Single-mother led families with disabled children in Aotearoa New Zealand

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Abstract

It is estimated that 11% of children who live in Aotearoa New Zealand are disabled children, with approximately 30% of these children living in a one-parent family. Currently, the vast majority, approximately 84%, of one-parent families are headed by women. Within the Aotearoa New Zealand context, relatively little is known about the space where these two spheres overlap: single mothers raising disabled children. The purpose of this study was to explore the experiences of single-mother led families with a disabled child/children in Aotearoa New Zealand. This research employed a qualitative approach, guided by social constructionism, to conduct interviews with six single mothers with a disabled child/children to explore their experiences. The topics covered included supports, networks and resources that the mothers and families have or use, experiences of accessing support services, what quality of life meant for the mothers and their family, coping mechanisms, and future considerations. A thematic analysis of the interviews was carried out. Findings from this research indicated that single mothers with a disabled child face many financial, emotional, practical and societal challenges. Despite this, mothers in this research overwhelmingly preferred their current single-parent status, valued themselves as experts in their child's life, and redefined their identity as mother-presence as opposed to the absence of a father. The findings of this study call for critical transformation of perceptions of single mothers and disability, and urge social work and healthcare professionals to challenge stereotypes and biases towards single mothers.

Acknowledgements

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Chapter One: Introduction

Background of the study

It is estimated that 11% of children who live in Aotearoa New Zealand are disabled children, with approximately 30% of these children living in a one-parent family (Murray, 2018). This is compared to approximately 17% of non-disabled children living in a one-parent family (Murray, 2018). While research is ambiguous regarding the impact of having a disabled child on the parents' relationship, it has been found that the instability of the child's impairment and very high levels of caregiver burden were associated with relationship breakdowns (McCoyd, Akincigil, & Paek, 2010). Currently, the vast majority, approximately 84%, of one-parent families are headed by women (Statistics New Zealand, 2013). Existing research into the experiences of single mothers in Aotearoa New Zealand have explored areas such as welfare reform in relation to single mothers (Patterson, 2004), resilience in single parents (Waldegrave et al., 2011), and the experiences of single mothers transitioning from welfare to work (Baker, 2002). Other research on families with a disabled child or children in Aotearoa New Zealand has provided valuable insights into their experiences on poverty, parental advocacy, activism, issues relating to the New Zealand education system, and family wellbeing (Ballard, Bray, Shelton, & Clarkson, 1997; Bell, Fitzgerald, & Legge, 2013; Child Poverty Action Group, 2015; Good et al., 2017; IHC, 2016; Murray, 2018; Tiso & Stace, 2015). However, there seems to be a dearth of literature and research about the space where these two spheres overlap: single mothers raising disabled children within the Aotearoa New Zealand context. The aim of this study was to explore the experiences of single-mother led families with a disabled child/children in Aotearoa New Zealand.

Research goals and objectives

This research employed a qualitative approach, and utilised semi-structured interviews with six mothers to explore their experiences as single mothers with a disabled child/children. The research aimed to provide insights into the strengths and challenges of being single mothers with a disabled child/children living in Aotearoa New Zealand. The topics covered in the interviews included supports, networks and resources that the mothers and families have or use, experiences of accessing support services, what quality of life meant for the mothers and their family, coping mechanisms, and future considerations. A thematic analysis of the interviews was employed to analyse the data collected (Braun & Clarke, 2006), which was synthesised in light of relevant literature and research material.

Rationale for the research

This study was underpinned by a growing body of overseas research into the experiences of single mothers with a disabled child/children (Beattie, 2009; Dyches, Christensen, Harper, Mandleco, & Roper, 2016; Gottlieb, 1998; Levine, 2008, 2009; Parish, Rose, Swaine, Dababnah, & Mayra, 2012). The research in this thesis is significant because within the childhood disability literature, a substantive amount of research that explores stress, coping and adaptation tends to focus on the experiences of mothers within traditional family structure, the two-parent family system (Case, 2000; Chou, Wang, Chang, & Fu, 2014; Gerstein, Crnic, Blacher, & Baker, 2009; Neely-Barnes, Graff, Roberts, Hall, & Hankins, 2010; Park, Turnbull, & Turnbull III, 2002). With the changing nature of the family structure, such narrow conceptions of family seem to isolate and marginalise families, particularly single mothers with a disabled child/children, who do not confirm to the dominant norm. Insofar as the researcher can establish, there are no existing studies on the experiences of single mothers in Aotearoa

New Zealand with a disabled child/children. The current research focusing on the experiences of single mothers who are raising a disabled child/children has potential significant implications for policy makers and service delivery professionals to gain a better understanding on how to support this group as some research has indicated that disabled children are more likely to reside in female-headed, single-parent families, who experience long-term inequality, social inclusion and poverty (Fujiura, 2014; Lloyd & Rosman, 2005).

Positioning of the researcher

This project was initially prompted by my work as a social worker, some of which involved supporting single mothers with a disabled child. However, I consider this research as an insider research as I have had the experience of being a single mother raising a disabled child. I was also drawn to a couple of incidents happened in the past 20 years as discussed below.

In 1997, a New Zealand mother who was unable to find support during a time of crisis, killed her autistic daughter, Casey. Nineteen years later, and the year before I began to write this thesis, another mother, Donella Knox, killed her autistic daughter, Ruby. Knox was also a single mother and chronicles her life in diary form in her book *Rubies & Pearls,* which was published a month before Knox killed Ruby. Stace (2011) outlines the decade of policy work that followed Casey's death in 1997, which lead to the 2008 publication of the New Zealand Autism Spectrum Disorder Guideline, and which I have read in my own journey with my autistic son.

Greene (2014) outlines the influence of one's theoretical and cultural viewpoints and the importance of acknowledging one's own biases in qualitative research. As a single mother of a disabled child I am an insider with participants of this research. Insider research status has

many advantages in qualitative research including expediency of rapport building, knowledge of the historical and practical happenings of the field, and richness interpretation of the data due to insider knowledge of political, social and historical contexts (Chavez, 2008). Being an insider allowed me to relate to the research participants and have an appreciation of their experiences as single mothers with a disabled child/children. However, I was very aware of the need to not over-identify with the experiences of the research participants, and to let the research findings speak for themselves. I drew on my experience of being a single mother while working as a social worker supporting single mothers, and the boundaries that I had established then, which acknowledged that while our contexts were similar, our experiences were unique. I also utilised supervision with my supervisors to discuss any ongoing concerns emerging from my insider status.

Definition of terms

For the purpose of this thesis, listed below are key terms that are used throughout the thesis to assist the reader in understanding the researcher's position and perspective on the context and content of the research study.

The Social Model of Disability

The social model of disability was developed by disabled people as a way to analyse and understand how society disables people (Goodley & Tregaskis, 2006). As stated by Oliver (1996, p. 22)

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an

oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability', of people with such impairment. Thus we define impairment as lacking all or part of a limb, or having a defective limb, organism or mechanism of the body and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.

Prior to the development of a social model of disability, the social disadvantage that disabled people encountered was seen as a result of their impairment, and something to be expected as just the way it was (Goodley & Tregaskis, 2006). Developments to the social model acknowledge that while there are functional limitations to what people with impairments can do, society could be organised in ways that take the needs of all people into account, which would contribute to more equality for disabled people (Goodley & Tregaskis, 2006). It is society that does the disabling, rather than the impairment (Goodley & Tregaskis, 2006).

Identity-first language

Within the social model of disability there is a rejection of person-first language, such as "person with disabilities", with the term disabled people being preferred to acknowledge that people are disabled by stereotypes, the environment and by attitudes (Barking and Dagenham Centre for Independent & Barking and Dagenham Council, 2001). Throughout this research, the phrase disabled child rather than child with disability is used. This in turn recognises that the child is disabled by society, rather than it being implied through the phrase "child with disability" that the disability is something intrinsic to the child (Colver, 2006). This is also in accordance with its usage in the New Zealand Disability Strategy 2001 and 2016.

Single parent and one-parent families

A single parent is defined as a parent without a partner, living with one or more dependent children in a household with or without adult children or other adults (Centre for Social Research and Evaluation, 2010). A one-parent family is a family led by a single parent. Single parents with shared-care arrangements with the other parent of their children have been included in this research.

Social constructionism

Social constructionism views the idea of reality as the shared social understandings that are sustained through rituals and customs, stories and mythology, symbols, and institutions such as religion and mass media (Berger & Luckmann, 1966; Charlton, 1998; Payne, 2014). These shared understandings between people about what is acceptable, and also how people should act, are almost always taken for granted, and become habitual and normalised (Payne, 2014). With this normalisation comes an acceptance of these shared understandings as truth, and these are institutionalised through rules being placed around these understandings (Payne, 2014). Individuals and groups are both creating and being created by their social interactions. This becomes a circular feedback loop, with people acting the way they do because they have accepted social norms, which are then institutionalised, so individuals create the structures that then dictate how they should behave (Payne, 2014).

Structure of the thesis

This thesis is organised into seven chapters.

Chapter One

This chapter introduces the topic and provides an overview of the research project. An overview of the research goals and objectives is given, along with a rationale of the research. The positioning of the researcher is discussed, and an explanation of the key terms is presented.

Chapter Two

The second chapter provides an overview of the literature related to the research topic of the experiences of single mothers with a disabled child/children. Firstly, a summary of the significant research and issues relating to families with a disabled child/children is provided. This is followed by an examination, specifically in relation to single mothers with a disabled child/children, of the areas of mental health and social isolation, poverty and paid employment, and access to support and service providers. The strengths and resilience of single mothers with a disabled child/children are then identified through literature. The next section focusses on the Aotearoa New Zealand context of families raising a disabled child/children, then explores Aotearoa New Zealand research on single mothers.

Chapter Three

This chapter discusses the theoretical underpinning of this research, which is social constructionism. This chapter provides a discussion of the socially constructed meanings of disability, parenting disabled children, single mothers, and parenting on welfare.

Chapter Four

Chapter four provides the overview of the methodology and data collection process. This chapter begins with a discussion on the study design and then describes the interviews of six

single mothers with a disabled child/children. It then provides a description of the sampling process, data collection, data analysis, and ethical considerations. The chapter is concluded with an overview of the process used to enhance trustworthiness of the research.

Chapter Five

The fifth chapter presents the results of the research. A brief background of the single mothers who participated in this research is outlined. Analysis of the data from the interviews resulted in four themes being identified: (1) social isolation and loneliness; (2) challenges in accessing support services; (3) coping and contentment; and (4) negotiating employment and care work.

