the disability in everybody. ... The presence of disabilities can ... be a doorway into ... healing a small unit ... of yourself.

4.3. Living with mobility difficulties

Eleven of the parents in this study experienced mobility difficulties. Because their mobility difficulties stemmed from a range of disabilities, their support needs and experiences varied. Some parents relied on equipment to assist them with mobility and others relied on people to support them. For example, one mother with paraplegia relied on her wheelchair to assist with her mobility:

Mother with a disability: I have full use of my arms and upper limbs; from chest down I have no feeling or movement. ... It impacts on everything in your life. You are sitting all day. You are looking up at people. Your pain is associated with discomfort, not standing, stretching; your insides sort of don't work the same. From a practical point of view, it takes longer to get in the car. You can still do everything but ... it takes longer to get in the car, get your kids ready in the morning, get yourself ready in the morning, takes longer to get dressed.

Another mother relied on the support of others to go places. She had Ménière's disease. This disorder of the inner ear causes intermittent episodes of vertigo and balance problems:

Mother with a disability: To go to the supermarket, to go anywhere, I had to go escorted for about three months until the incidents reduced.

The use of equipment such as crutches or wheelchairs provides other people with a visible clue that a mobility difficulty exists. However, some disabilities, such as Ménière's disease, are invisible and therefore can be misunderstood, as the following quote illustrates:

Mother with a disability: One time, ... after I left work, my balance went and I felt I was going to be sick and I just felt gross but no-one would help me because they thought I was drunk in the middle of the day. So I'm wandering round town and I'd arranged to meet my husband, this is before cell phones, and so I had to wait for him to come and collect me with our daughter... I eventually found the place where I said I'd meet him and I had a park bench I could lie down on. So that was fine.

In spite of their different experiences and support needs, there were two recurring themes: (a) having a mobility difficulty means that it takes longer to get from one place to another, and (b) it takes more energy:

Mother with a disability: It was almost two years ago now. ... I went from fit and healthy and running everywhere, to learning to walk again. ... These days it's more to do with stamina, how far I can go. I'm limited by what I can do and how fast I can do it. I have problems walking for more than two metres or so without needing to sit down and rest and recover.

4.4. Living with mental health conditions

Eight of the parents in this study identified themselves as experiencing a mental health condition. One described it as a mental illness. The other seven gave specific names to their disorders (which in some participants co-existed): (a) anxiety; (b) depression; (c) post-natal depression; (d) post-traumatic stress disorder; (e) bipolar disorder; (f) obsessive-compulsive disorder; and (g) borderline personality disorder.

When talking about their mental health conditions these parents described strong feelings that affected their self-esteem and their sense of wellbeing:

Mother with a disability: It's like being pushed down by a black cloud sort of thing, especially if I'm off

my meds, like I ran out of for a couple of weeks. ...You're lost; it's easy to think of suicide. Makes you feel very alone. Makes you hate yourself.

Mother with a disability: The post-natal depression was feeling that I couldn't cope. Feeling really sorry for him [her baby] because he got this really crap Mum [laugh]. He would be better off with someone else. I just didn't have what it took. He would suffer his whole life. Just no light at the end of the tunnel. Just an overwhelming sense of responsibility that I couldn't measure up to. And just feeling hopeless.

They expressed concern for how their mental health affected their family members:

Mother with a disability: It's not a nice feeling to be manic or depressed. It's really hard work. And it's a lot of stress and pressure on the family.

For example, one mother with obsessive-compulsive disorder described needing things to be just so:

Mother with a disability: It's like when you hang your washing up, I like my pegs to match, picky little things like that. When I hang my towels up, I like them all to be a certain way. ...To me if a towel's got a picture on it, it's got to be the right way [up]. Just stupid little things like that, that most people wouldn't bother them, but to me it's got to be so, so. Otherwise it just annoys me and I've got to go and re-do it.

She saw it as causing more difficulties for her daughter than for herself:

Mother with a disability: It just does her head in because I'm so picky. Everything's got to be so, so. ...Like I go into her room and I can't handle a mess. It irritates me; it makes me quite agitated. ...So nagging and stuff like that. But honestly it affects her more than me.

Another mother described how her post-traumatic stress disorder affected her wellbeing and interfered with her ability to relate to her baby daughter:

Mother with a disability: When [baby] was born, it was ... a pretty bad birth and stuff. ...I re-live it in dreams and in flashbacks ... during the day. And, in the worst ones, sometimes I think I'm back there. ... It's so bad that I see and I hear and I smell things like during the birth. ...It's like being on an adrenalin rush all the time and always being alert

and anxious. ...There's an avoidance bit, too. ...It was really hard in the early days with [baby] 'cause when I looked at her, I was reminded of the birth and so I didn't want to look at her and I didn't want to talk about the birth for ages and if I did I'd sort of freak out. ...I didn't want [to] cuddle her.

A high priority for these parents was looking after their mental wellbeing, so that they could look after their children.

4.5. Living with chronic pain

Eleven of the parents in this study experienced chronic pain. It is not just the chronic pain itself that intrudes on family life, the pain also saps energy from the person suffering:

Partner of a father with a disability: We had pain.

A massive thing to deal with. ...It's just that whole, what pain does, in a family situation. When people are in pain they are tired, grumpy and the stress.

Mother with a disability: When you're living with pain it robs you of your joy. ...You don't tend to plan very far ahead because you don't know what the next day's going to be like and what your next night is going to be like. And it's so tiring so you're not as patient as you'd normally be with your kids and ... you tend to snap at them more than you normally would do. You just don't have the same degree of patience and resilience.

Pain is often accompanied by a need for extra rest. For this mother who was parenting on her own, getting that extra rest was a challenge:

Mother with a disability: It would be so hard to swallow and just extremely painful and I could hardly turn my head sometimes because ... [my glands would] be so enlarged. ...I was told to have a lot of rest but that was quite hard, having ... a very chatty two-year-old who was not having day sleeps and my son, dropping him off and picking him up from school, and he was not settling into school.

Because of their extreme pain, some of the parents took strong pain relief. While it managed the pain effectively, it posed other challenges. One mother developed an addiction to morphine. Then she not only had to deal with managing pain, but also with stopping an addiction. Another mother described the challenges posed by the side effects of pain medication:

Mother with a disability: The problem with the pain thing is that the drugs have really severe side effects. ...I slept most of the time, had slurred speech, I had tremors, I had Parkinsonian-type effects but it was better than being in pain.

4.6. Living with sensory impairments

Five parents in this study had sensory impairments. Woven throughout the stories were difficulties in communicating with others because of their impairment:

Mother with a disability: I felt like I couldn't connect with people because I couldn't see people to be able to ... make that connection with that body language so ... I would have to rely on people to come to me all the time and that wasn't reality. People didn't do that you see, so that's where the isolation came in and I found it difficult to mix with people because I ... couldn't see them and I couldn't recognise them, 'Oh yeah that's so and so or Mary across the room' you see?

Medical interventions that improved their senses made a big difference in their ability to communicate with others:

Mother with a disability: I'm deaf. ...[It was] really, really hard, not so much when you're on your own but once I had my children, especially my oldest daughter, it was really, really hard to understand what she was saying. I had a cochlear implant two years ago and I finally got to be able to hear and I realised that people's voices don't just sound a set tone. It's all different. Like even the word 'no' is different to what I thought it was and I yelled a lot, not intentionally, stuff like that.

Another common thread was the support that their family members provided for them:

Child, age 11: Sometimes she doesn't hear. ...Sometimes at the supermarket when she goes up to the counter and someone says something like how much it is, she doesn't notice ... and I tap her and tell her.

4.7. Living with learning and processing differences

Four parents in this study experienced learning and processing differences. These differences influenced how the parents processed information:

Mother with a disability: Asperger's just means I can't cope with the world the same way everyone else does. There are certain words or actions or behaviours that drive me to a point of aggression because they just overload my system. I've learned how to work the aggression part out, but when I was younger, it was really, really hard. ...I couldn't cope with people touching me. ...But my son was different. ...I'm okay with him cuddling me and stuff.

It also influenced the type of support they needed to accomplish their objectives:

Father with a disability: My wife's got a learning disability and she's quite slow at thinking and I've got a learning disability. I can't spell or write properly. I can't spell or read properly and my wife can read a bit. [My wife]'s disability is a wee bit different to mine. She has trouble remembering a lot of things like cooking and stuff. She has to get help with that.

Because these parents do not process information in the same way as many other people, they experienced much criticism and social stigma:

Friend of parents with disabilities: They've had to put a trespass order against people, against one man who came by drunk all the time. Now they've got another situation where things are happening and they're being accused of things... So they get taken advantage of because of their disability ... like for instance ... the partner of the girl has said [mother] shoplifts. If she shoplifts she would have been picked up and prosecuted. She doesn't shoplift but that's very distressing to [mother] and things like that happen every so often.

When negotiating criticism and social stigma, this particular family had a range of support including the

friend who participated in the study, as well as other family and friends, and two disability support agencies.

4.8. Summary

According to the parents in this study, living with a disability posed a number of challenges. When a parent lives with a mobility difficulty, it takes more time and more energy to get places. When a parent lives with a mental health condition, his or her feelings affect his or her general sense of wellbeing and cause heightened

concern for how his or her mental health affects the rest of the family. When a parent lives with chronic pain, not only is the pain itself a problem but so, too, are the tiredness and grumpiness that result. In some cases, a parent may have to deal with problems associated with the side effects of pain medication. When a parent lives with a sensory impairment, communication with others is more difficult. When a parent lives with a learning or processing difference, they work harder to make sense of things and have to put up with social stigma because of their differences.

5. STRENGTHS, CHALLENGES AND HOPES

5.1. Introduction

The families were diverse in terms of their family structure, socio-economic status⁵ and the challenges of their different disabilities. In spite of this diversity, these 20 families exhibited remarkably similar strengths. And though their challenges were different, the overarching themes of their challenges also bore remarkable similarity. This chapter begins by highlighting their strengths. Next it discusses their challenges and the strengths with which those challenges were met. The Christchurch earthquakes gave us a unique window into the strength and resilience of these families. The chapter ends with their ideas of what they would like to see done differently to make life better for them.

5.2. Strengths

5.2.1. Love and closeness

The families freely spoke of their love for one another. They considered it to be one of their strengths. Two mothers described it like this:

Mother with a disability: We're very, very close and we're never afraid to show each other how much we love each other and we do lots of cuddles and stuff like that.

Mother with a disability: I think we are really plugged into each other, and really attuned to each other's, yeah, what our needs are.

This strong love was even evident when relationships were strained. One mother and daughter had frequent arguments, but, when the going got tough, their closeness was something that could be counted on:

Child, age 17: We come together when it's needed. Definitely. When things are bad, we become really close.

An eight-year-old boy talked about his extended family, many of whom live outside of Canterbury. He drew the following picture of them all holding hands to demonstrate their closeness.

Figure 1: Holding hands



5.2.2. Openness

The children and parents alike recognised their 'openness'. Here is how it was described by participants from two different families:

Child, age 12: Being straight up with each other about things. Being able to share whatever we want with each other.

Partner of a father with a disability: As a family we have no secrets, we're just completely open with each other.

5.2.3. Spending time together

Another frequently mentioned strength was spending time together. This was particularly valued by the children. They enjoyed doing things with their families. One eight-year-old girl drew the following picture of her and her mother at the school fair, selling the cupcakes they had baked.

⁵ We asked the parents their employment status, but we did not collect specific information regarding their household income. However, we were able to glean information regarding their standard of living during the interviews and, because many of the interviews took place in the families' homes, we were also able to observe their living conditions.

Figure 2: School fair



The children enjoyed spending time with their whole family all together:

Child, age 11: I think that something special about our family is that me, my Mum and my brother ... when we go and do something, we do it together and we have heaps of fun.

Child, age 8: Best moments of all is when the family goes out. Like one day all of us got in the van with Dad and we went to get Mum and [sister] and me some jandals. We just went out together. I just love those moments. We can't go on holiday ... because Dad's in a wheelchair. We can't go anywhere because he will be stuck in a car... I love the moments when we're out together – not just the four of us doing something. But I like it when Dad's there so there's five of us.