Chapter Six

Linking the data gathered in this study with the relevant literature, this chapter provides a critical and analytical discussion of the experiences of single-mother led families with a disabled child/children and their unique insights.

Chapter Seven

The final chapter provides a summary of the key findings derived from the research, addresses limitations of the current study, and provides recommendations for practice and future research opportunities.

Chapter Two: Literature Review

Introduction

A substantial amount of literature already exists to explore how a family adapts to having a disabled child. The current literature review will demonstrate that single mothers are more likely to parent children with disabilities; yet, their experiences are rarely found within health and social science research. This chapter will first provide a critical review of the significant research and issues relating to families with a disabled child/children. This will be followed by an examination of the literature in areas of mental health and social isolation, poverty and paid employment, and access to support and service providers specifically in relation to single mothers with a disabled child/children. The strengths and resilience of single mothers with a disabled child/children identified in literature, will then be identified. Following this, there is a focusses on the Aotearoa New Zealand context of families raising a disabled child/children, then an exploration of Aotearoa New Zealand research on single mothers. Finally, the summary provides a synopsis of the literature relating to this research, and outlines gaps in the knowledge, which in turn has informed the aims and objectives of this research. Literature was sought that was published after 2000, and in cases where none could be found on a specific topic, the search criteria was widened to include research from before 2000.

Families with a disabled child/children

Families caring for a disabled child/children face particular challenges compared to those caring for a non-disabled child/children. Challenges include increased parental stress, financial constraints related to health care, employment constraints, attitudes of professionals, reduced family support, and lack of adequate support services, limited opportunities for parental social interaction and advanced education (Bailey, Golden, Roberts, & Ford, 2007; Dowling &

Dolan, 2001; Emerson, Robertson, & Wood, 2004; Gerstein et al., 2009; Heywood, 2010; Olsson & Hwang, 2001). Families with a disabled child/children describe the process of securing support services or funding for support services as long, slow, time consuming, complicated and the source of much anxiety and frustration (Brett, 2002; Dowling & Dolan, 2001; Heywood, 2010; Jarrett, Mayes, & Llewellyn, 2014; McKeever & Miller, 2004). Emotional stress such as anxiety and frustration can be exacerbated by the service reassessment process, and it is noted that services are sometimes only provided when the family has reached crisis point (Dowling & Dolan, 2001; Heywood, 2010).

Raising a disabled child/children impacts on mental health problems, which include crises, depression and acute episodes of psychiatric symptoms, and these are compounded by the social isolation that disabled families experience (Dowling & Dolan, 2001). Social isolation is a common experience in families with a disabled child/children (Goodley & Runswick-Cole, 2012; Heywood, 2010; Home, 2002). Some of the issues identified are access and transport challenges, which hinder families' participation in shared activities, or the unique needs or abilities of the disabled child/children not being accommodated (Home, 2002). This may be attributed to people not being accustomed to being around others with disabilities, with the lack of exposure and understanding creating an uneasy feeling that can isolate disabled children and their families. In addition, the lack of public education about disabled people might contribute to the lack of understanding for the kind of stress that families with disabled children encounter and this may cause these families to withdraw from the environment. The community or leisure environment is usually constructed with only non-disabled children in mind, and community events are not organised with the consideration of the inclusion of disabled children, which serves to further isolate families with a disabled child/children (Heywood, 2010; Home, 2002).

It is also important to highlight that families with a disabled child/children have lower incomes, lack of opportunities, and carry the physical and emotional burden of caring for a disabled child/children (Brett, 2002; Dowling & Dolan, 2001; Goodley & Runswick-Cole, 2012; Green, 2007; Heywood, 2010; Home, 2002; Jarrett et al., 2014). In particular, the employment and career opportunities of mothers with a disabled child/children are often diminished, due to mothers taking on the main caring role, which limits their availability for work, (Dowling & Dolan, 2001; Goodley & Runswick-Cole, 2012; Heywood, 2010; Home, 2002). A recent report, *Women at Work: 1991–2013* (Statistics New Zealand, 2015), illustrated that the unequal distribution of unpaid care and household work between women and men, and between families and the society, is an important determinant of gender inequalities at work. Mothers who have a lifelong care responsibility for a disabled child/children are reported to be at a greater risk for non-employment or part-time employment than mothers of non-disabled children (Chou, Kröger, & Pu, 2018). Factors influencing workplace participation choices of mothers with disabled children are highly influenced by caregiving demand, support from spouse, support network and the availability of social services (Chou, Fu, & Chang, 2013).

In addition, there are many challenges to finding and keeping paid employment for parents of a disabled child/children (Dowling & Dolan, 2001; Scott, 2010). These challenges include the extra medical and therapy appointments that parents need to attend with their disabled child, which take place during work hours, and finding suitable after school care and holiday care for their disabled child (Cole, Crettenden, Roberts, & Wright, 2016; Dowling & Dolan, 2001; Scott, 2010). Another consideration is that the extra care needs of disabled children usually do not diminish as they get older, which means families with a disabled child often remain living on reduced income, due to the extra care requirements of that child. This goes some way to explain the lower household incomes of families with disabled children, compared to families

with non-disabled children. This limited income is coupled with the extra expenses for the resources and therapy often needed to assist the disabled child/children. Families are hit with a disabling double whammy; not only are they on a reduced income, but they have extra expenses to take out of it (Dowling & Dolan, 2001).

Caring for a child is an experience full of joy and happiness, as well as challenges and stress. The experiences of caring for a disabled child/children is likely similar in many ways to the experiences of parenting non-disabled children. However, as stated earlier, there are important distinctions that can contribute to increased psychological distress for parents with a disabled child/children such as the physical demands, disruption of family and social relationships, dealing with societal stigma, and financial and employment constraints (Floyd & Gallagher, 1997; Gerstein et al., 2009; Green, 2003; Heywood, 2010; Park et al., 2002; Safe, Joosten, & Molineux, 2012; Scott, 2010). Despite these challenges, research has identified that many of these stressors do not relate directly to the behaviours of the disabled child/children, the severity of the impairment or parenting tasks (Green, 2007; Murphy, Christian, Caplin, & Young, 2007). Instead, parental stress and risk of wellbeing is associated with a mismatch between the parent, child's and family's needs and the information, resources, and supports available to provide effective service. This suggests that raising a disabled child/children is not a personal tragedy or problem to be solved but requires creative adaptations and advocacy to create favourable and supportive social and environment situations (Resch et al., 2010). Furthermore, while existing research typically reported more stress in families with a disabled child than families with non-disabled children, families with a disabled child also reported a range of positive perceptions and experiences (Greer, Grey, & McClean, 2006). These positive perceptions and experiences included their child being seen as a source of happiness or fulfilment, their child bringing the family closer together, and their child being a contributing

factor to parents' personal growth and maturity (Greer et al., 2006), suggesting the need to identify factors related to successful adaptation rather than focus exclusively on poor outcomes for families (Folkman & Moskowitz, 2000).

Single mothers with a disabled child/children

Researchers and policy makers who study the family experiences of children often rely on the notion called "family structure", which centres on the biological relationship of parents, based on the marital status within the traditional, two-parent family system (Hodgkinson & Lester, 2002; Levine, 2009). This trend is not unusual in literature related to childhood disability. Levine (2009) argues that families who differ from the normative construction have been omitted from the discourse of childhood disability and this has problematised the experiences of families, particularly single mothers, who do not conform to this norm. Single mothers are commonly regarded as outsiders, despite the increasing number of one-parent families headed by many single women (Longhurst, Hodgetts, & Stolte, 2012). Even women who have been born and/or socialised into middle-class positions, as single mothers they are likely to experience a decline in income (Cheung, 2007), relative disadvantage in terms of educational attainment (Cotterell, von Randow, & Wheldon, 2008), and poor health (Avison & Davies, 2005). Single mothers are often regarded not just as cultural outsiders but also as members of an 'underclass' due to financial constraints and also the moral sentiments they provoke that prompts them to feel shame and guilt (Probyn, 2005). Studies exploring families with a disabled child/children historically concentrated on issues such as grief, caregiver burden, and stressors on family functioning (Floyd & Gallagher, 1997; Gerstein et al., 2009; Mallow & Bechtel, 1999; McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2008). Research has highlighted that single mothers with a disabled child/children have higher levels of common mental health issues, such as anxiety or depression, than partnered mothers with a disabled

child/children (Butterworth, 2004; Crosier, Butterworth, & Rodgers, 2007; Hope, Power, & Rodgers, 1999; Targosz et al., 2003; Wang, 2004). Factors contributing to this are suggested to primarily be the lower socioeconomic status of single mothers, however, the lack of social support, belonging to an ethnic minority, the increased responsibility of caring for their children alone, and historical family violence are also contributing factors (Butterworth, 2004; Crosier et al., 2007; Hope et al., 1999; Targosz et al., 2003; Wang, 2004). Research has confirmed that single-parent families, which are predominantly led by mothers, face higher rates of economic disadvantage than two-parent families (Crosier et al., 2007; Dyches et al., 2016; Gottlieb, 1998; McCubbin, 1989; Parish et al., 2012).

Emerson, Hatton, Llewellyn, Blacker, and Graham (2006) look more closely at the relationship between maternal wellbeing, household composition, socioeconomic status, and having disabled children, in the United Kingdom. This research reiterated the importance of investigating the social context of the family, to make the link between psychological distress and socioeconomic status, and especially taking into consideration that families with a disabled child/children are generally worse off financially than families without a disabled child/children (Emerson et al., 2006). The research concluded that after statistically controlling for differences in socioeconomic status, being in a two-parent or one-parent household, and maternal characteristics, all differences in maternal well-being were accounted for, and over half of the increased risk of low self-esteem and self-efficacy was accounted for (Emerson et al., 2006). Emerson et al. (2006) conclude that distress arises predominantly out of disabling poverty, rather than from the experience of having a disabled child/children and showed that by simply controlling for differences in socioeconomic status, 48% and 67% of the heightened risk of poor maternal wellbeing in mothers with a disabled child/children was accounted for. This is confirmed by Crosier et al. (2007), who suggest that financial hardship and perceived

lack of social support accounted for almost all of the differences in mental wellbeing between single and partnered mothers in the United Kingdom.

Poverty and paid employment

Financial concerns were researched in more detail by Gottlieb (1998) and Cole et al. (2016), who considered the effect of employment and mothering roles on the wellbeing of single mothers with a disabled child/children. Mothers in paid employment who also had other income streams, such as child support or disability assistance, rather than relying solely on their paid employment for income, had better mental and physical health than mothers who only had employment income or mothers who were not in paid employment (Gottlieb, 1998). Discussion on the findings point out that it is not unexpected that single mothers who worked full-time experienced high levels of stress, given their role overload of providing the sole financial, emotional and physical support to their family, which included a disabled child/children (Gottlieb, 1998). However, there are many benefits to being in paid employment identified by the research participants: their emotional wellbeing, greater financial security, having time away from their caring duties, maintaining their skills, and the social aspect of being in paid employment (Cole et al., 2016).

One of the main challenges for the mothers in paid employment was the juggling what needed to happen for them to attend appointments with/for their disabled child/children (Cole et al., 2016). Strategies used by mothers included, where possible, scheduling the appointments to happen at their child's school, prioritising appointments so that only those that they felt were beneficial to their child were booked, and scheduling appointments concurrently (Cole et al., 2016). However, the opportunity cost of being available to take their disabled child/children to appointments was additional money and career progression (Cole et al., 2016), so having

flexible working arrangements did come at both a short-term and long-term cost. The research findings indicate that the relationship between the mother and the school that their disabled child/children attends has a significant influence on their ability to be in paid employment (Cole et al., 2016). If the mother has confidence in the school and its inclusiveness practices, she was more likely to be in paid employment during school hours (Cole et al., 2016). The suggestion is made that policies should be targeted towards improving the financial wellbeing of single mothers with a disabled child/children to support mothers into paid employment, their children into appropriate childcare or school, and paid leave provisions made that recognise the extra time that is needed to take disabled children to medical and therapy appointments (Landis, 1992; Parish et al, 2012). All children bring joy to their parents; however, the increased expense and opportunity costs of raising a disabled child/children cannot be ignored (Porterfield, 2002). One way to gauge our development as a society is to measure how we support and enhance opportunities for all members, not just non-disabled people (Porterfield, 2002).

Support and service providers

Single mothers with a disabled child/children receive less total support than partnered mothers with disabled child/children (Bromley, Hare, Davison, & Emerson, 2004; Cigno & Burke, 1997), which is problematic given that partner support is not available in one-parent families, therefore support received from external sources, such as respite or friends and family, is even more important to single parents (Cigno & Burke, 1997; Cole et al., 2016). Single mothers were clear about the types of support that they needed, and interestingly, some types of support required was markedly different from the support required by two-parent families, and some was identical. Transport was the most needed support, which did not even feature for two-parent families, followed by help with behaviour problems, which was also the second priority for two-parent families (Cigno & Burke, 1997). Equipment for the home came next for one-

parent families, which was not listed as needed by two-parent families. Single mothers also said that they wanted more contact with their child's teachers (Cigno & Burke, 1997), and as identified above, this could be due to the school and teachers being named as the main providers of support as in-house partner support was not available in one-parent families.

The importance, but lack of, formal and organised emotional support to single mothers following their child's impairment diagnosis is highlighted in a pilot study of three single mothers (Beattie, 2009). This research also highlights the needs of mothers being frequently combined with fathers and the family unit as a whole in research (Beattie, 2009). Emotional support is suggested to be as important as practical support, especially for single mothers who do not have the support of a spouse, and may not have family support (Beattie, 2009).

Strengths and resilience

Single-mother led families scored significantly higher in adaptability than two-parent families in a study by (McCubbin, 1989). This adaptability was outworked by these families being able to change the power structures, communication styles, and relationship expectations and roles in response to stressful situations (McCubbin, 1989). This flexibility allowed the family to adapt and respond positively to challenges, rather than maintaining a rigid pattern of behaviour and thinking.

Levine (2009) described how single mothers with a disabled child/children manage the dual challenge of single parenthood and childhood disability. Single mothers in Levine's (2009) research, rather than seeing themselves through the lens of the negative stereotype of being a single mother, saw themselves as "chosen mothers". Rather than accepting the societal belief that single-mother led families were less preferred than a two-parent family, mothers reframed

their identity as favouring being a single mother and saw their role as the mother of a disabled child as part of a larger plan for their life (Levine, 2009). Mothers also reframed their child's impairment, seeing their child as unique and able in their own way, rather than constrained by the disability diagnosis (Levine, 2009). Single mothers trusted their judgement and knowledge of their children, and valued themselves as experts in their own and their child's life (Levine, 2009). Single mothers with a disabled child/children also thoughtfully and purposefully developed and maintained relationships with extended family to ensure that their child had access to social support, both in the present and in the future (Levine, 2009). In taking these actions, mothers moved from passive recipients of knowledge and advice, to being actively engaged in decision making processes about their child, and able to challenge situations where they felt their knowledge of their child should be taken more fully into account by others working with their disabled child (Levine, 2009).

Single mothers are frequently constructed by society as people who ought to feel 'bad' for burdening taxpayers, for raising children without a live-in father, for lacking discipline and moral fibre, and for contributing to be seen as a 'crisis' within the social and public policy domain (Longhurst et al., 2012). While this may apply to single mothers of disabled children, given that their circumstances may be more problematic than families of non-disabled children with two parents, feminist standpoint theory challenges the dominant and repressive social practices to which women such as single mothers are being subjected to as problematic, powerless, vulnerable and burden to the society (Hartsock, 1998; Smith, 1987). Levine (2009) continues to argue against this "one-size fits all" approach, which suppresses our knowledge building and exploration of the needs of single-mother led families, and limits the capacity of professionals and policy-makers to develop appropriate and inclusive support plans, policies

and strategies that involve the life experiences of single-mother led families with a disabled child/children.

Aotearoa New Zealand families with a disabled child/children

With approximately 11% of children in Aotearoa New Zealand being disabled (Statistics New Zealand, 2014), and approximately 30% of disabled children living in a one-parent household (Murray, 2018), there is a need to understand more about the challenges faced by and resilience of single-mother led families with a disabled child/children in Aotearoa New Zealand.

To provide direction on how Aotearoa New Zealand supports disabled people, the *Disability Strategy* (2016) outlines how government agencies should work on disability issues from 2016 to 2026. The principles that guide the work are Te Tiriti o Waitangi, the Convention on the Rights of Persons with Disabilities, and the disability rights principle of 'nothing about us without us' (Ministry of Social Development, 2016a). The approaches that are used are taking a long-term view of the person's life and implementing both specific and mainstreaming services. The outcome areas are: education, employment and economic security, health and wellbeing, rights and justice, accessibility, attitudes, choice and control, and leadership. The vision of the Strategy is "New Zealand is a non-disabling society - a place where disabled people have an equal opportunity to achieve their goals and aspiration, and all of New Zealand works together to make this happen" (Ministry of Social Development, 2016a, p.8).

With respect to disabled children, the *Disability Strategy* considers children's perspectives and circumstances. One example originates from the consultation process where disabled children expressed the desire to fit in at school and be able to do things with their friends, as do non-disabled children (Ministry of Social Development, 2016a). This supports the vision of the

Disability Strategy, that these children would like an equal opportunity to achieve their goals and aspirations. It was also recognised in the *Disability Strategy* that even though some gains have been made for disabled children and adults since its inception in 2001, they still are not able to reach their potential (Ministry of Social Development, 2016a). One of the outcomes in the *Disability Strategy* relates to choice and control, and specifically refers to children and those that are responsible to act as their voice and representatives. It is acknowledged that young children need the support of their families, whānau and carers, and the views of the children as well as those caring for them need to be considered.

To better understand the experiences of families with a disabled child/children IHC (2016) conducted a study of 21 families or representatives of family-based organisations, entitled *What's important for family wellbeing?* The study identified four key areas: attitudes of community members; having a sense of belonging and there being inclusive practices; good support and connections; and the importance of fair and enabling systems. Families described a warm and welcoming attitude by people in their community as being key to their and their children's wellbeing (IHC, 2016). This positive attitude flowed through to their sense of belonging in their communities and the inclusive practices that took place. Families said that it was helpful when their family was seen as a unit, siblings were included, and their disabled child/children was not left out because environmental adjustments had not been made. Lack of inclusion in society is a major disabling factor that families with a disabled child/children face.

Results from the IHC (2016) report continue to suggest that good support and connections stem from positive attitudes and belonging and inclusion. Families in this research highlighted the importance of having people around them who could provide support when needed, including parents having time for their non-disabled children and time as a couple. Being able to connect

with families who were going through a similar journey was also seen as important. An essential element to support was having a key person who the families could talk with and help them to work through challenges. This could be a professional, or someone who worked with their disabled child, and alongside the need for this key person, was the appreciation of professionals and other people working with their child who went the extra mile for their child and family. A recent development in the disability sector is the system transformation and the implementation of Enabling Good Lives (Enabling Good Lives, n.d.), within which a key Connector will be selected by each disabled person who wants one to fulfil this role. This Connector would have a role similar to the role of the key person that was identified as needed by these families.

As found in overseas research (Jarrett et al., 2014; Sousa, 2015; Whiting, 2014), with all the challenges a family with a disabled child/children might face, poverty, along with navigating a complex and difficult disability support systems remains one of the most challenging tasks for families with disabled children in Aotearoa New Zealand (IHC, 2016). To better understand this subject, the Child Poverty Action Group (2015) carried out a study of seven families with disabled children, entitled *'It shouldn't be this hard': children, poverty and disability*. With child poverty being the focus of the organisation, statistics were given from the 2013 *Disability Survey* showed that there are approximately 95,000 disabled children aged 0-14 years old in Aotearoa New Zealand, and 15% of these children lived in households with incomes below $30,000, which compared to 10% of 0-14 year olds in all households (Child Poverty Action Group, 2015). Looking closer at the numbers, 13,500 children receiving the Child Disability Allowance in 2012 relied on a social benefit for family income, which was extrapolated to suggest that 14% of disabled children lived in families that relied on a social benefit for their family income (Child Poverty Action Group, 2015). Murray (2018) also expands on the link

between having a disabled child/children and family poverty in Aotearoa New Zealand, and compares this with the United Kingdom, where households with disabled children are less likely than in Aotearoa New Zealand to be at risk of income poverty. Alongside disability specific allowances, there is more support given to parents and carers in the United Kingdom than in Aotearoa New Zealand, to assist them to participate in paid employment (Murray, 2018).