5.2.4. Recognising the need for individuality

Although the families valued closeness and spending time together, they also recognised the need for individuality. Here is how participants from two different families described it:

Child, age 12: We like hanging out with our friends, but separately. We'll [child and her Mum] go to the mall together, but she'll go her way with her friends and I'll hang out with my friends.

Partner of a mother with a disability: We have a lot of commonality, both in our upbringing and ... the whole belief system. We support each other... We do have different views on things as well. It's interesting. It's not like I'm living with my shadow.

5.2.5. Positive outlook/spiritual beliefs

As the previous quote mentions, shared beliefs such as their faith and spirituality were important to many of these families. It gave them hope. In a similar vein to faith were hope and optimism:

Father with a disability: Faith is a big thing for us.

Friend of a mother with a disability: She's always been quite optimistic.

5.2.6. Humour and play

Humour and play were recognised and valued by parents, children and family friends:

Friend of a mother with a disability: She's also this incredibly fun person as well. She's got a wicked sense of humour (laughs); she's really witty and that comes through in the cheekiness of the boys.

They recognised the need for taking time away from difficulties:

Partner of a mother with a disability: Just doing things that have nothing to do with this sort of thing [referring to difficulties related to the disability], like I play indoor football on a Thursday night, which is a nice sort of stress reliever. ... You get caught up in this and it sort of snowballs and it just gets more and more stressful so just having something to do outside of that.

5.2.7. Persistence

A common theme was persistence. In spite of challenges big or small, these families just kept going. One mother's disability was a source of considerable pain and often sapped her energy. Here is what persistence looked like to her:

Mother with a disability: Some days you wake up and you have so much energy ... other days you wake up and have no energy and I've got to deal with this girl... I just do it... I just get up and do it. Every mother has a bad day.

A father, who also experienced pain due to his disability, did not let it stop him from renovating his home:

Partner of a father with a disability: He renovated an entire house in absolute agony. He got to a point where he was vomiting from the pain. He would still keep going.

Another mother was pursuing a dream in an environment where some people told her she would not be able to achieve it. Here is how her friend describes her persistence:

Friend of a mother with a disability: She's got this perseverance and she's determined to make it [to her goal].

As a conversation with another family illustrates, family members helped each other to persevere:

Mother: [Explaining the interviewer's question about resilience] If things aren't going very well, like yesterday when mummy put the tree up and you all decorated it and then it fell down and it was a big sad loss, and a lot of work was wasted, what made us bounce back again as a family?

Child, age 6: We helped again.

Child, age 5: We put all the decorations on the table.

Child, age 8: And then today it was put back up again and we got to decorate it.

Mother: So we just pick things up and carry on again, don't we?

Child, age 8: Keep calm and carry on. See that picture frame there, 'Keep calm and carry on'.

5.2.8. Social support

The parents' disabilities sometimes restricted the activities that they could do with their children. The children spoke of those limitations, but also voiced their understanding of why that happened. As the following example illustrates, they appreciated the support that they were given by extended family and friends:

Child, age 13: Another thing ... was [the] beach, cause the sand his foot would just sink in and be really sore, but in [city name] we had great friends that ... knew Dad and how much pain he could bear and they would take us out to the beach to go swimming and stuff. So it was good to have Dad there to do like fun stuff, but also have friends to take us to places that Dad couldn't go.

5.2.9. The children themselves were seen as a source of strength

The parents' love for their children was a source of strength to the parents. One parent mentioned giving

up an addiction because of the birth of her son. Another mother put it like this:

Mother with a disability: I love my kids to pieces and they're what keep me going. ...My kids give me my strength.

A family friend put it this way:

Friend of a mother with a disability: I wonder if actually having children ... even though you're having trouble coping, the fact you have got a little person that is dependent on you pushes you to just keep going.

As the following quote illustrates, in families with more than one child, sometimes siblings were a source of strength for each other.:

Child, age 15: Relying on my brothers and sisters as well to just be there... We kind of just like told each other how we were feeling. We both felt the same way ... about things. So we could just talk about it and support each other.

5.3. Challenges

These families possessed a number of strengths which they brought to bear when challenges came their way.

5.3.1. Employment and economic challenges

Financial or employment challenges were woven into all but two of the families' stories. A common shared experience was living on a low income, either receiving a benefit (most commonly the Domestic Purposes Benefit), or just getting by with low-paid jobs:

Friend of a mother with a disability and a father with a disability: He manages on a small budget for food ... for three people. But I think a lot of us buy extras, but he doesn't.

Some families had to try to make ends meet while a parent was in hospital. Two fathers left their full-time jobs to look after their families while the mother was unwell.

Others spoke of how their disability interrupted their ability to work or pursue study. They spoke of how their disability restricted what careers they could choose. Some spoke of the extra financial burden posed by their disability.

Though the nature of their financial challenges varied, 18 families were faced with employment

and/or economic challenges. Their persistence was unmistakable in the face of this challenge. A common phrase in our conversations was: “We just got on with it.”

One mother lost the use of her legs due to a medical condition when she was 17 years old. Because it was not an accident, she and her family did not receive funding through ACC and any equipment or modifications to aid her independence needed to be paid for by her or her family. At the time, she was living with her mother, a single parent. Their home was not wheelchair accessible, so they needed to find another place to live. The following quote illustrates this mother’s ability to carry on in the face of an economic challenge:

Mother with a disability: We bought a house that was already wheelchair accessible because there was no funding... But the extra cost of that house compared to my Mum’s – she could not afford it. She was 62 at that time. So at 17 I had to have a mortgage on the rest of the house. My Mum still lives in that house. I am married, just finished that mortgage. ...For 20 years I’ve had ... [that mortgage] as well as our own house... It’s had to go ticking along in the background because there was no other options.

5.3.2. Adapting the ways things were done to accommodate the disability

Another challenge that all the families faced was adapting family life to accommodate the disability. As Chapter 4 highlighted, the challenges posed by the disabilities varied widely, but the families met these challenges with similar strengths.

As the following quote illustrates, the families were flexible and together they adapted to the changes:

Child, age 17: [Speaking of her mother after a brain injury] Like she’s just changed into a different person. It seems like she’s lost who she is. She’s changed.

Interviewer: So how has that made a difference for you?

Child, age 17: Me and my sister changed with her. We had to get used to the different things.

The following example illustrates how a baby adapted to assist her Mum:

Mother with a disability: This is where having no sense of vision was difficult. Again I had to find a way to gently drag the spoon up without getting it on to her, over her chin and into her mouth. And then after a while I got other things to help like touching my finger to her chin and then putting the spoon in above that. ‘Cause it’s easy to feed yourself when you can’t see but it’s quite difficult with another person and then after a while she would just grab the spoon and after a while she put her little hand on mine and guided the spoon to her mouth... It’s a really good little way that she adapted to help Mum who couldn’t see. ...I thought, ‘Shit, I’ll have to do all this’, but it didn’t occur to me that she would adapt and she began to adapt in her own little way to get the food in.

Several parents mentioned that they had taught their children household tasks and they spoke positively of their children’s self-sufficiency:

Mother with a disability: I have quite self-sufficient children. My five-year-old is very responsible. I’ve sort of taught her to do certain things ... younger than others do. You know, in the morning she’s probably got more things that she needs to do than most of her classmates, I would guess. In terms [of] that she is responsible to get herself dressed. She feeds the dog. She opens the garage. She takes the bags out to the car. She will open and close the gate.

The parents themselves often modified how they managed tasks. At times, they relied on support from people outside the family:

Mother with a disability: I had to do everything on the floor in terms of changing my babies. I would do that anyway but a lot of stuff had to be [done] on the ground. I can’t do those sorts of activities where you swing your child around ‘cause it makes me want to throw up. ...I learned how to conserve my energy. ...I was fortunate in that there was help available in terms of meals. I had people who [were] willing to look after my kids. I mean that was a godsend.

They also recognised the individual needs of the different family members and tried to support each other appropriately. One striking example was where the mother, the father and the child each had different disability needs:

Father with a disability: It's challenging when three of us has got a disability, plus they're all different. We have to have our thinking caps on. ...Well, with [child], because she's got two types, we've got to work out which is naughty and which is not naughty 'cause she doesn't really know what's naughty or what's not acceptable. 'Cause she's got a learning disability plus ADH[D] so we've got to ... explain it to her why she's getting told off. ...Say ... she pulls the cat out from under the bed and she'll think she's just grabbing it and taking it from under the bed but we have to tell her, 'That's not acceptable 'cause that can hurt the cat.' 'Cause her brain doesn't work like that; her brain works overtime and she moves quite fast so she doesn't have time to process things.

5.3.3. Emotional challenges

Woven throughout our conversations were emotional challenges.

Grief

In the case of the family where the father had motor neurone disease, a terminal condition, grief was an additional challenge to that family. As the following quote illustrates, the family spoke openly about emotions and grief was met with comfort:

Child, age 8: I start crying. I don't want him to die. Mum, you comfort me and I feel okay. I should enjoy the moments when he is here. I know he'll always be with us. ...I get quite emotional.

Guilt and frustration

Some parents expressed complicated emotions regarding how their disability affected their parenting:

Mother with a disability: Having a totally different relationship with my son to what I had with my daughter. I enjoy him so much more. I still have that guilt that I didn't have it with her. It's not so much guilt, it's just a shame that my mental illness wasn't diagnosed way back before I had her because I would have enjoyed her a lot more that what I did.

These feelings were dealt with in a variety of ways. Sometimes, frustration and guilt were met by learning to accept help from others:

Mother with a disability: Incredibly frustrating and guilt, lots of guilt, because you expect to be able to do those things. It's part of your role and it was

really difficult ... to realise that you couldn't do it on your own; you had to let others help. So you learn to give up your pride pretty quickly. You can't afford to be proud and you can't afford to say 'no' to help.

Sometimes it helped to 'look on the bright side':

Mother with a disability: I'm not as capable as I wish I were, for things like tramping in the bush and kicking a ball around in the yard and to not let that frustrate me. ...That's probably the biggest challenge and it's in your face. ... I've cried myself to sleep a few times but arguably kids, on the other hand, are a blessing. In as much as you barely have time to brush your teeth at night ... [much less] to wallow in your own [problems]. You know the words of the song, look on the bright side. It could be a whole heap worse; however, it's not fatal, but it's frustrating.

Some parents said they might gain benefit from talking to someone outside the family about these complicated emotions, but finding a suitable person was difficult. Professional services were expensive and finding just the right person in their social network was difficult.

Worry

One of the emotional challenges for children was worry:

Child, age 12: I was quite worried about what Mum was going to do... I was scared to leave her alone because she couldn't walk properly. I went out once and she almost fell over, so I didn't want to go out after that.

In particular, children worried when parents had been in hospital or were visibly unwell. The parents dealt with worry by offering reassurance:

Mother with a disability: [Speaking to her eight-year-old child] It seemed to me that you were worried about going to school because you didn't know who was going to look after me... I had to reassure him that my sister-in-law was going to look after me.

One child expressed worry when her mother was in hospital. This worry eased after spending time with her mother. In contrast, another mother did not want her children to see her when she was unwell. So while she was unwell and in the hospital she maintained her relationship with her children by sending them letters and faxes. Years later her daughter still remembers the little puzzles that her mother drew in the letters.

5.3.4. Getting appropriate support

Getting appropriate support was sometimes a challenge for families. Many parents valued their independence and found it difficult to ask for help:

Mother with a disability: I coped mainly by just shutting myself off and if I didn't have so much pride I could have asked for help in a lot more ways. And I know especially with my church that they're very open to helping. But a lot of the times I put a lot of pressure on myself to live up to the standard that I set myself, for being a mother and this is what I must achieve and, you know, it's not good enough for other people to bring meals over.

Information about their disability, information about how to access appropriate support and general information regarding community life strengthened families. For example, when the condition of one mother was first diagnosed, she received information related to her condition as well as information about support agencies and various social activities. However, not all the families had the same access to information or knew how to find the information. Two families stood out in their ability to access information. In one family, the mother had worked in the hospital, so when she required hospital services she was able to navigate the sometimes complicated hospital system. Another family didn't take no for an answer. The father was actively monitoring his disability support needs and anticipating possible future needs. He identified the support that was needed and then searched until suitable support was found:

Partner of a father with a disability: [Father] is always looking ahead as to what is going to happen. ...He doesn't sit back and just get given. He manages it. ...A lot of other people sit back and say, 'Well that's what the medical people say.' In fact that might not be necessarily right at all. ...Not in a bad way. If someone says no, you just go away and research it. No doesn't work for us.

5.3.5. Involvement with Child, Youth and Family

Another challenge for some families was having their children removed from their care or facing the risk that their child might be removed. One couple who went through this process and managed to retain custody described it as "one of the most stressful things you can do as a parent". A father whose children were in the care of Child, Youth and Family described his feelings:

Partner of a mother with a disability: It is very, very difficult. I know it's difficult enough for me but it's doubly more difficult for [mother with a disability]. ...We miss them very, very much. These are their formative years growing up and we're missing out on a lot of all that. Just the everyday things so it's very, very difficult. I don't probably show it as much as I should.

One mother has made her parents the legal guardians of her child to avoid the risk of having her son removed from her care should her suitability as a parent be questioned. At the time of the interviews two of the families had their children in the custody of Child, Youth and Family. We will share one family's story. This family includes a mother, a father and two daughters. To begin with they all lived together. Then the parents split up and the two little girls lived with their mother. The mother received home assistance because of her disability. Complaints were raised concerning her ability to look after her daughters. Her children were removed from her care and the father was not consulted until after the children had been removed. Here is how they tell their story:

Partner of a mother with a disability: Well it still is difficult to this day 'cause the children were ... actually taken off her. It was more health and safety 'cause of the sight issue, because of them being so small, that's the reason why. So that is difficult 'cause I don't think any normal, average parent wants their children taken away from them. And I still have reservations about the way it was done and that I think [mother with a disability] could have been offered a lot more help than what she was getting [rather] than taking the children away. ... This wasn't an ongoing thing, this was the first strike sort of thing and that was it, done, taken away...

Interviewer: What qualities do you think the four of you have that helped you be resilient in those couple of huge changes where you used to live together and then you didn't and [then the children were removed from their mother]?

Partner of a mother with a disability: I think it's the love that we have for each other. I still have some love for [mother with a disability]; she's the mother of our children and I think it's the love that [they] still have for us 'cause we keep in contact as much as we possibly can with them, by letters

and phoning and getting down there as much as we possibly can. [Mother with a disability] probably goes down there more than I can. So there's that bond that's never been broken so I think that's probably what keeps us together.

Mother with a disability: I agree with that because even though our relationship didn't work out, we stayed ongoing in some kind of relationship or friendship for the girls. And it's for them, because even if we're not living together and even if we're not in a relationship, the girls still need both of us. To me that's resilience because it produces the resilience in them and it's really important that that's ongoing.

Their story emphasises the central role that love plays in family life. It also highlights the need for more support for parents with disabilities in matters of care and protection. For example, when the mother and father were living together the father assisted with a variety of disability-related support, such as advising her on how things looked. The mother took considerable care in laundering the children's clothes, but could not see if the laundered clothes were stained. So she asked her partner to check the children's clothes. After the parents separated, the mother received home help. However, the home help worker did not assist her in the same manner. Subsequently, complaints were made to Child, Youth and Family because the children were arriving at daycare in dirty clothing.

Other matters were raised that also could have been addressed by increasing the mother's level of disability-related support. However, increased disability support was not suggested as an option and the decision was made to remove the children from her care.

5.3.6. The Christchurch earthquakes

On 4 September 2010 Christchurch was surprised by a 7.1 earthquake in the early hours of the morning. This was followed by months of aftershocks. Then on 22 February 2011 in the middle of the day a 6.3 earthquake rattled the city and claimed the lives of 181 people. Again, there were more months of continuing aftershocks and another 6.3 earthquake occurred on 13 June which caused additional damage to the city.

Needless to say, these natural disasters caused widespread distress and interruptions to many facets of life, including the progress of this project. We

paused our recruitment process and data collection process for a season to give families time to regroup. As researchers we were dealing with our own circumstances and, like many in Christchurch, we experienced "earthquake brain", which interfered with our concentration. Parents who were caring for children faced the challenge of looking after their children while distressed and, for many, their homes and jobs were also in disarray.

This section takes the children's perspective and focuses on what the families did to help the children cope with this crisis.

Being together

When talking about their ordinary life, the children valued being together. During the earthquakes and their continuing aftershocks, being with their family was instrumental in helping them to feel better. Both young children and older children took comfort in being physically close to their parents. The following examples are from three different families:

Child, age 8: I grabbed on to Mum.

Child, age 15: The first few nights I slept in Mum's bed with her, because I was way scared and then I went back in my bed but I slept with the radio on, 'cause our house creaks a lot and there's birds on the roof and stuff.

Child, age 17: Mum let me sleep in her bed for ages! Every night that I was here. ... So I didn't feel completely alone.

Reassurance and nurture

The children also spoke of being helped by hugs and reassurance:

Child, age 12: I cuddled with Mum sometimes. And people reassuring me.

They also spoke of special things their parents did to comfort them:

Child, age 15: [Mum] bought us yummy food.

Mother with a disability: Earthquake food. We ate our feelings (laughter).

Social support

Sometimes the extra nurturing involved people outside the family:

Child, age 8: We had a barbeque on the street and it just cheered me up.

Extended family and friends also provided practical support:

Child, age 11: I went into shock but the thing I think that helped us not be so worried is our neighbour [name], he came over and he checked everyone up the driveway and [saw] if they were okay and said if it happens again he's got water and stuff like that and that really helped. ... My uncle [name] he put the cabinet in so it would be earthquake safe.

Helping the community

In addition to receiving help from others, some of the children helped others in the community:

Child, age 11: We went and helped get all the sand away ... it was amazing how much sand came up under the ground.

Another child's story of helping out in the community illustrates his family's cohesion and their shared beliefs:

Child, age 13: We've got our family motto which is 'We're the [family name] and we help people'. So when the earthquake hit we were quite happy to sit in a room and [Dad] would drive. He drove around the neighbourhood to go and see if everyone was alright and then we went down and we went out to a BP station and Civil Defence was there and so we got heaps and heaps of boxes of bottled water and we just walked around the street knocking on people's doors and giving them water. Just so they could drink and stuff like that. Just kind of caring.

Being brave for each other

Family members tried to be brave for each other.

Children were calmed by their parents' 'brave faces':

Child, age 17: The Boxing Day [earthquake] wasn't so good, but Mum was really helpful for that - even though she was petrified of them... She acted really brave, 'cause we were in the [store name] and stuff was flying off the shelves and I sat down on the ground and started crying and I couldn't breathe and Mum was telling me it was alright and took me outside. She was just trying to be strong even though I could see she was scared as. She was probably just as scared as me. But she was telling me it was okay... That was really good... And her brave face worked.

Children also tried to be brave for their parents:

Child, age 8: Scared for Mum, not for me ... because it shook and she had a broken leg. ... I ran to the door and then ran back. ... I ran back inside to get the crutches. And I got 'spicy teddy'.

Humour and play

The families used humour to lighten the severity of the earthquake. Families with young children told them that "the house is having a party" or "the earth is farting". Young children's play incorporated the earthquake.

Partner of a mother with a disability: With the Duplo they've built, they'd smash them anyway, but they'd say, "It's an earthquake!" And smash it down.

When asked about the earthquake, one child was quick to recall one funny aspect. He thought it was funny watching his Dad running around without his artificial leg:

Child, age 13: It was funny though because we were in the room and I was already awake before the earthquake happened. So ... it started and I ran to the doorway and Mum comes whizzing past me, 'cause ... my eyes were used to the darkness ... then Dad said, 'Ah my leg' - and he was running around with no leg on and that was kind of funny.

At the time of the earthquake, the father made light of his experience, to the delight of his three sons. However, underneath the humour lay a number of issues:

Father with a disability: Such an event was out of this world really, so you switch into survival mode. And my survival mode was directed towards the kids, as most parents with young kids would be. So on the night of the earthquake, I jumped out of bed and started to run to their room and of course, I hadn't put my leg on and so I hit the floor at a great rate of knots and had to crawl up the hallway. At the time you just acted on auto pilot, but afterwards I thought about it and I had that awful sudden realisation that I was of no use to my children or to my wife. That she was the one that would have to go and get them all out of the house. So that hit me for a bit. It was like, 'Oh my goodness', and for no other reason other than the safety thing. ... There is a strong possibility that I might not be able to get out myself. ... Not being able to get to them was ... you feel responsible for your kids and like to know that you can keep them safe. And to know

that I couldn't was, 'Oh my goodness'. ...But I was actually the safest person in the house on the floor!

Interviewer: So how did your family cope during the earthquake? How did your kids handle the fact that you [were crawling around without your leg]?

Father with a disability: Oh they laughed their heads off. I made a joke out of it. A bit of humour which diffused it. If they were a bit older they might have seen it a bit more seriously. ...They are still making jokes about me coming over to them on my hands and knees. ...Humour was the best. But they did get affected by ...the earthquake itself. Waking up like that gave them a fright so it took a month to get them back into their own room.

Information and teaching

The children were comforted by knowing what to do in an earthquake:

Interviewer: So what kinds of things did you guys do to help [child, age 8] not be so scared?

Father with a disability: Told her what to do when there was an earthquake.

Some parents also engaged in teaching their children about earthquakes. Here is how one parent and child described what their family did to learn about earthquakes:

Partner of a father with a disability: Daddy helped set up a system to measure earthquakes.

Child, age 5: We had blocks and balloons under the tree and we built towers into the shape and the blocks fell down...

Partner of a father with a disability: We had lots of science experiments, didn't we?

Some children appreciated the learning, but one eight-year-old mentioned being distressed by receiving too much information.

5.4. Hopes: Ideas for how support could be improved

Several participants mentioned the importance of looking at families holistically. As the following quote highlights, a disability affects the whole family:

Partner of a father with a disability: I think there is a lack of awareness that how one disabled person within a family can impact the entire family and certainly the spouse... There is still an expectation on you to be able to carry on living normally and do what they might expect. I think the disability doesn't just stop at the person who's got the disability. It permeates the rest of the family as well.

Participants would like support organisations to include other family members. In particular, they wanted more support for fathers:

Partner of a mother with disability: We sat down for 20 minutes and they [an agency focused on supporting fathers] asked me what sort of things I might need ... and then they said, 'Well, we don't offer those services,' and I said, 'Okay.' ...Yeah so it's been a bit lacklustre for support for myself so I just try and do things. And it's hard too because ... none of my sort of guy friends, they don't have kids or anything like that and so they don't really understand.

Mother with a disability: [Speaking of a service assisting her baby] All the focus is on the baby. There's very little focus on the mother and even less on the father. So whether the father is struggling or not, it's not even in the picture. It's not even a consideration.

Some participants experienced a range of feelings about the issues they faced in family life, but struggled to find avenues for sharing those feelings with others. One mother wished that there could be more openness about talking about struggles with parenting:

Mother with a disability: There is a lot of judging between other mothers ... because there is so much secrecy around, you know, the issues around the parenting, the emotional stuff. That's why I'm really keen to do this study. I wish there was more openness. More openness about the struggles with it.

Interviewer: If it were more open how would that be of benefit?

Mother with a disability: I think that I personally would have gone for help a lot sooner than I did.

Some participants said others needed to take time to listen and support people in their goals:

Friend of a mother with a disability: I don't think it should be so much a struggle to get people to listen and I think it has been for her. The attitude of: ...'Well, if you can't do this, why don't you ... leave and forget it?' ...I think people forget about all the other people out in the world who've struggled and achieved and done wonders and that everyone needs a fair go.

One child wished for more clarity and less paperwork:

Child, age 12: Try to help them first and then getting to the details after. ...Because when you ask for something they [disability support agency] dump a whole lot of stuff on you first without telling that this is going to happen and that is going to happen. ...We had a big booklet just to decide what we wanted and they wanted to know on the spot.

When asked what could be made better, one mother was quick to say how fortunate she felt to be living in a country that offered so much support. She echoed the sentiments of many of the families who expressed satisfaction with many services they received.

5.5. Summary

This chapter highlighted the families' strengths, challenges they faced and what they would like to see changed. Examining their strengths in light of

keys to resilience, framed by Walsh (2006), we can see strengths in all three domains. Regarding family belief systems, the families spoke of their faith, maintaining a positive outlook and persevering. Their family organisational patterns included an ability to be flexible and adapt, with a closeness that included an awareness of the need for individuality and support from extended family and friends. They communicated openly, expressed love and affection, used humour and worked together to solve problems.