The Child Poverty Action Group (2015) report noted that a significant finding of their interviews with parents with a disabled child/children was parents having high hopes and dreams for their children, despite the lack of resources or services. As outlined in research by Cigno and Burke (1997) and Sousa (2015), the importance of the ability of parents to be able to 'work the system' is highlighted in the Child Poverty Action Group (2015) report. Working the system means using knowledge and social capital to access or qualify for support for their family or disabled child/children. This report also highlights what research has shown, that having a disabled child/children means incurring extra costs that are not incurred by families with a non-disabled child/children, and includes the opportunity cost of one parent not being able to be in paid employment because the disabled child/children requires the full-time care of one parent (Dowling & Dolan, 2001; Parish et al., 2012; Scott, 2010). The report also discusses the importance of children with disability having a diagnosis, as a gateway to support being able to be accessed (Child Poverty Action Group, 2015). This is the context of undiagnosed impairments easily mistaken as behavioural concerns, and this was compounded by the overlay of children with undiagnosed impairments being more likely to live in low-income households, with fewer resources to use to access support (Child Poverty Action Group, 2015).

The importance of fair systems and families being able to plan means that families have choice and control over services, and as with the *Disability Strategy*, a long-term view of the disabled person's life is taken (IHC, 2016). Unfortunately, families have experienced support services as having siloed thinking and ways of working with families, which is not helpful for families, and results in services being perceived to be fragmented, with policy and funding disconnected from each other, and funding insecure (IHC, 2016; Stace, 2011). Wills and Chenoweth (2005) describe this silo way of providing support as compartmentalisation and express their concern with the risk that this way of working with people often results in them not getting the support that they need, especially if they have two or more areas of need. Families have also experienced only receiving help when they were in crisis, another difficulty when the aim of families is to make long-term plans. Again, some parents of disabled children felt that there was the expectation that they be grateful for the support they receive, whatever the quality (IHC, 2016).

Education is one of the main pathways to children reaching their potential. However, inclusion in the education system has proven challenging for families with a disabled child/children (Armstrong, Armstrong & Spandagou, 2011; Miles & Singal, 2010). What has been found in both Aotearoa New Zealand and overseas research is that there are many challenges to inclusive education, which include the organisation and delivery of resources and support, professionals and their accountability to parents, and lack of inclusion (Ballard et al., 1997; Case, 2000; Murray, 2000; Runswick-Cole, 2007; Tiso & Stace, 2015). Even though society has chosen to include disabled children and provide for them, some parents describe feeling like they should be grateful for sub-standard support that their child received from their school, even if this support was expected (Ballard et al., 1997; Tiso & Stace, 2015). This suggests that the level of support some families experience is so low, that even services they are entitled to,

when provided in a sub-standard fashion, are perceived as above the norm. This lack of inclusion is also mirrored in early childhood education (Lyons, 2013; Purdue, Gordon-Burns, Rarere-Briggs, Stark, & Turnock, 2011; Rietveld, 2014).

Research conducted in Aotearoa New Zealand has specifically looked into the experiences of disabled children within the school setting (Clark & Macarthur, 2008). Of the disabled children surveyed, 59% had difficulties joining in games or sport at school, 47% faced barriers playing at school, 35% needed extra support making friends, and 28% had challenges going on school outings or camps (Clark & Macarthur, 2008). Overall, 67% of disabled children had one or more challenges being included at the school they were attending (Clark & Macarthur, 2008). These experiences can be understood alongside a critique of inclusive education in Aotearoa New Zealand. The critique suggests approaches that some schools use to discourage disabled children from enrolling, including complaining about lack of funding, talking about how well the school down the road does inclusive education, or showing parents an uninviting special education area (Tiso & Stace, 2015). These behaviours are explained in the context of special education resourcing in Aotearoa New Zealand: Ongoing Resourcing Scheme (ORS) funding only is available to 1% of students who meet the high or very high eligibility criteria but not covering the total cost of education provision; and special education funding for disabled students not being based on the number of disabled students attending the school but rather being based on the total number of students at the school (Tiso & Stace, 2015). This underfunding of inclusive education results in some school preferring not to enrol disabled students, and disabled students' education needs not being met.

In relation to working through challenges and negotiating the education, health and disability system, Good et al's (2017) Aotearoa New Zealand based research provides insights into the

advocacy and activism roles of mothers with disabled children. In their study, mothers of disabled children in Aotearoa New Zealand experienced discrimination and disablism, as do mothers of disabled children overseas (Ryan & Runswick-Cole, 2008), and their research highlighted that mothers of disabled children are continuously navigating and negotiating services and support for their disabled children. Through this navigating and negotiating, mothers of disabled children develop expertise in their roles of advocates and activists, a role that Good et al. (2017) recommends is acknowledged as valuable. Recognition and support of the advocate and activist role that mothers of disabled children take on also needs to be acknowledged by professionals and others who work with these mothers and families (Good et al., 2017). This self and external acknowledgment is essential in the work towards disabled children living in communities that value them as members and are inclusive (Good et al., 2017).

Although less research has been conducted in Aotearoa New Zealand, compared with the overseas context, similarities between the shared experiences of families with a disabled child/children both here and overseas are observed. The research into Aotearoa New Zealand families with disabled children has provided valuable insights into their experiences. While the Aotearoa New Zealand research is broad in nature, the overarching themes can be drawn together: that inclusion of disabled children and their families into schools and communities, both physically and emotionally is vital; the development of appropriate resources and support for disabled children and their parents is a key indicator of this inclusion, including inclusive education; the impact of poverty on disabled children and their families cannot be ignored; and the role of professionals and the quality of relationships and communication with and between professionals has a strong influence on families with disabled children.

Single mothers in Aotearoa New Zealand

Much of the discourse on single mothers in Aotearoa New Zealand has focussed on the diminished levels of physical and mental health of single mothers, as well as the high levels of poverty that they experience. In regards to disabled children in one-parent families, these households make up most of the low-income households with disabled children (Murray, 2018). With the link between health and socio-economic status being well documented (Arcaya, Arcaya, & Subramanian, 2015; Crosier et al., 2007; Currie & Stabile, 2003; Graham, 2005), for single mothers in Aotearoa New Zealand this is also the case, with lower socio-economic status correlating with poorer health (Baker, 2002; Tobias, Gerritsen, Kokaua, & Templeton, 2009).

Poverty levels in one-parent families can be linked to inconsistencies in government policy. Areas of inconsistencies that directly negatively impact one-parent families are related to the financial implications of their relationship status, the Work and Income welfare system Accommodation Supplement and Working for Families in-work tax credits. In Aotearoa New Zealand, under the Work and Income welfare system, single parents who enter into a co-habiting relationship are given up to six weeks to declare if the relationship is a de facto relationship, in which case the single parent is then moved off the Sole Parent Support benefit as it is assumed that their partner will financially support them (Dwyer, 2015). This is in contrast to the Property (Relationships) Act, which states that if a de facto relationship lasts for less than three years, the Act will usually not apply, and each party will take out what they brought into the relationship and retain the property that is in their own name (Dwyer, 2015). Financial implications of a newly formed de facto relationship take effect almost immediately for single parents receiving a welfare payment; however, financial implications of a de facto relationship do not take effect until after three years for people not receiving a Sole Parent

Support payment. Likewise, the Accommodation Supplement is based on the number of people per family, however, it does not recognise that a two-parent family with one child requires the same number of bedrooms as a one-parent family with one child (Dwyer, 2015). Accordingly, a three-person family in Area 1 (the main urban areas in Aotearoa New Zealand) can receive up to $305 in Accommodation Supplement; however, a two person family can only receive up to $235 (Budget, 2017).

Similarly, to the disparities between one-parent and two-parent families in relation to the Accommodation Supplement, the Working for Families in-work tax credit requires that a one-parent family works a minimum of 20 hours per week to receive this tax credit. However, a two-parent family is only required to work a combined minimum of 30 hours per week (Dwyer, 2015). A one-parent family must balance childcare responsibilities with being required to work 50 per cent of 40 full-time hours, whereas a two-parent family must only balance childcare responsibility with being required to work 37.5 per cent of 80 combined full-time hours. Given that the majority of one-parent families are headed by women, this directly impacts single mothers.

As well as health and socio-economic disparities between single-mother led families and two parent families, single mothers in Aotearoa New Zealand have been constructed as a problematic 'Other', and perceived as different to "ordinary" women, mothers and citizens (Beddoe, 2014; Breheny & Stephens, 2009; Patterson, 2004). In addition to this, within the context of welfare reform, women who parent alone are judged negatively and single mothers have been the subject of continued welfare reforms (Patterson, 2004). Being a mother on welfare is described as transgressing the social norms of appropriate family structures, and the relationship norms sanctioned within these structures (Breheny & Stephens, 2009). Mothering

while on welfare is regarded as undermining rather than contributing to society (Beddoe, 2014; Breheny & Stephens, 2009). The finding that there is a negative Aotearoa New Zealand construct of single mothers receiving welfare payments is similar to overseas research, which also shows that the single mother status is stigmatised. (Usdansky, 2009; Zartler, 2014).

The Social Report uses statistical indicators to monitor trends across key dimensions of people's lives to provide a picture of progress towards better social outcomes for New Zealanders (Ministry of Social Development, 2016b). *The Social Report* finds that women more likely to feel lonely than men, that people who lived in single-parent households were more likely to feel lonely than people in any other family type, and people earning less than $30,000 per year having the highest levels of loneliness (Ministry of Social Development, 2016b). Smith (2015) distinguishes loneliness as both an individual problem and as a social problem; as an individual problem it is associated with negative health outcomes such as suicide and depression, and social exclusion being associated with obstructing community well-being (Smith, 2015). As in *The Social Report*, loneliness is identified as declining with age but peaks again at the end of life, and is linked to socio-economic status, gender and health (Ministry of Social Development, 2016b; Smith, 2015). In relation to this research, single mothers fall into the female, single parent, and possibly lower levels of socio-economic status groups identified as having higher levels of loneliness. The exploration of loneliness matters because humans rely on a safe, secure social surround to survive and thrive (Hawkley & Cacioppo, 2010). The physical and mental health consequences of loneliness have been linked with personality disorders, impaired cognitive performance, and depression (Alan J, Alison, Martha C, Lawrence J, & Ian J, 2007; Bunney, Kleinman, Pellmar, & Goldsmith, 2002; Hawkins-Elder, Milfont, Hammond, & Sibley, 2018; Hawkley & Cacioppo, 2010; Neeleman & Power, 1994).

Summary

Within the available overseas literature, it is perceivable that single mothers of disabled children are, in most cases, poorer than families with non-disabled children (Currie & Stabile, 2003; Graham, 2005; Heywood, 2010; Park et al., 2002). Research by Emerson et al. (2006) suggests that the increased risk of psychological distress among mothers with a disabled child/children could be attributed to their increased probability of having a lower socio-economic status, compared to mothers with non-disabled children. This is based on research findings on well-being and psychological distress are linked to socio-economic position (Fryers, Melzer, & Jenkins, 2003; Power, Stansfeld, Matthews, Manor, & Hope, 2002). The experiences of single mothers with disabled children who were in paid employment identified many positives, such as increased family income, career progression, and increased social opportunities; however, challenges were also identified, including needing to juggle attending appointments with their disabled children with employment commitments, and the need for a good support network to make employment a viable option (Cole et al., 2016). As in the Aotearoa New Zealand research, resources and support are essential for single mothers with disabled children (Waldegrave et al., 2011).

It is evident that overseas research on single mothers with disabled children is similar to the Aotearoa New Zealand context. However, much of the research or literature conducted in Aotearoa New Zealand still largely focused on the two-parent families. Examining single mothers' strengths and challenges in raising disabled children on their own will support and contribute to the growing this knowledge base. The following chapter will focus on an in-depth discussion on social constructionism, the theoretical underpinning of this research, and how this relates to both disability and single mothers.

Chapter Three: Social Constructionism

Introduction

The purpose of this chapter is to discuss social constructionism, the theoretical underpinning of this research. This research draws attention to the experiences of single-mother led families with disabled children. Social constructionism guides this research firstly because of the socially constructed meanings of disability, single mothers, parenting disabled children, and mothering on welfare. Secondly, this research focusses on the experiences of these mothers, and interprets the meanings that they have created within their experiences. Social constructionism is a meaning making activity (Crotty, 1998), and this meaning making is both unique to each single mother, and also collective in shared understandings, and allows the development of alternative knowledge and understandings. This chapter provides a discussion on the socially constructed meanings of disability, parenting a disabled child/children, single mothers, and mothering on welfare.

The social construction of disability

The oppression of disabled people is deeply ingrained in the political, economic and cultural dimensions of everyday life (Goodley & Runswick-Cole, 2011). Commonly held attitudes towards disabled people are framed in terms of personal tragedy, and impairment is seen as abnormal by the prevailing medical model, which portrays disability as a problem that is located within the individual (Barton & Oliver, 1997; Goodley & Runswick-Cole, 2011; Morris, 2014; Oliver, 1986; Stone & Priestley, 1996). Studying disability from a medical perspective was done to increase knowledge and information about how to make the impairment cease to exist (O'Brien & Sullivan, 2005). Impairment as a medical condition is seen as something to either be prevented or cured (O'Brien & Sullivan, 2005). However, the

disability rights movement has challenged this social construction of disability. The social model of disability, first developed by the Union of the Physically Impaired Against Segregation in the United Kingdom and summarised by Oliver (1996), argues that disability is caused by the way society is organised, rather than by a person's impairment; it is society that disables. Having a social model of disability view locates external factors as the source of disability, rather than the impairments of an individual.

The social model of disability has since been expanded and developed, with there now being a number of social models of disability. Shakespeare and Watson (2001) reject the strong separation of disability and impairment, with their view being that impairments do cause restrictions in activity, some of which are not imposed by society. The social relational model of understanding disability considers the social construction of disability, as well lived experiences of impairment and social relationships (Cologon, 2016; Thomas, 1999, 2004). The social relational model also outlines barriers to doing, barriers to being, and impairment effects (Cologon, 2016; Thomas, 1999, 2004). Barriers to doing are the material, physical or economic barriers such as inaccessible buildings, playgrounds or community events, which prevent disabled people from being involved (Connors & Stalker, 2007). Barriers to being are external factors such as inappropriate or hostile words or actions by individuals or organisations/society that impact a person's sense of self, such as parents experiencing discrimination or intolerance in relation to their disabled child/children (Jarrett et al., 2014). Families with disabled children also experience inequalities that are not experienced by families with non-disabled children (Cologon, 2016; Colver, 2006; Dowling & Dolan, 2001; Goodley & Runswick-Cole, 2012; Goodley & Tregaskis, 2006; Heywood, 2010; Jarrett et al., 2014). These inequalities are both of opportunities and of outcomes, such as increased rates of poverty and decreased rates of employment for the main caregiver, and are experienced by the whole family, with the

inequalities resulting in a reduced quality of family life (Cologon, 2016; Colver, 2006; Dowling & Dolan, 2001; Goodley & Tregaskis, 2006; Heywood, 2010).

Parenting a disabled child/children, single mothers, and mothering on welfare

The meanings of disability and impairment in relation to parents having a disabled child/children are created and recreated in the interactions between the parents, professionals, and other non-disabled people (Goodley & Tregaskis, 2006). Meaning also follows the diagnostic label, and its repetition creates a category, with the associated signs, symptoms, behaviour and normative expectations (Hughes & Paterson, 1997). Common throughout parents' experiences of the diagnosis is the deficit story of personal tragedy or loss (Brett, 2002; Case, 2000; Cologon, 2016; Goodley & Tregaskis, 2006; McKeever & Miller, 2004). Parents describe feeling the tension between hearing the deficit story and seeing their disabled child as their child who was loved and very much part of the family (Brett, 2002; Case, 2000). Some professionals' view of the child's impairment is that it is all-encompassing of the child, in contrast to parents' views, which is to experience their child's impairment as one aspect of who their child is, with the recognition that having a disabled child does not mean that they love their child any less, or that their child's life is not worth living (Goodley & Tregaskis, 2006). This challenges the medical model discourse around grief, and loss of hopes and dreams, which parents are expected to experience, and while these feelings may be present, they can be held alongside love and acceptance of their child (Goodley & Tregaskis, 2006). This links to the concept of radical acceptance in relation to parenting disabled children. Although parents aim to help their disabled children grow and learn to the best of their potential, parents also want to change the world to accept their disabled children just as they are (Good et al., 2017). Parents advocating for their disabled children work to create an accepting and inclusive society for their or other disabled children to grow up in (Good et al., 2017)

Green (2007) and Ryan and Runswick-Cole (2008) point out that the way that parents with a disabled child/children are portrayed in the current body of literature is narrow and often negative. These parents are commonly described as delusional, acting in their own self-interest, or having grief, loss or denial issues to deal with (Green, 2007; Ryan & Runswick-Cole, 2008). Parents face the challenge of describing the experiences of raising a disabled child/children, along with the difficult everyday tasks that come with this, while at the same time not confirming the societal view that raising a disabled child/children is an all negative experience (Green, 2003; Ryan & Runswick-Cole, 2008). Likewise, there is the risk of romanticising families with a disabled child/children, which puts families into the category of other, rather than a family with goals and dreams, just like any other family, once they have established their new normal (Green, 2003; Ryan & Runswick-Cole, 2008).

The experience of receiving the diagnosis of their child's impairment can be a very powerful and lasting memory for parents with a disabled child (Goodley & Tregaskis, 2006; Smith & Daughtrey, 2000). For some parents, the diagnosis process highlights the stigma associated with having an impairment, and the societal context of disabled adults being devalued, and from this, experiencing the reality of some professionals not seeing a disabled child as having value (Brett, 2002; Case, 2000; McKeever & Miller, 2004). Parents find that they and their children are often treated with disrespect. For other parents, having a diagnosis provides them with certainty, as well as access to support services (Goodley & Tregaskis, 2006), although it is also suggested that the current cultural context of mother-blaming may be a reason why some parents embrace the diagnosis label that their children receive (Ryan & Runswick-Cole, 2008). The notion of 'mother-blaming' describes mothers being held responsible for the actions, behaviour, health and wellbeing of their children, and this includes their adult children (Caplan

& Hall-McCorquodale, 1985). A diagnosis can be seen to shift the blame from the mother to the impairment.

Many women also carry the weight of societal mother-blaming either because they do not fit society's view of motherhood or because they behave in ways considered inappropriate for mothers (Jackson & Mannix, 2004). In her auto-ethnographic study on raising a disabled child, Zibricky (2014) talked about since she became a mother of a disabled child, she has encountered the beliefs created by the authoritative institutions of society such as medical institution, educational and legal system of what counts as valid, normal and legitimate, particularly when the dominant culture has historically been "men who are White, middle-class, Christian, heterosexual and able-bodied" (p. 39). Mother-blaming is very evident in women's experiences of single parenting (Jackson & Mannix, 2004). For decades, Feminist scholars have argued that women are cultivated into the culture of motherhood as they navigate a world dominated by men and authoritative knowledge that define the roles of women, mothering practices and motherhood (Badinter, 1981; O'Reilly, 2010; Rich, 1995). The increase in the number of single-parent families, the majority of which are led by mothers, has been one of the most studied social changes in the 20th century (Heuveline, Timberlake, & Furstenberg Jr, 2003; Moynihan, Smeeding, & Rainwater, 2004; Usdansky, 2009). A universal Western trend is that childrearing is being shifted from married parents to single mothers, more than to cohabiting parents, stepfamilies, or single fathers (Heuveline et al., 2003). This is especially relevant for children born in Aotearoa New Zealand, as this country is second only to the United States in the percentage of a birth cohort in the 1990s being in a single-parent family, at 49% (Heuveline et al., 2003). In recent times, it has been argued that the issues facing mothers have been extended well beyond the traditional feminist argument of patriarch oppression but "intersect with other forms of oppression such as race/ethnicity, gender and

class" (Stitt & Powell, 2010, p. 9). For example, single mothers are claiming their space in terms of their own lived experiences (Duquaine-Watson, 2010); lesbian mothers are challenging the societal discrimination about normative family structure and child-rearing (Epstein, 2010); and mothers raising gay or transgender children in a society that is underpinned by heterosexuality (Pearlman, 2010). However, there is still a lack of research and literature about mothers, especially single mothers, raising disabled children.

There are three paths through which single-mother led families are created: children born or adopted to/by a single mother, parental separation of either a cohabiting or married couple, and the death of a parent based on Usdansky (2009). In relation to divorce, disparaging portrayals of divorce fell dramatically between 1900 and 1998, which was due to debates about the moral aspects of divorce ceasing . However, this silent acceptance of divorce did not extend to non-marital childbearing, which was portrayed just as unfavourably in the 1990s as it was in 1900s. It was suggested that this was because of the number of people who were affected by divorce was much higher than those affected by non-marital childbearing. The depiction of non-marital childbearing continues to be synonymous with blame of the single mother, as well as questions about her morality. Within Aotearoa New Zealand, single mothers are constructed as lacking discipline and moral fibre, with assumptions about her character based on her family formation (Longhurst et al., 2012). This links back to mother-blaming, women carrying the weight of disapproval because they do not fit society's view of motherhood (Jackson & Mannix, 2004). Single mothers are also expected to feel guilt for burdening taxpayers through receiving welfare payments and for raising children without a live-in father (Longhurst et al., 2012).
Women receiving welfare payments are stereotyped as trying to find ways to cheat the system, whether by getting pregnant to receive welfare payments, or failing to declare extra income, or receiving numerous welfare payments while sitting idly at home (Davis & Hagen, 1996).