The challenges they faced were similar to those mentioned in the literature: (a) economic challenges; (b) disability-related challenges; (c) emotional challenges; and (d) challenges in accessing appropriate support. Their strengths stood them in good stead when they encountered challenges, including the Christchurch earthquakes. Although their economic challenges were met with persistence, many still remained in low-income situations.

The chapter concluded with their ideas for improvement. They would like others to know that one person's disability affects the whole family. They would like services to be holistic and family-centred. In particular, they would like more attention paid to fathers. They would like more avenues for talking about their struggles. They would like more clarity around support services and less paperwork. They also expressed satisfaction with many of the services they had received.

6. DISCUSSION AND CONCLUSIONS

This chapter discusses how the findings from this report can be incorporated into our existing knowledge and common practices, and highlights areas for future research.

6.1. Introduction

This project was motivated by our desire to learn more about the experiences of families that include a parent with a disability. We begin this chapter by summarising the factors that influenced the wellbeing of the families in this study and the challenges they faced. Next we discuss the question, “What can communities do to be more supportive of families that include a parent with a disability?” This discussion is structured around five principles to bear in mind when engaging with families that include a parent with a disability. The chapter concludes by discussing the strengths and limitations of this study and by providing some ideas for future research.

6.2. What factors contribute to the wellbeing and resilience of families that include a parent with a disability?

The factors that contributed to the wellbeing and resilience of the families in this study can be viewed in three areas: (a) family qualities, personal attributes and processes; (b) community resources; and (c) financial resources.

Using the model of resilience posed by Walsh (2006), we can see that the families’ individual qualities and personalities, and processes, contributed significantly to their wellbeing and resilience. The families spoke of loving one another and expressed a strong sense of commitment to one another. Their shared belief systems and positive outlook kept them ‘bouncing forward’ in challenging circumstances. Their patterns of flexibility and connectedness helped to buffer them when crises came their way. They readily communicated a range of emotions and showed considerable initiative and perseverance.

To varying degrees, community resources played a role in the families’ resilience. According to Mirfin-Veitch

(2010), “to experience community participation, one must feel a sense of place in one’s community, be involved in a variety of networks, and feel a sense of belonging” (p. 96). Some families in this study actively participated in community life. They played sport or were involved in their church, their neighbourhood or their children’s school. Other families were more insular. According to Mirfin-Veitch, families that are socially isolated are more at risk than families that are experiencing community participation. Future research could explore why some families participate in community life and others end up being more insular.

According to the literature (eg, Benzies & Mychasiuk, 2009; Seth-Purdie et al, 2006; Walsh, 2006) financial resources play an important role in family wellbeing and resilience. However, for 18 of these families, financial resources were a challenge rather than a protective factor. More in-depth research exploring what families themselves think may help reduce this challenge.

6.3. What challenges do these families face?

The families managed a variety of disability-related issues: (a) mobility difficulties; (b) mental health conditions; (c) chronic pain; (d) sensory impairments; and (e) differences in learning and processing. Many of the families juggled these issues while experiencing financial hardship and struggling to find appropriate support. Some families had to maintain family life without having custody of their children. These challenges echo those mentioned in the literature: Morris and Wates (2006) described challenges posed by disabilities, as well as poverty, unemployment, poor housing, negative attitudes and discrimination. However, this study also explored how the families utilised their strengths when they were confronted with challenges.

The families met ongoing difficulties with persistence and adaptability. They supported each other and communicated openly. They laughed together. However, some challenges remained despite their strengths. Some children still remain in the care of Child, Youth and Family. Financial hardships persist. Families are faced with the ongoing challenge of adapting as children grow and disability needs change. In these areas, family, whānau and the wider community can be of support.

6.4. How can communities more effectively support families that include a parent with a disability?

Resilience is forged in the midst of challenges. It is not forged on our own, “resilience is forged through openness to experiences and interdependence with others” (Walsh, 2006, p. 5). Extended family, whānau and the wider community can play a key role in fostering the wellbeing and resilience of families that include a parent with a disability. Several participants expressed their appreciation for the ways that extended family, friends, neighbours and organisations have supported them. In these instances, the people interacting with the families showed a personal interest in them, demonstrated sensitivity to the challenges they were facing and addressed their needs appropriately. Mirfin-Veitch (2010) and Thomson et al, (2010) described how these types of supportive relationships typically resulted in positive outcomes for families.

We propose five principles which can serve a basis for establishing and maintaining supportive relationships with families that include a parent with a disability.

6.4.1. Appreciate the uniqueness of each family

Whilst it may seem obvious to say that every family is unique, it is critically important to emphasise the diversity within families. Families have different structures, different ethnicities, different social and educational experiences and different experiences of disability (Ministry of Social Development, 2004).

Implications for practice

While general principles can be applied to many families, there is no “one size fits all” model. Take time to get to know the specific family you are engaging with. As noted by Thomson et al, (2010), it does take time to get to know individual families. However, the likely positive outcomes are well worth the time invested.

Implications for research

Families have different preferences and needs. Because of their different preferences, research designs need to be robust enough to be flexible. For example, we designed the project intending to first interview the families as a group and then as individuals. Because we prioritised the families’ preferences, sometimes our initial interview was with an

individual parent with a disability, rather than a family. Also, as it turned out, only one child ended up being interviewed on her own. In some cases the parents chose to do a family group interview rather than individual interviews. In the other cases, the children declined an individual interview.

Because families have different needs, researchers would do well to anticipate what some of these needs might be. For example, because we anticipated a range of literacy abilities, we had prepared a variety of information sheets, some with pictures and some without. Although this took extra preparation time, we were rewarded for our efforts with smiles from people who enjoyed the pictures and from children who were pleased to be able to choose the length of the consent form.

6.4.2. Be mindful that disabilities co-exist with abilities and strengths

By concentrating only on a family’s problems and a family’s failings, we ignore the fact that it takes a positive approach in life to succeed. ...All families have strengths. And, all families have challenges and areas of potential growth. (DeFrain & Asay, 2007, pp. 3,5)

When engaging with families it is important to keep their abilities and strengths at the forefront because these will buoy them up when challenges come their way. The families in this study demonstrated a wide range of abilities and strengths as did families in other studies. One of the most commonly mentioned strengths was love (eg, Mirfin-Veitch, 2010; Office for Disability Issues, 2005; Stevens et al, 2005). Other strengths included the ability to adapt and change (eg, McDonald, 2008), emotional expression and emotional regulation (eg, Wilson & Crowe, 2009), and initiative and persistence (eg, Munford et al, 2008). These strengths are cited as factors that contribute to family resilience (Benzies & Mychasiuk, 2009; Walsh, 2006).

While keeping their strengths in full view, it is also necessary to be sensitive to the challenges posed by their disabilities. This study, along with previous studies, points to a need to increase the level of disability awareness within the wider community (eg, Morris & Wates, 2006; Olsen & Clarke, 2003). The Ministry of Social Development has recognised this need and in 2010 the Government set aside \$3 million over three years to work “with employers, educational

and health services, community organisations and the media to develop a programme of activities that raise public awareness of the issues facing disabled people in New Zealand" (Ministry of Social Development, 2010, para. 2).

Implications for practice

Professionals often begin engaging with families in response to a perceived problem. Thus, establishing and maintaining a strengths-based focus can be a challenge. However, as Walsh (2006) has stated, "it is essential for professionals to hold an optimistic bias, identifying and building on family strengths and potential to master their challenges" (p. 132). Solution-focused therapy offers some strategies for moving towards a more strengths-based focus. For example, noticing when the problem is lessened or absent provides insight into how to keep the problem at bay (eg, Wehr 2010).

It is also crucial for practitioners to seek to increase their level of disability awareness. Certain professions do not necessarily incorporate disabilities education into their professional education programmes, so individual practitioners may need to be creative and spend extra time learning about the topic.

Implications for research

As in practice, problems are often the focus of research. The existing literature clearly highlights the challenges that families face, but it would be worthwhile to pay more attention to what is going well for families that include a parent with a disability.

6.4.3. Safeguard families' downtime and provide opportunities for family fun

Spending time together and enjoying loving relationships are well recognised as important characteristics of family wellbeing (eg, Seth-Purdie et al, 2006). Humour and play help to foster resilience (O'Connor, 2010; Patterson, 2004). The families in this study valued time together and spoke often of laughing together and having fun. Spending time together having fun helps to build family resilience. However, living with a disability poses a number of challenges, and many of these are time consuming. Extended family, whānau and the wider community can play a vital role in providing opportunities for families to have fun together.

Implications for practice

Appointments with professionals, time spent in hospitals, time spent in therapy and the demands of family life can crowd out time for fun. When suggesting interventions for families, it is important that professionals safeguard families' downtime.

Implications for research

Participating in research takes time and time is a valuable resource for families that include a parent with a disability. It is likely that families are sharing their downtime with researchers. Thus, it is important to value the participants' time and to create an environment that enables the participants to be at ease and, hopefully, to enjoy the research process.

When Munford et al (2008) interviewed families in their homes they were mindful of the time that the family was spending. They assisted with "tasks such as folding washing, holding babies, doing dishes and help with shopping" (p. 337). They considered that "these tasks serve[d] a number of purposes, including forming part of the reciprocity built into qualitative research" (p. 338).

While such practical assistance may not be suitable for every project, valuing participants' time and establishing reciprocal relationships is crucial. For example, we attended to the give and take of relationships by taking on the roles of guest or host in the same manner that one typically does in other daily situations. We chose the interview locations in conversation with the participants. Some chose to have the interviews in their own homes. In those cases, we took on the role of guest and often brought small gifts such as flowers or baking, as is customary for a guest. Other times the participants chose to meet in a restaurant or café. In those cases, we took on the role of host, and paid for the cuppa.

Establishing reciprocal relationships and valuing participants' time is a delicate balance because in some cases it can take time to develop rapport. For example, there were three children (from three different families) who were noticeably nervous during the initial interview, however they gradually relaxed during the course of the interview. If the interviewer had spent more time getting acquainted prior to the initial recorded interview, perhaps the children would have been more at ease when the interview began. However, extending these interviews to include informal playing would have taken

more of the parents' time. Future projects could be structured so that they include extra time getting to know the children, but still safeguard the parents' time.

In addition to safeguarding families' downtime, researchers can make participating in research an enjoyable experience. For example, one little boy, who was noticeably nervous during the interview, relaxed and had fun while drawing a picture.

6.4.4. Recognise that families function as a unit

In a family, a parent's disability is not theirs alone; family members adapt and work together to meet the demands of family life. Support and interventions targeted at the individual miss out on the opportunity of harnessing the strengths of a family unit.

Providing support is often tied to one's view of disability. The literature has suggested two common ways of viewing disability: the medical model and the social model. Using the 'medical model' lens, one views disability as residing within an individual, and focuses on supporting individuals to cure or alleviate their disability. Using the 'social model' lens, one views disability as residing in society, and focuses on promoting change within the wider community by reducing barriers and fostering inclusion. Shakespeare, Lezzoni and Groce (2009) have suggested that both models benefit people with disabilities.

The participants in this study have suggested that disability should also be viewed through a family lens. They experienced disability as residing within an individual but affecting and belonging to the whole family. When a parent has a mobility difficulty, it is not only that parent who expends more time and energy to go places, other family members do so as well. When a parent lives with a sensory impairment, the whole family's communication patterns are affected.

Implications for practice

This view of disability suggests that organisations should also consider the needs of family members when they are supporting an individual. Leadbitter (2008) also recommends providing support from a 'whole family' perspective. Some parents with a disability in this study expressed their distress at having their partners excluded from meetings with professionals. In particular, they would like more attention paid to fathers. They would like to see communication between professionals and fathers improved, and more services designed to support fathers.

Implications for research

This call to pay more attention to fathers is also relevant to research. Much of the research involving parents with disabilities has focused on mothers' experiences. Although it was not our intention to focus primarily on the experiences of mothers with disabilities, we ended up recruiting 18 mothers and only two fathers. It may be more difficult to recruit fathers with disabilities, and if that is the case, it is fitting for researchers to take deliberate steps to include fathers.