Central to these stereotypes is the belief that women who receive welfare payments are lazy and lack the motivation to find paid employment to support themselves and their children (Davis & Hagen, 1996). There is also a belief that because of these stereotypes, women who receive welfare payments are undeserving, devious and dishonest (McCormack, 2004). In Aotearoa New Zealand, mothering on welfare has been constructed by some health professionals as a social problem because these mothers are transgressing social norms of appropriate family formations (Breheny & Stephens, 2009). Normative understandings based on a nuclear family ideology are linked to negative constructions of single-mother led families, with single-mother led families being constructed primarily in terms of deficits and disadvantages (Zartler, 2014). The nuclear family is portrayed as the family type to be aspired to, and is portrayed as normal and stable (Zartler, 2014). This portrayal of the nuclear family being the family type to be aspired is similar to the medical perspective that the un-impaired body is what should be aimed for. These social constructions of single-mother led families and disability as less than aspirational are central to analysing this research.

Summary

Social constructionism provides a foundation for understanding and analysing this research, which is to explore the experiences of single-mother led families with a disabled child/children, in particular, the understandings of the social constructs of single mothers and of disability, and the impact of these social constructs. The methodology of this research draws on the principles of an interpretative approach, which also stems from social constructionism. The research methodology is outlined in the following chapter.

Chapter Four: Methods

Introduction

The aim of this research was to produce insights into the understanding of single-mother led families with a disabled child/children and their journey dealing with the challenges and opportunities of caring for their child. An interpretive, qualitative approach was employed to guide this research on how to make sense of their experiences. This chapter begins with a discussion on the study design and then describes the interviews of six single mothers with a disabled child or children. It then provides a description of the sampling process, data collection, data analysis, and ethical considerations. The chapter is concluded with an overview of the process used to enhance trustworthiness of the research.

Study design

This research has the theoretical underpinning of social constructionism, and within this, principles of a qualitative approach, alongside interpretive description methods, were used to address the aims of the research. Qualitative research is described as being interpretivist, subjective, and exploratory (Spicer, 2012), and focusses on interpretation and contextualisation (Davidson & Tolich, 2003). Using a qualitative research approach was essential in the research design because the experiences of single mothers with disabled children are the foundation to this study, and the exploration of these experiences provide the underpinning of the analysis of the data. Qualitative research allows investigation into specific areas by going into a great deal of depth on the subject (Davidson & Tolich, 2003). These experiences are located within the wider context of being a single mother in Aotearoa New Zealand, and within the context of parenting a disabled child/children. The research aims to understand the experiences within these contexts, while also recognising the individuality and distinctiveness of each situation.

Interpretive description principles and methods were used alongside the qualitative approach. These principles include the research being to understand and describe meaningful social action, the nature of social reality being changeable and subject to situational context, and people's interpretation and meaning making of their contexts and life (Davidson & Tolich, 2003). Interpretive description principles provide the basis for the conceptual links that develop when the particular is located within the general, and the subjectivity of experience positioned within commonly understood social constructions (Thorne, Kirkham, & O'Flynn-Magee, 2004). These principles inherently align with the acknowledgement that subjective experiences are fundamental in forming the reality of the individuals interviewed, and therefore the information they have provided for this research. In this research, the subjective experience is the experience of being a single-mother, in a single-mother led family with a disabled child/children, and the research explores this experience.

Study participants

The recruitment process was commenced upon receiving ethics approval from Massey University Human Ethic committee (Appendix A). To be eligible to participate in this research, the three selection criteria were: (1) single mothers who reside in the greater Wellington region; (2) who have a child aged between 5 and 12 years old with a disability that qualifies the mother to either receive a Work and Income child disability allowance and/or carer support through a Needs Assessment and Service Coordination (NASC) agency; and (3) can speak and understand English without needing to use a translator during the interview. A broad view of what defined a single mother was taken, with single mothers being either: never married; separated; divorced; or widowed. The single mothers needed to have children in their care, and this included mothers with shared care arrangements. The reason to specify the age range of the child being between five and 12 years old was because during this age, there may be broader

social connections and interactions taking place when compared to the preschool years. It was anticipated that the child aged five and above would be old enough to attend school and/or respite. Parents with a teenage child with a disability were excluded to keep the focus of the research away from any potential relationship complexities between the parent and the teenager (Williams, 2003). Recruitment took place between April 2017 and November 2017.

I first contacted the manager of an organisation that works with one parent families in Hutt Valley and they agreed to circulate my letter requesting permission (Appendix B) and information sheet (Appendix C) to potential participants in their client database. An organisation consent form was provided to this organisation (Appendix D). Organisation staff circulated the advertisement (Appendix E) and information sheet, and interested mothers had my contact details from the advertisement and could contact me directly regarding the research. Two of the participants involved in the research were recruited via this organisation, with neither of these participants receiving current social work support from their staff. I contacted this organisation in Hutt Valley because of their targeted work with single parents. My knowledge of the organisation came from previously working at there as a social worker, although I had ceased my employment from there approximately two years before I began the recruitment for research participants.

In addition to the support from the organisation mentioned above to recruit potential participants, a snowballing process was also employed. Snowball sampling is a qualitative method used to reach a target population, with potential participants being referred by previous participants. With the aim of this study being primarily explorative, qualitative and descriptive, snowball sampling offered a practical advantage in accessing a participant group who may be harder to reach (Atkinson & Flint, 2001). With single mothers doing the job of two parents,

spare time to be involved in a research project might be limited. By using snowballing, potential mothers were encouraged by previous participants to find out more about the study. Three mothers were recruited via snowballing; I was told they might be interested in being involved in the research by three other mothers who had expressed an interest in the research but did not meet the criteria. The mothers' who potentially had an interest in being involved in the research agreed with their contact details being given to me. The advertisement and information sheet were sent to these three mothers who expressed an interest in the research project, and they decided, once reading the information sheet, that they wanted to be involved in the research. The sixth and final mother was recruited through posting the advertisement on my Facebook page.

By November 2017, six mothers were successfully recruited and the final interview was completed that same month. During the recruitment period between April 2017 and November 2017, as mentioned previously, I had three mothers express an interest in the research, but who did not meet the criteria, one because of the age of her child and the other two because of their marital status. I needed to decline their involvement due to the specific area that I was researching; however, these three mothers went on to pass the information about the research on to three other mothers, who did meet the criteria to be involved in the research.

Data Collection

Qualitative, semi-structured interviews were used for the data collection. Qualitative interviews achieve depth, reflect complexity, and allow participants to answer in their own words (Byrne, 2012). Furthermore, this form of interviewing allows the participants to give answers that do not conform to the researchers' expectations, whether these expectations are known or unknown (Ackerly & True, 2010). A semi-structured interview template with key questions

(Appendix F) was constructed but an open and fluid process was also employed to ensure there was flexibility for participants to discuss any related experiences and topics during the interview process.

Once email confirmation was received from the participants with consent to be involved in the research, a mutually agreed time and venue was arranged for the interviews to take place. Before commencing the interview, each participant was presented with the information sheet to remind them of their rights and responsibilities, followed by signing the consent form (Appendix G). They were further reminded of their right to ask for the recorder to be turned off at any time, to seek clarification from the questions and to take a break if needed. The six interviews lasted on average between 40 and 60 minutes. Four interviews took place in the participant's home, and two in public spaces. For safety reasons, if the interview took place at the participant's home, I advised another person of the address, and let them know when I arrived at the address, and again when I left. All interviews were digitally recorded and transcribed verbatim by the researcher. Once transcribed, they were sent to the participants for accuracy checking. None of the participants made any changes to what was transcribed from the research interview. They all agreed for the transcripts to be used for data analysis and write-up.

Data Analysis

A thematic analysis of the interviews was carried out using an interpretive descriptive approach. Thematic analysis is a foundational method for qualitative analysis, and can provide a rich and detailed, yet complex, account of data (Braun & Clarke, 2006). Thematic analysis focusses on the lived experience of the individuals of interest (Ravis, 2012), and is a method for identifying, analysing and reporting themes within data (Braun & Clarke, 2006). In

preparing for thematic coding, Ravis (2012) describes theoretical sensitivity, which is the researcher's sensitivity to concepts, meanings and relationships within the data, which comes from the researcher's professional and personal experiences, and is also influenced by reading relevant literature. An interpretive description approach reasons that it is the researcher who determines what constitutes data, which data is relevant, and how the findings will be structured and disseminated (Thorne et al., 2004). There is a strong awareness that the research interpreter is an essential element in making sense of the data and producing research findings (Thorne et al., 2004).

Thematic analysis began during the data collection process, with the researcher reflecting on earlier interviews and identifying themes and ideas from these interviews to consider during future interviews. Following this, transcribing the interviews laid the foundation for in-depth engagement with the interview material. Formal data analysis took place with interpretive skills used to begin coding ideas that related to the research aims, alongside reviewing the earlier reflections. The transcribed interviews were re-read numerous times to identify patterns, which were then grouped into themes. These themes were scrutinised against the research aims, relevant literature and researcher knowledge, and also overlaid with the data, to ensure that the themes remained consistent with the original data. This movement between the data and the themes took place several times to ensure the accuracy of the data that was determined as relevant and the interpretation of that data. Following this, a detailed analysis of the themes took place, describing the experiences of single-mother led families with a disabled child/children in Aotearoa New Zealand.

Ethical Considerations

The research was approved by the Massey University Human Ethics Committee, application 15/54, (Appendix A), and research commenced once ethics approval had been gained.

The Massey University (2015) Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants' major ethical principles include: respect for persons; minimisation of harm to participants, researchers, institutions and groups; informed and voluntary consent; respect for privacy and confidentiality; and social and cultural sensitivity to the age, gender, culture, religion, social class of the participants.

The ethical principles of the Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants were the foundation for the research process. With regards to respect for persons and minimisation of harm, the interview process had the potential to bring up previously unresolved issues or unexplored feelings in the participants. If this happened, a list of support organisations was to be left with the participant for them to self-refer to. The emotional safety of the participant was of utmost importance. Although that plan was in place, none of the interviews did bring up previously unresolved issues or unexplored feelings in the participants.

Informed and voluntary consent was gained at the onset. As outlined previously, I provided the participants with an Information Sheet when they enquired about the research, and if they expressed their interest in being involved, I went through it again when I met with them for the interview. I also went through the Consent Form with the participants and explained that I would provide them with a written copy of our interview for them to review, which I transcribed myself.