6.4.5. Be aware of the effects of poverty and social isolation

People with disabilities face higher costs due to their disability, and they typically earn less money than their non-disabled peers (Disability Resource Centre, 2010; Morris & Wates, 2006). A number of parents with disabilities experience criticism and social stigma (eg, Olsen & Clarke, 2003; Wilson & Crowe, 2009). Such experiences can lead to social isolation.

Poverty and social isolation are challenges in themselves. When families that include a parent with a disability are facing numerous challenges, it may be that poverty or social isolation is the root cause rather than the disability itself. When families are well resourced financially and socially, they are better able to meet the day-to-day challenges posed by the disability.

Implications for practice

When working with low-income and/or socially isolated families, disability support will be most beneficial when coupled with interventions that target the broader issues of poverty and social isolation.

Implications for research

The combination of a low income and disability-related support needs created social barriers for some of the families. It was difficult to find free activities with appropriate disability support and/or it was difficult to find money to pay for disability-friendly activities. Some of the families with more financial resources also expressed a desire to find disability-friendly activities. The families said that suitable, affordable activities might exist, but they were unaware of them. Gathering information on such activities and making it readily available to families could make a useful research project.

6.5. Strengths and limitations

The report is based on interviews with 60 participants exploring family life from multiple perspectives. The study was designed as a multiple case study and it included 20 cases. By gathering this information, we sought to gain new insights about how communities can better support New Zealand families that include a parent with a disability. When viewed within the confines of its intention, this study provides some valuable information. Therefore, we wish to be clear about its strengths and limitations.

Case studies are often criticised because the results cannot be generalised to “a broader clinical population” (Roth & Fonagy, 2005, p. 25). Studies that aim to make such “statistical generalisations” (Yin, 2003, pp. 32–33) begin by selecting a representative sample from a specific population and then generalising the findings to that population. Making broad statistical generalisations was not our aim. That is not the purpose for which case studies are designed (eg, Roth & Fonagy, 2005; Yin, 2003).

The aim of case studies is to provide “rich, specific descriptions” and “arguments about the generality of his or her findings” so that researchers and readers can use their own “reasoned judgment” about how to apply case study findings to other similar situations (Kvale, 2007, p. 127). Yin (2003) refers to this as making “analytic generalisations” (pp. 10, 32–33). Analytic generalisations often take the form of strategies or guiding principles. One of the strengths of this study is that common themes were found amidst multiple viewpoints and across a wide spectrum of disabilities. By providing a variety of case examples that shared common themes, the reader is well equipped to use this report to develop other strategies and principles specific to his or her circumstances.

Another strength of this study is that we spent time getting to know each participant well. As is common in qualitative research, the goal of our interviews was “to generate a depth of understanding, rather than breadth” (Rubin & Rubin, 2005, p. 30). Because of a desire for depth, rather than breadth, qualitative studies tend to be significantly smaller than quantitative studies. Thus they are often criticised for having too few participants. Once again, this criticism stems from a misunderstanding about the sort of generalisations that are intended to be made from qualitative case studies.

The findings from this study are not intended to be used to extrapolate what is happening in other families

throughout New Zealand. Rather, this study is intended to give people sufficient reason to pause and to consider the situations of these specific families in light of relevant literature. And then given what has been learned, our hope is that this knowledge can be put to use in order to promote the wellbeing of families that include a parent with a disability.

6.6. Future research

Because there is a shortage of research involving parents with a disability, there is a broad scope for future research. In particular, there is a lack of New Zealand research involving fathers with disabilities and children who have a parent with a disability.

Given the challenges that these families face, it is critical that research results in a practical outcome for families. For example, although there are a number of disability support services in New Zealand, the families in this study have identified a need for easily accessible family-focused services. In the United Kingdom, Leadbitter (2008) has created a web resource to enable practitioners to practice from a ‘whole family’ perspective. This resource summarises research findings and provides links to United Kingdom funding, resources and services. Future research could help develop a similar resource that provides information for families and practitioners.

6.7. Closing remarks

Munford et al, (2008) reminded us of the importance of a balanced view of disabilities. People with disabilities should neither be rendered invisible nor placed under too much scrutiny. We began this report by drawing a sharp line between parents with disabilities and parents without disabilities. This report is now drawing to a close and it is time for that line to be erased. The focus of resilient communities is to build strong connections, not to draw sharp distinctions. It is in the context of relationships that disabilities take their rightful place: a back seat to human connections. The presence of a disability within a family needs to be acknowledged and supported, but it does not need to set families apart. We will close this report with the words of an 11-year-old participant:

I like spending time with my brother... Even though we've got disabilities, it doesn't matter. ...Even though we struggle with some things ... when me, Mum and my brother are spending time together it's like we don't have disabilities.

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APPENDICES

Appendix A: Descriptions of the disabilities represented in this study

Disabilities related to mental health

Mental health disorders disrupt how a person thinks, feels and acts (National Alliance on Mental Illness, 2011). To be diagnosed with a mental disorder, one's daily functioning has to be significantly impaired. According to the 2006 New Zealand Mental Health Survey, "Mental disorder is common in New Zealand: 46.6 percent of the population are predicted to meet criteria for a disorder at some time in their lives, with 39.5 percent having already done so and 20.7 percent having a disorder in the past 12 months" (Oakley Browne, Wells, & Scott, 2006, p. xix).

In this study, eight mothers identified themselves as having a mental disorder. One described it as a mental illness. The other seven gave specific names to their disorder. Two experienced post-natal depression and post-traumatic stress disorder. Two experienced depression. One experienced anxiety. Two experienced bipolar disorder. In addition to having bipolar, one mother also had obsessive-compulsive disorder and borderline personality disorder.

Anxiety

We are all familiar with feelings such as fear and worry. People who experience an anxiety disorder feel "intense, prolonged feelings of fright and distress for no obvious reason. The condition turns their life into a continuous journey of unease and fear and can interfere with their relationships with family, friends and colleagues" (Canadian Mental Health Association, 2011, para. 1). One mother in this study mentioned that she experienced a period of anxiety in the months following the birth of her first child:

Mother with blindness describing her anxiety: When [firstborn] was a baby I was very anxious about feeding her because I couldn't see to get the bottle in her mouth. I remember that and it took a bit of practice. ... But I think I actually had a bout, about two days of acute anxiety after she was born. ... I could do everything else for her but I was really scared that I wouldn't be able to get food into her. I had real anxiety around that and that lasted ... a

long time. ... And after a while I just got the hang of it. Sort of couldn't understand, well, why was I so worried about it?

According to Oakley Browne et al (2006) anxiety disorders are among the most common mental disorders, with mood disorders being the second most common. They have estimated the lifetime prevalence rate for anxiety disorders to be 24.9 percent in New Zealand (p. 57).

Bipolar disorder

Bipolar Support Canterbury (2005) provided the following definition of bipolar:

This is a recurring disorder which affects a person's mood. There may be extreme mood changes for no obvious reason, with episodes of uncontrollable energy (mania, hypomania or 'high') and episodes of depression ('low'), and/or mixed mood, and periods of stable mood. (para. 1)

Two mothers in this study had bipolar disorder. Here is how they described bipolar:

Mother with bipolar: It goes both ways. It falls into depression, and it goes up being manic. Depressed means ... less energy, depressed, dark ... not thinking properly, being upset, not seeing any positivity in future or anything, and feeling not able to act. ... The other way is manic, is being kind of out of control, being really fast, lots of ideas. ... Some are quite genius, but not for long. ... Anger with the family, partners. ... Not sleeping, and being just really wild and following ideas they are ridiculous. ... It's not a nice feeling to be manic or depressed. It's really hard work. And it's a lot of stress and pressure on the family.

Mother with bipolar: When you're on a high it's really good (laughs). You're indestructible and everything is just so good and so sweet and you're just running round, like I don't know, like you get your housework done and just running round like a headless chook really, running here and there. When you have your lows it's a struggle to get out of bed. It's a struggle to look after the children. Yeah the lows are horrible.

The 2006 New Zealand Mental Health Survey indicated a lifetime prevalence rate of 3.6 percent (Oakley Browne et al, 2006, p. 62).

Borderline personality disorder

Borderline personality disorder is characterised by “pervasive instability in moods, interpersonal relationships, self-image, and behaviour” (National Institute of Mental Health, 2010, para. 1). Symptoms include: “1. fear of abandonment; 2. intense mood shifts; 3. impulsivity; 4. problems with anger; 5. recurrent suicidal behaviours or self-injurious behaviours; and 6. patterns of unstable and intense relationships” (Hoffman, 2007, para. 1). It mostly affects young women and the intensity of the symptoms often diminishes with age (Grohol, 2010). According to Lieb, Zanarini, Schmal, Linehan and Bohus. (2004), 1–2 percent of the general population is affected by borderline personality disorder (p. 453).

One mother in the study was diagnosed with borderline personality disorder. She described it like this:

Mother with borderline personality disorder: I tend to be overly sensitive to things. So if I've got a friend and I've said something to them and I think I've offended them (when I haven't but I think I've offended them) and I haven't heard from them for a few days, I get upset because I think I've offended them. Like when I try and stand up for myself I tend not to because I don't want to upset people. ... What the average person would just let go and go 'Oh yeah', I don't. I take it on board and I get highly distressed over it.

Obsessive-compulsive disorder

Obsessive-compulsive disorder is an anxiety disorder accompanied by repeated, intrusive thoughts, feelings, ideas or images (obsessions) which drive people to do certain actions (compulsions) in an attempt to rid themselves of the unwanted obsessions or to reduce their level of anxiety about them (eg, Choi, 2009).

One mother in this study had obsessive-compulsive disorder. Here is how obsessive-compulsive disorder affects her daily life:

Mother with obsessive-compulsive disorder: It's like when you hang your washing up, I like my pegs to match, picky little things like that. When I hang my towels up, I like them all to be a certain way. ... To me if a towel's got a picture on it, it's got to be the right way. Just stupid little things like that, that most people wouldn't bother them, but to me it's got to be so, so. Otherwise it just annoys me and I've got to go and re-do it.

She saw it as causing more difficulties for her daughter than for herself:

Mother with obsessive-compulsive disorder: It just does her head in because I'm so picky. Everything's got to be so, so. ... Like I go into her room and I can't handle a mess. It irritates me; it makes me quite agitated ... so nagging and stuff like that. But honestly it affects her more than me.

The 2006 New Zealand Mental Health Survey indicated a lifetime prevalence rate of 1.6 percent (Oakley Browne et al, 2006, p. 62).

Post-natal depression

Post-natal depression is a type of depression that affects women, and occasionally men, after the birth of a child. Here is how one mother in this study described her post-natal depression:

Mother with post-natal depression: The post-natal depression was feeling that I couldn't cope. Feeling really sorry for him [her baby] because he got this really crap Mum [laugh]. He would be better off with someone else. I just didn't have what it took. He would suffer his whole life. Just no light at the end of the tunnel. Just an overwhelming sense of responsibility that I couldn't measure up to. And just feeling hopeless.

The New Zealand Mental Health Survey did not include a specific category for post-natal depression. Prevalence rates from other countries vary from 2 percent to 25 percent, with a majority of articles reporting “an average of 13 percent” (Miles 2011, p. 221).

Post-traumatic stress disorder

In addition to experiencing post-natal depression, two mothers in this study also experienced post-traumatic stress disorder in response to difficult childbirth experiences. The symptoms of post-traumatic stress disorder are typically grouped into three categories: (a) re-experiencing symptoms; (b) avoidance symptoms; and (c) hyper-arousal symptoms (eg, National Institute of Mental Health, 2009).

Each of those symptoms is included in the following description by a mother in this study:

Mother with post-natal depression and post-traumatic stress disorder: When [baby] was born, it was ... a

pretty bad birth and stuff. ...I re-live it in dreams and in flashbacks ... during the day. And, in the worst ones, sometimes I think I'm back there. ...It's so bad that I see and I hear and I smell things like during the birth. ...It's like being on an adrenalin rush all the time and always being alert and anxious. ...There's an avoidance bit, too. ... It was really hard in the early days with [baby] 'cause when I looked at her, I was reminded of the birth and so I didn't want to look at her and I didn't want to talk about the birth for ages and if I did I'd sort of freak out.

Although no New Zealand prevalence rates were found specifically for post-traumatic stress occurring after childbirth, overseas research has suggested prevalence rates of 1 to 6 percent (Alcorn, O'Donovan, Patrick, Creedy, & Devilly, 2010, p. 1849), with some studies showing rates as high as 9 percent (Declercq, Sakala, Corry, & Applebaum, 2008).

Physical disabilities and medical conditions

According to the 2006 Disability Survey (Statistics New Zealand, 2007), the most common type of disability was physical disabilities; 12 percent of adults over the age of 15 had a physical disability (p. 6).

Charcot-Marie-Tooth disease (peroneal muscular atrophy)

Charcot-Marie-Tooth disease is a hereditary progressive neurological disorder that causes a loss of sensation, muscle weakness, and wasting away of the muscles. In this study, one father and his 13-year-old son had Charcot-Marie-Tooth:

Father with a disability: I have a neurological condition, CMT, Charcot-Marie-Tooth disease. Sometimes it is known as peroneal muscular atrophy, but it is essentially a breakdown of myelin sheath around the ends of the nerves, and your peripheral nerves and so they short out basically and you don't get muscle growth ... you also lose sensation, and as a result of that I had a below knee amputation. This one is affected as well, so I could end up bi-amputee.

We did not find New Zealand statistics, but according to Reilly, Murphy and Laurá (2011) it "is the commonest inherited neuromuscular disorder, affecting at least one in 2,500" (p. 1).

Diabetes

Diabetes occurs because of the body's inability to control blood sugar levels. When not well controlled, diabetes can damage the eyes, kidneys, feet and heart. Two mothers in this study had diabetes. Here is one mother's description:

Mother with diabetes: I'm disabled because in a way I'm not able to do things that normal people do. Though I can walk [and] talk, when it comes to diet or eating I'm not able. I'm not able to have sweet things. I'm not able to have too many fatty things. So that is a kind of disability... Not looking after yourself very well can lead to having cataract or having bleeding veins in the back of your eyes. It's part of diabetes.

According to the Ministry of Health (2010), "In New Zealand it is estimated that the number of people diagnosed with diabetes exceeds 200,000 people... There are also about 100,000 people who have diabetes but have not yet had it diagnosed" (para. 2).

Glandular fever/chronic fatigue

Glandular fever is caused by the Epstein Bar virus. The symptoms include a sore throat, fever, swollen glands and tiredness. Typically the symptoms resolve themselves in several weeks. In some cases, the fatigue persists much longer. When it lasts beyond six months it may be diagnosed as chronic fatigue (News Medical, 2006). One mother in this study experienced glandular fever and chronic fatigue:

Mother with glandular fever and chronic fatigue: What would happen is it would be so hard to swallow and just extremely painful and I could hardly turn my head sometimes because [my glands would] be so enlarged. ...I was told to have a lot of rest but that was quite hard, having ... a very chatty two-year-old who was not having day sleeps and picking up my son, dropping him off and picking him up from school, and he was not settling into school. ...Bad memory is something that goes with it. ...I couldn't even get my head around reading. ...My head was so foggy I'd be re-reading the same line over and over again and I was really passionate about cross-stitch back then and just couldn't. I couldn't play the piano. I just couldn't concentrate on anything. It was really debilitating in that it stripped me of a lot of the ways I would have downtime.

There are an estimated 10,000 to 20,000 people in New Zealand with chronic fatigue (Southern Cross Medical Library, 2009).

Injury to feet and legs

Three mothers in this study experienced injuries to their feet and/or legs, which caused significant mobility difficulties. One mother injured her Achilles tendon and she was unable to bear any weight on the injured foot for six weeks. Her injury was expected to heal completely in time; at the time of our interviews her injury was still healing. One mother was injured in car accident in 2006 and was on crutches for a season and then some years later experienced nerve damage in her feet. The third mother became seriously ill and, as a result of treatments, suffered nerve damage in her feet and legs. Though the two mothers with nerve damage expect to see some improvement with time, they also expect to have continuing difficulties with their feet.

Each mother's injury had a different cause, but each lost an ability that they used to enjoy:

Mother with nerve damage in her feet and legs: It was almost two years ago now. ...I went from fit and healthy and running everywhere, to learning to walk again. ...These days it's more to do with stamina, how far I can go. I'm limited by what I can do and how fast I can do it. I have problems walking for more than two metres or so without needing to sit down and rest and recover.

Ménière's disease

Ménière's disease is a disorder of the inner ear that causes intermittent episodes of vertigo (the sensation that the world is spinning), tinnitus (ringing in the ears), balance difficulties, a sense of fullness in the ears and hearing loss. An episode can last from half an hour up to 24 hours (National Institute on Deafness and Other Communication Disorders, 2010). One mother in this study had Ménière's disease:

Mother with Ménière's disease: I'd look down at the writing and the words would start to blur and the room would spin and then I would have 10 minutes to lie down before I would start throwing up and you just keep throwing up until there's nothing in your stomach and you still throw up. One time ... after I left work ... my balance went and I felt I was going to be sick and I just felt gross but no-one would help me because they thought I was drunk in the middle of the day.

We did not find data for prevalence rates in New Zealand. According to Hain (2009) "there is considerable disagreement ... about ... the prevalence ... of Meniere's disease" (para. 1). Hain considered that "Meniere's disease has a prevalence of about 200 cases/100,000 persons in the United States, or in other words, about 0.2 percent of the population has Meniere's disease" (para. 1).

Motor neurone disease

Motor neurones are cells that control muscles. Motor neurone disease is a progressive degenerative neurological disorder that affects the motor neurones, causing the muscles to waste away. One father in this study had motor neurone disease. At the time of the interview he was no longer able to speak, so he communicated by slowly typing into his computer, which then read his typed words aloud:

Father with motor neurone disease: It affects muscles by the death of motor neurons in the brain or/and spinal cord.

His wife elaborated:

Partner of a father with motor neurone disease: Muscles waste away so you can't use your arms. You can't use your legs; everything's really a muscle, respiratory etc. So you end up locked in your body, completely mentally able but you can't move, eat, talk, walk.It's a terminal illness.

According to the Motor Neurone Disease Association, "the prevalence or number of people living with MND at any one time is approximately seven in every 100,000. In the case of New Zealand this amounts to ... about 300 in New Zealand at any one time" (Motor Neurone Disease Association New Zealand, 2010).

Neurosarcoidosis

Sarcoidosis is an inflammatory disease that affects organs in the body. The immune system typically uses inflammation as an effective defence mechanism. However, in sarcoidosis, the immune system over-acts and the inflammation damages the body. Microscopic clumps of inflammatory cells group together to form granulomas. (Foundation for Sarcoidosis Research, 2010). In neurosarcoidosis, the granulomas form in the central nervous system. One mother in this study had neurosarcoidosis:

Mother with neurosarcoidosis: It's a nerve disease. It attacks on the nervous system. ...All the nerves

in ... the body ... die, but they're trying to rebuild, so you've got that constant pins and needles, electric shocks, numbness. Some days I don't feel my fingers. Other days they are 10 times sensitive. ...Like my stomach ... I've had gastroneuritis, tummy pains. My lungs ... they treat me for asthma.

According to Joseph and Scolding (2007), sarcoidosis has a prevalence rate of 40 in 100,000.

Paraplegia

Paraplegia refers to "an impairment in motor or sensory function of the lower extremities" (Disabled World, n.d.). One mother in this study experienced paraplegia:

Mother with paraplegia: I have full use of my arms and upper limbs; from chest down I have no feeling or movement. ...It impacts on everything in your life. You are sitting all day. You are looking up the people. Your pain is associated with discomfort, not standing, stretching; your insides sort of don't work the same. From a practical point of view, it ... takes longer to get in the car. You can still do everything but ... it takes longer to get in the car, get your kids ready in the morning, get yourself ready in the morning, takes longer to get dressed.

We were unable to find New Zealand statistics specifically for paraplegia. According to Access Economics Pty Limited (2009) in Australia, in 2008 there was an incidence rate of 0.6 for paraplegia (p. 35).

Trigeminal neuralgia

The trigeminal nerve is one of the largest nerves in the head. Trigeminal neuralgia is a chronic condition that causes extreme pain in the face. The jolts of pain are sporadic and can last from a few seconds to a few minutes and can occur one after another. "The intensity of pain can be physically and mentally incapacitating" (National Institute of Neurological Disorders and Stroke, 2011, para. 1). One mother in this study had trigeminal neuralgia:

Mother with trigeminal neuralgia: Trigeminal neuralgia's considered to be one of the worst pain disorders you can have. ...The problem with the pain thing is that the drugs have really severe side effects. ...I slept most of the time, had slurred speech, I had tremors, I had Parkinsonian-type effects but it was better than being in pain, and I slept and I slept and I increased my appetite. When eventually, my body did adjust to the drugs but I still

would sleep incredible amounts of time. ...I'd wake up in the middle of the night in agonising pain. ...During this time I was trying to parent as well and that was really tough on my kids.

"The incidence of trigeminal neuralgia is 4.3 per 100,000 persons per year" (Obermann & Katsarava, 2009, p. 323).

Sensory disabilities

According to the 2006 Disability Survey, 8 percent of adults have a sensory disability, that is a "hearing and/or seeing disability" (Statistics New Zealand, 2007, p. 6).

Visual impairments

There is a variety of conditions that can cause visual impairments. In this study a number of participants wore glasses that adequately corrected their vision. Three mothers had visual impairments that were not correctable by glasses. One mother had macular degeneration, but could still see well enough to drive. One mother had cataracts and had just had surgery on one of her eyes a few weeks before her interview. The third mother began losing her sight as a teenager. Here, the third mother describes her blindness:

Mother with blindness: Now for me, I've got partial blindness, which means I've got some peripheral vision but no central vision. ...Peripheral vision is just the outside. If I look straight ahead, say at you, I can see things out the side, like objects. That means for me I've got no central vision which means that I haven't got the ability to read print or watch a television, or even [it's] hard to see people's facial expressions and so forth. And often people with central vision loss can find it hard to make eye contact with people.

Hearing impairments

According to the National Foundation for the Deaf there are "nearly half a million deaf and hearing impaired New Zealanders" (National Foundation for the Deaf, 2007a, para. 1). In this study one father had a hearing aid and he thought that his child might also have a hearing impairment. One mother identified as deaf and had a cochlear implant. A cochlear implant is composed of two parts, an external speech processor and an internal implant. The external speech processor converts sounds to digital signals, which are transmitted to the internal implant. The implant then bypasses the

damaged cells and stimulates nerve and then brain interprets the sounds (National Foundation for the Deaf, 2007b). Here she describes her experiences:

Mother who identified as deaf: I had a cochlear ear implant two years ago and I [was] finally ... able to hear and I realised that people's voices don't just sound a set tone. It's all different. ...[Before the cochlear implant] I had hearing aids. They were enough to get me by but that was it. ...I was born with it [deafness]. Mum said that when I was a baby... I'd jump all the time, probably 'cause I couldn't hear people coming. ...My speech is more that my mum pushed my speech therapy.

Disabilities related to learning, processing, communicating and remembering

Asperger's Syndrome

Asperger's syndrome is considered to be one of the Autism spectrum disorders. It "is a lifelong disability that affects how a person makes sense of the world, processes information and relates to other people" (National Autistic Society, 2011, para. 4). Many people with Asperger's syndrome interpret communications literally and have difficulty with non-verbal communication. They often experience sensitivity to noise, light, texture or taste and may have an intense focus on a particular topic of interest (National Institute of Child Health and Human Development, 2011). One mother in this study had Asperger's syndrome:

Mother with Asperger's syndrome: Asperger's just means I can't cope with the world the same way everyone else does. There are certain words or actions or behaviours that drive me to a point of aggression because they just overload my system. I've learned how to work the aggression part out, but when I was younger, it was really, really hard. ...I couldn't cope with people touching me... But my son was different... I'm okay with him cuddling me and stuff.

According to Autism New Zealand, "1 person in 100 has an Autism Spectrum Disorder... The estimated population of people with Autism Spectrum Disorders in New Zealand is approximately [sic] 40 000" (Autism New Zealand, n.d., para. 1).

Dyslexia and Irlen syndrome

According to the Ministry of Education, "dyslexia is a term used to describe a range of persistent difficulties with reading and writing, and often including spelling, numeracy or musical notation" (Ministry of Education, 2010, para. 3). Dyslexia is sometimes described as a learning difference or learning preference. "Dyslexia's greatest difficulty is self-esteem – it only becomes a disability if not appropriately addressed. On the flipside, dyslexia can deliver great creative gifts, innovation and entrepreneurship" (Dyslexia Foundation of New Zealand, n.d. -b, para. 1).