The participants had the option of having their audio file returned to them, which respected their rights regarding person data. The participants could ask for the voice recorder to be turned

off at any time during the interview, all recordings were securely stored, and only I listened to and transcribed the recordings. Participants had their transcript sent to them for editing and proofing, and only the approved draft was used. A summary of the research was also given to the research participants at the conclusion of the research.

Finally, throughout the recruitment and interview process I needed to recognise the power relationships involved in this research due to the participants being single parents and belonging to a socially vulnerable group. I also needed to be aware of any socioeconomic and/or educational disparities between myself and the research participants, and I had a responsibility to recognise my own cultural location.

Trustworthiness

The list of questions for the semi-structured interview was reviewed by my research supervisors for the purposes of content validity. These questions had been generated following the literature review, and I also used my knowledge from working as a social worker with single parents who had disabled children. Goodley (2011) asks if, when doing disability research, we are capturing our research participants' meaning in the research. In this research, this was done through giving the research participants the opportunity to read through their transcribed interview and make modifications or corrections, to ensure it was an accurate reflection of their experiences. Triangulation also took place through using data from overseas research on this subject area and combining this with the data obtained from the interviews (Flick, 2015), as well as regular supervision sessions between the researcher and the supervisors to reflect on the research and discuss concepts during the analysis.

Other credibility indicators for qualitative research are dependability and transferability. Given my insider perspective, it was essential that these credibility indicators were used to avoid biases. Dependability involves a study design linked to clear research questions, a specific explanation of the status and role of the researcher, and identifying theoretical constructs and analytical frameworks (Toma, 2011). The aim of this research was to produce insights into the experiences of single-mother led families with a disabled child/children, and this was clearly linked to the study design. The theoretical underpinning of social constructionism and principles of a qualitative approach, alongside interpretive description methods and thematic analysis, are the theoretical constructs and analytical frameworks for this research. Theoretical constructs and analytical frameworks also contribute to transferability, as connecting the theoretical framework with a body of theory allows those who make policy or design research to determine whether the findings are applicable to them and thus transferable (Toma, 2011).

My credibility, competence, and perceived trustworthiness as the qualitative researcher, due to my insider perspective, also needed to be addressed. The researcher is the instrument in qualitative inquiry (Patton, 1999), and as the researcher I have located myself, which includes, most importantly, the perspective I bring to the field. As discussed previously, I bring the perspectives of having worked as a social worker alongside single mothers who have a disabled child/children, as well as having been a single mother, and more recently, having a disabled child of my own. The notion of the researcher locating themselves is to report any personal and professional information that may have affected data collection, analysis, and interpretation either negatively or positively in the minds of users of the findings (Patton, 1999). It also acknowledges that researchers do have a background that has led them to the current position of researching the specific topic. I used a journal to document my thoughts during the research processes for critical reflection.

Summary

In summary, this chapter has presented and discussed the methodology and methods for the research, with the purpose of this research to provide insight into the experiences of single-mother led families with a disabled child/children in Aotearoa New Zealand. This research has used a qualitative methodological design to explore, interpret and contextualise the experiences of single mothers with disabled children. Furthermore, this research was informed by the principles of an interpretive descriptive approach, acknowledging the nature of social reality being changeable and subject to situational context, with people's interpretation of this providing meaning through context in their life. Qualitative, semi-structured interviews achieved the depth of information and experiences of single mothers with a disabled child/children required by allowing participants to answer in their own words. By allowing the participants to elaborate where they had placed significant meaning and importance in their experiences and lives, insight is provided into the personal contexts, which further aligns with the qualitative methodology. To gain this insight into the shared experiences of the participants, thematic analysis of the interviews was carried out, identifying patterns and themes among and between them. Finally, trustworthiness of the research was reviewed and addressed. The following chapter presents the data from the six single mothers with disabled children who participated in the research.

Chapter Five: Results

Introduction

The current research explored the experiences of single-mother led families with a disabled child/children in Aotearoa New Zealand. A brief background of the single mothers who participated in this research will first be described. Pseudonyms have been used to protect the identity of the mothers. Analysis of the data from the interviews resulted in four themes being identified. *Italics* have been used to indicate a direct quote or statement from the participants. The four themes are: (1) social isolation and loneliness; (2) challenges in accessing support services; (3) coping and contentment; and (4) negotiating employment and care work. The themes are presented in the order in which they were identified.

Brief background of the mothers

The six mothers who participated in the research were aged between their 30s and 50s, and all were parenting alone. One participant had a shared care arrangement, with her children being with her one week and her ex-husband the following week, and the other five participants had their children with them full-time. Two of the mothers were in paid employment, one was a student, and the other three parented full time. Two participants had unique relationships with their child/children: one participant was a caregiver of her two grandchildren, while another participant had fostered her non-biological son since birth. Three mothers had one disabled child and three had two or more. Table 1 provides a brief description of the mothers who participated in the research.

Table 1: Brief descriptions of the six single mothers who participated in the study

Name	Age	No. of children	Ages of children	No. of disabled children	Impairment of child/children	Employment status
Lucy	30s	3	9, 5, 3	2	Autism, global developmental delay	Full-time
Kate	30s	4	18, 16, 8 (twins)	3	Cerebral palsy, autism, intellectual disability	Not employed
Ruth	30s	2	6, almost 5	1	Autism	Not employed
Vera	40s	1	10	1	Chromosome disorder	Not employed
Lara	40s	1	8	1	Multiple diagnoses	Part-time
Rose	50s	2	8, 6	2	Autism, ADHD	Not employed

Lucy was in her 30s with three children, two who had impairments. Lucy's children come from two relationships. Lucy had recently returned to paid employment and shared the care of her three children with her most recent ex-husband, with the care arrangement being that Lucy had her children in her care for a week, then her ex-husband had them in his care for a week. Lucy employed a nanny to look after her children while she was at work. Lucy described herself as a very organised person: *I've always been the one who has managed everything to do with their (children's) medical stuff, any schooling, all that sort of thing.*

Kate was in her 30s with four children, three who had impairments. Kate identified herself as a student and spent most of the school hours doing her study. Kate has two children from one relationship and two from another. All of Kate's children live with her full-time. Kate said she keeps strict routines to keep things on track: *Getting up about an hour and a half before the children to prepare lunches, breakfasts and everything I can think of to keep the routine the same.*

Ruth was in her 30s and has two children, one who has an impairment. Both of her children came from the same relationship. Ruth had a successful career prior to having her children and has been the full-time caregiver to her two children since they were born. Ruth said: W*hen he got the diagnosis, I realised I couldn't even return back to work… so I had to just completely surrender to everything, just completely surrender to what the situation is.*

Vera was in her 40s and has one child with impairments. Vera has not been in employment since her child was born and has been his full-time caregiver. Vera has been very involved with Facebook support groups relating to her child's impairment and considered this a way to give and get support. Vera said: *I found other families with similar variations across the world, and also through Facebook groups, so that's my big support now.*

Lara was in her 40s and has fostered her son, who has multiple impairments, since his birth. Lara has been working during school hours and was very passionate about fighting for her and her child's rights and calling out inconsistencies. She described one incident at Work and Income:

> *The case manager was trying to tell me that normal single mums live on $256 per week. So I just turned around and told him he was full of shit [sic]. Because not even rent is less than $250 a week, so don't lie.*

Rose, in her 50s, has been raising her two grandchildren who both have impairments since their birth. Rose remained out of paid employment to care for her grandchildren, who live with her full-time. She expressed hopes that her daughter would one day come back and be involved in their lives. Rose said: *That would be an awesome buzz, if she just gets herself sorted, and be here for us.*

Theme One: Social isolation and loneliness

All of the mothers in this research discussed the social isolation that they experience, which is predominantly due to practical factors such as not having enough money to go out, not going out because of perceptions of their child's behaviour, and the limiting factors such as unfenced playgrounds and no extra support available to assist with level of supervision needed at environments outside of the home. Financial stress was also identified as one of the leading factors that prevented these mothers from being socially engaged. Kate stated that *we very seldom do anything now, the cost is far too high.* Even when the outing was not a family event, the cost of a babysitter alone was high enough to prevent some families from going out to spend time with friends. This was the case for Lara who said:

> *I have no social life, I have no friends, I sit at home on my own watching TV. I just can't be spending $50 to get a babysitter, who has to be a specialised babysitter in case he has a tantrum or a meltdown, he can trash the house. And I can't afford anything else. That's just one income, and we budget on the one income.*

In addition to the financial stress, the extra support required for the disabled child/children to be in social situations was also a contributing factor to social isolation. These mothers have expressed that the stress associated with managing the social perception of their child's behaviours being inappropriate as being a strong deterrent in going out, socialising, or pursuing and maintaining friendships. The anticipation of what an outing would probably end up like was enough to stop Lara from taking her child out. She said y*ou can't go to the park because he doesn't like the bloody [sic] swing or he doesn't like that kid because he's got a red jumper on.* Ruth shared similar experiences in which she said, *it would only take that one child to come up and snatch something from him, or them cry and it would just ruin the whole day. It would be very, very stressful.* Vera identified the challenge of meeting up with parents who have non-

disabled children: *It's hard and it's also quite lonely because you don't often match up with other parents with children who don't have issues.* These are some of the experiences that single-mothers with disabled child/children face both in social situations and when alone. Most of these mothers have discussed their concerns over the stress associated with the perceptions of their child's behaviour needing to conform to the norm or being judged by other parents and outsiders, and this has made them choose to distance or isolate themselves rather than having to take time and effort to try to manage the perceptions of others.

Aside from dealing with social and public perceptions of the issues attached to the 'disabled family', environments in which people may be familiar or accustomed to non-disabled children may present significant barriers or safety hazards to disabled children. Lucy who has three children, two of them with impairments, said she often had to set limits and boundaries when going out with her children (or choose not to go out) because she knew the type of capacity and capability that her and her children would be able to handle. She said, *when I'm on my own I don't really get out of the house a lot with the boys because it's quite a lot to handle all three of them on my own.* Lucy, like many of the mothers in the current study, had to structure and organise her home environment to cater to the needs of her children by having extra safety latches on exits, keeping the surroundings uncluttered and limiting high-sensory items or situations. Although Lucy felt she has no difficulties managing her three children in her own home, she said by choosing a "manageable" environment for her and her children to live and play in , it has somewhat reduced their opportunities to participate fully in the community; thus, increasing their social isolation and loneliness.