Irlen syndrome is a perceptual processing disorder that makes reading difficult. The print is perceived differently and people often experience eye strain. Helen Irlen developed an intervention that uses colour filters to improve perception; it is called the Irlen method (for more information, see Irlen, 2005).

One mother in this study had dyslexia and Irlen syndrome:

Mother with dyslexia: Irlen's, that's where I can only read with tinted glasses. I didn't know about that either until I was tested for my dyslexia. ...There are many different types of dyslexia and it's to do with the neurons connecting in your brain. ...I'll write something down and my brain was working too fast for my hand to write things down so it was always jumping. And I'll do an essay and I'll look at it and I'll think, 'Why I have I gone and put that there, where it doesn't belong?' ...We tend to think outside the box.

Dyslexia was only formally recognised in New Zealand in 2007, thus it is difficult to know exactly how many people in New Zealand have dyslexia. The Dyslexia Foundation estimates that 1 in 10 New Zealanders have dyslexia (Dyslexia Foundation of New Zealand, n.d. -a, para.1).

Global developmental delay and attention deficit hyperactive disorder

Children's development is often viewed in terms of speech and language, thinking, social and emotional development, activities of daily living and co-ordination. Global developmental delay means that a child's development in two or more of those areas is behind their chronological age. Shevell (2003) has estimated

a prevalence rate of 3–5 percent for global developmental delay.

Attention deficit hyperactive disorder is characterised by inattention, hyperactivity and impulsivity. According to Austin, Reiss and Burgdorf (2011) the prevalence rate is about 3–7 percent (para. 2). One child in this study was diagnosed with global developmental delay and attention deficit hyperactive disorder. Here is how her father describes her disabilities:

Father with a disability: [Child] has got global developmental delay. She's slow at reading and writing plus she's, the teacher diagnosed her with hyperactive disorder. ...It means she's on the go non-stop and she has to have things to do or she'll take off into somewhere and ransack the place. She has to have things to do all the time. ...

Interviewer: What is global developmental delay?

Father with a disability: That means that ... her brain is a bit slow, slow at processing all the information.

Both her mother and her father had intellectual disabilities.

Intellectual disability

An intellectual disability is defined as: "a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; A reduced ability to cope independently (impaired social functioning); which started before adulthood with a lasting effect on development" (Department of Health (United Kingdom), 2001, p. 14). According to Bray (2003) "there are probably about 7 to 13 people with an intellectual disability in every group of 1,000 people". In this study one mother and one father had intellectual disabilities; they were a married couple:

Father with an intellectual disability: My wife's got a learning disability and she's quite slow at thinking and I've got a learning disability. I can't spell or write properly. I can't spell or read properly and my wife can read a bit. [My wife]'s disability is a wee bit different to mine. She has trouble remembering a lot of things like cooking and stuff. She has to get help with that.

According to Mirfin-Veitch (2010) "prevalence figures suggest that 2.51 families per 1,000 families in New Zealand include one or two parents with intellectual disabilities" (p. 97).

Traumatic brain injury

The New Zealand Guidelines Group (2006) defines traumatic brain injury as "an acute brain injury resulting from mechanical energy to the head from external physical force" (New Zealand Guidelines Group, p. 22). Symptoms following a brain injury can include "headache, nausea, dizziness, blurred vision, confusion, fatigue, poor concentration, memory problems, sleep difficulties, irritability and noise intolerance" (p. 125). One mother in this study had a car accident which resulted in injury to her brain, back and shoulder:

Mother with brain injury: I got side-on whip lash, knocked back to front. I got a pain in my lower back. ...A stabbing pain in the shoulder. It's not too bad. My lower back clicks in and out and I walk funny but that's the way it is. ...I had ... headaches. ...I was short sighted, had the car accident and my eyes went back to normal which is amazing. Awesome to have no glasses to wear and then it deteriorated and I've gone long-sighted. ... My moods would change from the head injury. ...I forget a lot anyway. ...Even after these four years when I watch a movie on TV or hire a movie from the movie shop that looks like a good one, I thought I'd never seen it and I have. ...Memory is the biggest thing.

The New Zealand Guidelines Group (2006) estimates that between 16,000 and 22,500 New Zealanders seek medical attention each year for traumatic brain injury. Because many people do not seek medical attention for traumatic brain injury, the New Zealand Guidelines Group estimates that the total incidence per year increases to between 20,000 and 30,000 cases per year (p. 24).

Appendix B: Information sheets

College of Education

School of Educational Studies and Human Development
Tel: +64 3 364 2987, Fax: +64 3 364 2418, Email: admingeshd.canterbury.ac.nz



You are invited to take part in a study about families. This study is about families where one or both parents have a disability. This study is about the strengths that these families have.

You are being invited to participate in this study because you are a parent with a disability. We are seeking 20-30 families to participate in this study.

This study is being carried out by researchers at the University of Canterbury in Christchurch. This information sheet is provided to help you decide whether or not you wish to participate in this study.

What is the study about?

This study is about the strengths and resiliences of families headed by parents with a disability.

The aims of this study are to explore:

- > What factors contribute to the success and resilience of parents with a disability?
- > What factors interfere with family life?
- > What trade-offs do these families make to achieve well-being?
- > How can organisations improve their support for families headed by parents with a disability?
- > These questions will be considered from the perspectives of parents with a disability, their children and their support network.

Who can be included in this study?

This study includes parents with a disability, their partners, their children and a friend of the family.

It is your choice whether or not to take part in this study.

What do I do if I want to take part in this study?

If you want to participate, contact Marilyn Raffensperger by phone on 03 364 2987 ext. 3540 or by email at marilyn.raffensperger@canterbury.ac.nz

We will meet and talk about the study. We will meet somewhere that is easy to get to and is suitable for private talking. You can ask me any questions you have about the study. This talk will last about an hour. After asking questions, if you are sure you want to help, then we will sign consent forms and arrange our future meetings.

I would like to talk one time with the whole family and then talk one time with each family member by themselves. At any point during the interviews children can be with a parent or a caregiver, if they wish.

I would also like to talk one time with a family friend.

What happens if I change my mind during the study?

You can leave the study at any time.

From time to time during the study I will check with you to make sure that you are still happy to continue participating.

What happens if I don't want to take part in the study?

If you don't want to take part in the study, you don't need to do anything.

What if I want to learn more about this study?

If you want to learn more about this study, contact **Marilyn Raffensperger**.

Phone: 03 364 2987 ext. 3540

Email: marilyn.raffensperger@canterbury.ac.nz

Mailing address: Marilyn Raffensperger
c/o Dr. Missy Morton
College of Education
University of Canterbury
Private Bag 4800
Christchurch 8140

If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate.

This is a free service provided under the Health and Disability Commissioner Act.

Telephone (NZ wide): 0800 555 050

Free Fax (NZ wide): 0800 2787 7678
(0800 2 SUPPORT)

Email (NZ wide): advocacy@hdc.org.nz

This study has been approved by the Upper South A Regional Ethics Committee and the University of Canterbury Human Ethics Committee.

Information sheets were also available for families and family friends, see Appendix D, page 63, for forms available. Please contact the author direct.

Appendix C: Consent forms

College of Education

School of Educational Studies and Human Development

Tel: +64 3 364 2987, Fax: +64 3 364 2418, Email: admin@eshd.canterbury.ac.nz



If you want to take part in this study please read this form very carefully. It outlines your rights as a study participant.

1. I have read or have had read to me the information about this study.
2. I understand the information I have been given.
3. I have had a chance to talk to the researcher about this study.
4. I have been able to ask questions and I am happy with the answers I have been given.
5. I have been able to use family or whānau or a friend to help me ask questions and to understand the study.
6. I understand that taking part in this study is my own choice.
7. I know that I can stop taking part in the study at any time.
8. Information about my family is private. The researcher needs my permission before she can ask other people about my family. The researcher will ask me to sign a form before she asks anyone questions about me or my family.
9. I understand that the researcher wants to talk to my partner about our family. I give the researcher permission to ask my partner questions about me and my family.
10. I understand that the researcher wants to talk to my children about our family. I give the researcher permission to ask my children about our family.
11. I understand that the researcher wants to talk to one of our friends about our family. I give the researcher permission to ask _____ about our family.
12. I understand that the researcher needs to talk to the other researchers in her team about things people say in this study. The other researchers are named Missy Morton, Jeffrey Gage and Frances Caldwell. I give permission to the researcher to talk to them about things I say. The information that I give during the study is confidential. I understand that confidentiality may be broken if I am in danger or if someone else is in danger.
13. This study is private. My name will not be used in reports on this study. No information that could personally identify me will be used in reports on this study.
14. I have had enough time to decide whether or not I want to participate in this study.
15. I understand that I will be interviewed.
16. I understand that these interviews will be recorded.
17. I understand that I can ask to have the recorder turned off at any time during the interviews.
18. The recordings of the interviews will be typed out. The typing will be done by Marilyn or Frances or another professional transcriber.
19. I understand that I will have a chance to check what I have said during the interviews. I can make changes at this time.
20. I know that the researcher may take notes during the interviews.
21. If I give written responses to interview questions I understand that these answers will be used as information for the study.
22. I understand that I will receive a copy of a report on the findings of this study. I understand that there will be a delay between my taking part in the study and receiving the final report.

23. I know that if I have any questions or concerns about my rights as a participant in this study that I can contact a Health and Disability Services Consumer Advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide) 0800 555 050

Free Fax (NZ wide): 0800 2787 7678
(0800 2 SUPPORT)

Email (NZ wide): advocacy@hdc.org.nz

24. I know that if I have any complaints I can talk to the chair of the University of Canterbury Human Ethics Committee, Mike Grimshaw at 366 7001

25. I know that I can contact Marilyn Raffensperger if I have any questions about this study. I can ask questions at any time.

Researcher: Marilyn Raffensperger

Mailing address: c/o Dr. Missy Morton
College of Education
University of Canterbury
Private Bag 4800
Christchurch 8140

Phone: 364 2987 extension 3540

Email: marilyn.raffensperger@canterbury.ac.nz

I _____ (full name)

want to take part in this study on family strengths.

Date: _____ Signature _____

This section will be completed by the researcher at the time of the interview.

Researcher: Marilyn Raffensperger
Phone number: 03 364 2987 extension 3540
Email: marilyn.raffensperger@canterbury.ac.nz

Mailing address: c/o Dr. Missy Morton
College of Education
Educational Studies and Human Development
University of Canterbury
Private Bag 4800
Christchurch 8140

Date: _____ Signature: _____

Consent forms were also available for children and family friends, see Appendix D, page 63, for forms available. Please contact the author direct.

Appendix D: Letters





Upper South A Regional Ethics Committee
c/- Ministry of Health
Montgomery Watson Building
6 Hazledan Road
Christchurch
Phone: (03) 974 2304
Email: uppersoutha_ethicscommittee@mdh.govt.nz

12 November 2009

Marilyn Raffensperger
C/- Missy Morton
College of Education
University of Canterbury
Private Bag 4800
Christchurch 8140

Dear Marilyn Raffensperger,

Through the eyes of parents, children and friends: Exploring the resilience and success factors of parents with a disability.

Investigators: M Raffensperger, Dr M Morton, Dr J Gage, Ms F Caldwell

Locality: University of Canterbury

Ethics ref: URA/09/10/074

The above study has been given ethical approval by the **Upper South A Regional Ethics Committee**.

Approval is given subject to the following condition:

The minimum age of participants must be 8 years.

The reviewers gave further consideration to your response to this requirement, however their stance remains unchanged. There is no objection to younger children being present while their parents and older siblings are interviewed.

Approved Documents

Information sheet for families (with pictures) dated 4 November 2009
Information sheet for parents (without pictures) dated 4 November 2009
Information sheet for family friends (with pictures) dated 4 November 2009
Information sheet for family friends (without pictures) dated 4 November 2009
Consent form for recording conversations dated 4 November 2009
Consent form for parents (with pictures) dated 4 November 2009
Consent form for parents (without pictures) dated 4 November 2009
Consent form for children (short form) dated 4 November 2009
Consent form for children (long form) dated 4 November 2009
Consent form for family friend (with pictures) dated 4 November 2009
Consent form for family friend (without pictures) dated 4 November 2009
Confidentiality form for transcriber dated 4 November 2009

Certification

The Committee is satisfied that this study is not being conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the trial is being carried out.

Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Progress Reports

The study is approved until **31 July 2011**. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator's

responsibility to forward a progress report covering all sites prior to ethical review of the project in November 2010. The report form is available on <http://www.ethicscommittees.health.govt.nz>. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Requirements for SAE Reporting

The Principal Investigator will inform the Committee as soon as possible of the following:

- Any related study in another country that has stopped due to serious or unexpected adverse events
- withdrawal from the market for any reason
- all serious adverse events occurring during the study in New Zealand which result in the investigator breaking the blinding code at the time of the SAE or which result in hospitalisation or death.
- all serious adverse events occurring during the study worldwide which are considered related to the study medicine. Where there is a data safety monitoring board in place, serious adverse events occurring outside New Zealand may be reported quarterly.

All SAE reports must be signed by the Principal Investigator and include a comment on whether he/she considers there are any ethical issues relating to this study continuing due to this adverse event. It is assumed by signing the report, the Principal Investigator has undertaken to ensure that all New Zealand investigators are made aware of the event.

Amendments

All amendments to the study must be advised to the Committee prior to their implementation, except in the case where immediate implementation is required for reasons of safety. In such cases the Committee must be notified as soon as possible of the change.

Please quote the above ethics committee reference number in all correspondence.

The Principal Investigator is responsible for advising any other study sites of approvals and all other correspondence with the Ethics Committee.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

We wish you well with your study.

Yours sincerely



Alieke Dierckx
Administrator
Upper South A Regional Ethics Committee
Uppersoutha_ethicscommittee@moh.govt.nz



Research and Innovation

Tel: +64 3 364 2688, Fax: +64 3 364 2696, www.research.canterbury.ac.nz

Monday 3 August 2009

Tēnā koe e Marilyn,

Re: Māori Consultation for Research Proposal: 'Through the eyes of parents, children and friends: Exploring the resilience and success factors of disabled parents'

Ngā mihi ō te wā ki a koe, te kairangahau ō tēnei kaupapa whakahirahira. Ngā mihi hoki ki a koe i runga i tēnei te whakowhitihiti koreo ki te whakopakari te mahi.

Thank you for the opportunity to discuss the research proposal that you have submitted for the project 'Through the eyes of parents, children and friends: Exploring the resilience and success factors of disabled parents'. This letter is to acknowledge the researchers consultation with Māori through consulting the Research Consultant Māori, the Professor of Māori Research and/or the Karuhiruhi Group at the University of Canterbury.

University of Canterbury Te Roopu Karuhiruhi.

This group is made up of academic staff from throughout the University that are leaders in their respective fields. Members include Sir Tipene O'Regan, Assistant Vice Chancellor, Māori; Gail Gillon, Pro Vice Chancellor, College of Education; and Māori academic staff from disciplines across the university including Social Work, Speech-language Therapy, School of Māori and Indigenous Studies, Education, Law, History, Māori Arts and Science as well as Māori student representation.

Consultation with Māori is integral to ensuring that research proposals and projects remain robust and transparent to the Māori community. The possibility for strengthened relationships through the exchange of knowledge between researcher and the Māori community is limitless and beneficial for both parties.

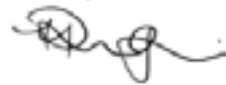
Throughout the discussion about this project we have found that there is the potential for Māori to be involved as participants in the research and should this occur, culturally sensitive knowledge and/or material is likely to be exchanged. It is the view of the committee that the researcher considers the following key points:

- Mason Durie's literature discussing 'Te Whare Tapa Wha' be consulted. This model encourages interventionists and professionals to look at the 'whole individual'
- Throughout the research, face to face interviews will take place. The researcher should seek support for how to engage with Māori whānau on a personal level. In order to ensure that the researcher and the participants remain culturally safe, a Māori colleague and/or kaumatua should accompany the researcher whilst interviewing is taking place
- From a cultural perspective, it is often more acceptable to put the person before the disability. For example, use 'parents with a disability' rather than 'disabled parents'.

Thank you once again for the opportunity to provide feedback on this important and exciting piece of research. Please ensure that you let the group know of the outcome of your proposal and planned research.

All the best for your future endeavours.

Nāku noa,



Nā Theresa Rongonui
Research Consultant – Māori
Research and Innovation
University of Canterbury

Appendix E: Interview topics

Preliminary discussions included: Discussion about the study

Filling out the consent forms

Subsequent conversations covered the following topics:

- > Demographic information such as ethnicity, marital status, family members' ages and employment status.
- > General discussion about the concept of disability.
- > Specific discussion about their particular disability. (Tell me about your disability/your parent's disability/your friend's disability?)
- > Discussion about their family life. (What are things like for your family when you are at home? What things do you enjoy doing together? What are your hobbies and interests?)
- > Discussion about difficulties and resilience. (Tell me about difficult situations or stressful situations that your family has faced. What do you do to deal with stress? What have you done in the past that has been successful in dealing with stressful situations? What have you learned from that?)
- > Discussion about the social support. (Who do you consider to be close and supportive in your life? Tell me about them. What sorts of things do they do that are helpful to your family?)
- > Discussion about their involvement in the community. (What are things like for your family when you go out? Is your family involved in any organisations or groups, for example, disability support organisations, church, cultural groups?)
- > Do you receive support from any organisations? If so, what do you like and not like about the support the organisation provides?
- > Interviews which occurred post-earthquake also included conversation about the earthquake's impact on the family and what helped them during that difficult time.

Appendix F: Interview lengths

Length			
hours:minutes:seconds	Family	File	Date
00:19:57	1	Father 1 and Mother 1, part one	10 February 2010
00:31:02	1	Father 1 and Mother 1, part two	10 February 2010
00:21:17	1	Mother 1 (phone interview)	10 December 2010
00:28:14	1	Father 1	14 December 2010
00:40:13	2	Mother 2	4 March 2010
01:14:10	2	Mother 2 and Father 2	8 November 2010
00:11:02	3	Child 3 (This child was intrigued with the digital recorder and so we ended up making multiple short interviews which added up to a total of 11 minutes.)	22 March 2010
00:36:00	3	Father 3 and Mother 3	16 March 2010
00:39:21	3	Father 3 and Mother 3	9 March 2010
00:27:38	3	Family 3 and Friend 3	3 December 2010
00:00:08	3	Family 3 and Friend 3	3 December 2010
00:13:15	3	Friend 3, part one	15 April 2010
00:08:31	3	Friend 3, part two	15 April 2010
00:17:12	3	Friend 3, part three	15 April 2010
00:01:33	3	Friend 3, part four	15 April 2010
00:27:41	4	Friend 4	20 May 2010
00:55:54	4	Mother 4 and Father 4	16 February 2011
01:13:57	4	Mother 4 and Father 4	18 March 2010
00:02:22	5	Child 5	3 May 2010
00:42:12	5	Family 5	22 April 2010
01:05:01	5	Friend 5	29 November 2010
01:03:29	5	Mother 5	23 March 2010
00:38:48	6	Child 6, part three	21 April 2010
00:03:13	6	Child 6, part four	21 April 2010
00:01:04	6	Child 6, part five	21 April 2010

00:03:07	6	Child 6, part six	21 April 2010
00:00:07	6	Child 6, part one	21 April 2010
00:01:04	6	Child 6, part two	21 April 2010
00:48:31	6	Family 6	8 December 2010
01:01:30	6	Friends 6	10 November 2010
01:11:00	6	Mother 6	29 March 2010
00:19:21	7	Child 7, part two	19 April 2010
00:00:01	7	Child 7, part two	19 April 2010
00:41:02	7	Friend 7	14 April 2010
00:19:30	7	Mother 7, part one	12 April 2010
00:41:04	7	Mother 7, part two	12 April 2010
00:00:12	7	Mother 7, part three	12 April 2010
00:00:06	7	Mother 7	19 April 2010
00:42:51	8	Family 8	27 October 2010
00:01:25	8	Friend 8, part two	
00:24:36	8	Friend 8, part one	
00:59:08	8	Mother 8 and Father 8	27 October 2010
00:54:27	8	Mother 8	27 April 2010
00:46:17	9	Father 9 and Mother 9	7 August 2010
00:52:06	9	Mother 9	24 May 2010
00:26:19	10	Child 10	31 January 2011
00:19:28	10	Mother 10, part one	27 October 2010
00:21:29	10	Mother 10, part two	27 October 2010
00:52:41	11	Mother 11	11 November 2010
01:05:23	12	Family 12	26 November 2010
00:46:26	12	Friend 12	19 January 2011
00:26:35	12	Mother 12	26 November 2010
01:00:45	13	Father 13, part one	14 December 2010

00:00:17	13	Father 13, part two	14 December 2010
00:00:17	13	Family 13, testing the microphone	10 December 2010
01:00:45	13	Family 13, testing the microphone	10 December 2010
00:35:13	13	Friend 13	10 May 2011
00:34:48	14	Mother 14	9 December 2010
00:47:19	15	Family 15, part one on 20 December 2010.wav	20 December 2010
00:00:03	15	Family 15, part three on 20 December 2010.wav	20 December 2010
00:00:49	15	Family 15, part two on 20 December 2010.wav	20 December 2010
00:16:55	16	Child 16, part two	2 May 2011
00:07:51	16	Child 16, part one	2 May 2011
01:24:59	16	Mother 16	14 March 2011
00:01:32	17	Family 17, part two	13 May 2011
00:30:26	17	Family 17, part one	13 May 2011
00:18:24	17	Friend 17, part two	13 May 2011
00:10:22	17	Friend 17, part one	13 May 2011
01:17:11	17	Mother 17	18 April 2011
00:32:51	18	Father 18	11 May 2011
01:31:19	18	Mother 18	11 May 2011
00:09:30	19	Child 19, part two	2 June 2011
00:08:31	19	Child 19, part one	2 June 2011
00:35:28	19	Friend 19	31 May 2011
00:00:17	19	Mother 19	2 June 2011
00:01:05	19	Mother 19 part one	24 May 2011
00:54:14	19	Mother 19, part two	24 May 2011
00:44:34	20	Child 20	23 May 2011
00:32:07	20	Family 20	23 May 2011
00:19:15	20	Mother 20	23 May 2011

Total time of recorded interviews: 40 hours and 6 minutes

Families Commission Research Fund

- 1/09 *Childbirth Education: Antenatal education and transitions of maternity care in New Zealand.*
Dr Sarah Dwyer, May 2009.
- 2/09 *Healthy Families, Young Minds and Developing Brains: Enabling all children to reach their potential.*
Charles Waldegrave and Kasia Waldegrave, May 2009.
- 3/10 *Passing It On: Intergenerational transmission of human capital in New Zealand families.*
David Maré and Steven Stillman, February 2010.
- 4/10 *Family Resilience: The settlement experience for Asian immigrant families in New Zealand.*
Professor Robyn Dixon, Professor Samson Tse, Dr Fiona Rossen and Dr Amritha Sobrun-Maharaj,
April 2010.
- 5/11 *Work Experience of Asian Immigrants: Impact on family wellbeing.*
Dr Amritha Sobrun-Maharaj, Dr Fiona Rossen and Sun-Woong Kim, November 2011.
- 6/11 *Eating Together at Mealtimes: The role of family meals in the health and wellbeing of young people in New Zealand.* J Utter, S Denny, S Grant, E Robinson, S Ameratunga and T Fleming, November 2011.

These reports are available on the Commission's website www.nzfamilies.org.nz or contact the Commission to request copies.

Families Commission
PO Box 2839
Wellington 6140
Telephone: 04 917 7040
Email: enquiries@nzfamilies.org.nz

families commission kōmihana ā **whānau**

➤ Giving New Zealand families a voice *Te reo o te whānau*

Wellington office

Public Trust Building, Level 6
117–125 Lambton Quay
PO Box 2839, Wellington 6140
Phone 04 917 7040
Fax 04 917 7059

Auckland office

Level 5, AMI House
63 Albert Street, Auckland 1010
Phone 09 985 4106

Email

enquiries@nzfamilies.org.nz

Commission website

www.nzfamilies.org.nz

The Couch website

www.thecouch.org.nz