Financial constraints, constant encounters with public and societal perceptions of the 'disabled family' and safeguarding their disabled children to live and play in a 'manageable' environment

were some of the key barriers identified by the mothers in this study that contributed to their sense of social isolation, not just for themselves but also for the other members of the family. Two of the six mothers in this research explicitly stated that they have no friends. Rose stated that *I really don't worry about friends, I'm all on my own.* Lara stated that *I have no social life, I have no friends, I sit at home on my own watching TV.* When the family includes a disabled member, time and effort must be dedicated to them as they normally have greater requirements for care.

In the current study, the repercussion of the extra time required for the disabled child's needs is putting the needs of the mothers and other siblings to one side, creating more pressure for the families. This was echoed by Ruth who discussed the negative impact on her non-disabled child due to additional care and requirements she spent looking after the disabled child: *she's [non-disabled daughter] very social, and that was very isolating for her.* While parents, such as single-mothers in the current study, of disabled children can experience loneliness and exhaustion from battling with schools and social services, struggling with a lack of support from family members, to challenging the sometimes ill-informed and negative public attitudes, siblings of disabled children can often feel overlooked and in need of emotional support.

Theme Two: Challenges in accessing support services

Several challenges in accessing support services were identified by mothers in this research. These include lack of guidance and visibility of what support services are available to them and their disabled child, the cost associated with receiving these services, and using carer support allocation.

Five out of the six mothers said that support services they found to be useful, either to them or their family, were encountered by chance or through their own proactive investigation. Mothers talked about the process of finding helpful information for them and their children as being predominantly through good luck and using their existing networks. Lara explained:

> *You're never told what you are entitled to, you have to try and figure it out yourself. Basically, I thumb a ride through Facebook and ask other parents what they got and how they got it.*

Some of the support services, such as respite, that these mothers found out by accident were essential to them and their children. Lara said: *Like I didn't know respite existed, someone told me. I was like, holy crap [sic], we can get respite, we can get care.* This view was echoed by Kate, who described finding out that she could use the Driving Miss Daisy companion driving service, instead of regular taxi services, and how helpful and accommodating the drivers of Driving Miss Daisy had been to her and her children, even going as far as carrying her children's car-seats back into the house for her. She said *we accidentally stumbled across them and they have been just amazing.* Vera also shared similar experiences of only recently finding out about a service that has been very beneficial to her son and said *but I think it's also knowing what's available out there to be able to access. Sometimes it's only by word of mouth that you find out from another parent.*

Two mothers, Vera and Lucy, identified the need for some form of disability navigation service that parents would be able to connect with, to inform them which disability organisations are available, and the services and support that they offer. Vera voiced her concern about the passivity of support organisations she experienced: *I think it's also knowing what's available out there to be able to access. There's nothing handed to you that says these are all the things that the organisations do.* In one instance, Vera described parents with disabled children not

knowing that they may be eligible to receive the Child Disability Allowance or that they may be able to access behaviour support services to help them with their child's behaviour. Because of this, Vera wanted support services to be proactive in their approach in working with families with disabled children through referring to other organisations who could also be of assistance:

> *It would also be nice if organisations talked to each other and I think that even when you first get your diagnosis, you got an information pack that said these are the services. I know so many people who don't know about things like the Child Disability Allowance and things like that.*

Many of the mothers in this study shared their frustration that they had to fight to get support and often the support available was insufficient or inappropriate. They often felt exhausted because they ended up being left to cope alone. Most mothers reported a convoluted process involved in assessment and in accessing services. A certain level of skill was expected of them in understanding the processes, which for some mothers was a difficult and time-consuming task. Lucy suggested that responsibility could reside with the support organisations to actively contact and engage with eligible clients. Lucy said:

> *I think it would be good if with some of the organisations, it was an automatic referral, where they contacted you, rather than you needing to be on top of it and contacting them.*

Lucy also identified that the day to day challenges of parenting with more than one disabled child should enforce the health system to be proactive rather than relying on parents to make and follow up referrals. Lucy explained:

> *Trying to make sure that I was on top of referrals for two different kids and at two different stages too, trying to keep on top of all of those by making referrals for one, then a year or so down the track I would have to make a referral for the other one.*

It was not unusual for these mothers to be in contact with a range of services and professionals and they have to deal with a bewildering number of appointments and assessments. This can leave them feeling like they spend too much time coordinating different agencies rather than being supported to care for their family and be a mother. As a result, some of these mothers did not have time to take part in everyday activities such as going out to work, going to the park or helping their children with homework. This was exacerbated by the need to attend to the needs of the non-disabled children, which Lucy described as:

Trying to keep on top of all of those as a mum, and trying to make sure that you are managing everything else, and not neglecting the kids that don't have extra needs too.

Another challenge in accessing support services was the financial cost of unsubsidised disability related therapy and medication. Rose talked about the challenge that she had getting unsubsidised medication reimbursed via a Work and Income approved Disability Allowance, and the amount of time and advocacy work that it took for this to be achieved. She said:

I wasn't getting any Disability Allowance, it was really hard. They needed some reports from the doctors that my grandson goes to. So I went through all that channel, and when I got it, they had to back-pay me for two years.

Rose also described the cost of unfunded medication for her grandson, compared to the cost of her medication: *Melatonin for sleeping, that's $52, they wouldn't give me the funding for it. $52! Not even my medication costs that much. Mine's $5 per prescription. It's ridiculous.* Despite the fact that Rose was receiving a benefit, her very limited income meant that the cost of this medication that her grandson needed put a great deal of strain on the family finances. During the interview, Rose said that there was insufficient follow up from the disabilities services that she has been dealing with to discuss the issue of the unfunded medication or to provide her with additional advice on her eligibility to get reimbursed for the medication.

Access to advice and information is critical in helping these mothers understand their rights and what they are legally entitled to in terms of assessments, eligibility and support services. Some of these mothers were concerned about the current environment of tightening eligibility criteria due to pressures on reduced budgets so only those with the most critical or 'crisis' needs get support. There seemed to be frustration derived from many of these mothers that assessments rarely focused on their needs as a caregiver and inconsistencies in the allocation of services following an assessment of need has remained a problem.

Not all mothers in this research were fortunate enough to be able to access unsubsidised disability related therapies. Three of the luckier mothers, Vera, Lucy and Ruth, were able to access these due to the financial generosity of their extended family or past savings. Vera and Lucy's children were fortunate that their grandparents pay for their therapy. Vera explained:

> *If it wasn't for my mum and dad, I wouldn't be able to do half of these activities. We are trying to keep them going because they are really important for him.*

Likewise, Lucy said:

> *We have great therapists on board, which has been funded by my mother in law. If she wasn't around and we didn't have this amazing therapy that we were able to access, then my kids wouldn't be making the amazing progress that they are.*

Ruth has self-funded the unsubsidised therapy that her son receives through using savings that she built up prior to having children: *I had some savings but that just went. I should have sat down and figured out how many thousands I've spent.*

Another challenge that mothers faced in accessing support was using their Ministry of Health Carer Support allocation. Carer Support is a subsidy that helps carers take some time out for themselves. It provides reimbursement of some of the costs of using a support person to care

and support a disabled person, while the main carer has a break. One difficulty in using the Carer Support allocation is that the funding provided is only partial and requires top up funding by the main carer. This challenge of using carer support was relayed by Vera:

> *In terms of carer support, the amount that you get paid is not enough to cover a professional person, and I couldn't top it up. There's no way I could top it up.*

Lara also identified the limited reimbursement amount of carer support and not being in a financial position to be able to top it up as a problem: *Who are you going to find [someone] for $76 [for an eight-hour care period]?* Another difficulty in using Carer Support was the amount of time and effort to train and sustain good and responsible carers to pay them with Carer Support hours. This was explained by Kate: C*arer support has taken me about six years, from start to finish. I've finally got four really good carers.* The issue of finding appropriate carers was also identified by Ruth, who said: *I did get some funding for carer support, but I couldn't utilise it because I didn't have anyone who was trained up to look after him.*

Theme Three: Coping and contentment

Mothers in this study talked about the boundaries that they have put in place in some of the areas of their lives to keep their overall life manageable. Many of the mothers shared similar coping strategies, such as ensuring that the many appointments associated with their child's disability were scheduled at times that suited them and their child, being open and honest with their feelings and emotions with their children, or if the feelings had built up having a safe way to let these out away from their children.

Disabled children often require additional medical appointments, which can be strenuous on mothers, and are time intensive. Lara elaborated on how she has managed all the medical appointments for her foster son:

> *With his diagnoses I probably have one medical appointment a month. But I have tried to combine all those, and they all have to be within the school holidays because I can't take time off work as I don't get paid.*

Kate also put the similar boundaries around medical appointments:

> *Unfortunately, I just say well if you don't do them before 12 then I'm not coming. I never used to be that strong, but life toughens you up, and if you want to see them, before 12, otherwise I'm not coming.*

Even though parenting on their own required time and effort to develop strategies to put in place to cope with day to day activities or other challenges, almost all of the mothers were not bothered by their single parent status. As single mothers without having a partner for emotional support, one strategy for managing their emotions was to let their emotions out at the time, when the emotions are manageable, for their children to see. Being honest with her children about how she felt was important for Rose to cope with the demands of parenting alone. Rose said: *I just tell them, I'm straight up with them, I tell them, I'm tired, I'm sick.* Another mother, Ruth, said she used to keep her feelings from her children, but decided she needed to be honest with them: *I've got emotions, you're just going to have to see them, because you break me down and I just have to cry sometimes.*

While some of the mothers chose to discuss or express their emotions and feelings to their children, other mothers found alternative avenues to let their guards down. Vera said sometimes she chose to deal with her emotions away from her children. *There are days when you do have*

down days and sometimes it all builds up and I have a big cry and then I'm fine. Kate said she used other media such as Facebook to express her emotions: *I have a big meltdown to Facebook and get it out of my system, and then I pick myself up and I just keep going.*

In another case, the lack of support and resources to assist with coping with her son's challenging behaviours meant that Lara takes medication for her resulting anxiety. Although the medication has helped Lara to calm down and cope with her family situation, she wondered about the underlying causes of her needing to take medication: *Should I have to start taking medication because there is a lack of resources, because there is a lack of support.* For many families with disabled children, the lack of information, accessibility and availability of services can contribute to stress and anxiety for the caregivers. Challenging behaviours from a disabled child can also contribute to social isolation, as in this case Lara would withdraw from social situations with her disabled child as a result of the behaviours that were deemed as socially unacceptable.

While the label of single mother is not considered as the ideal and typical family type, most mothers in this study did not feel that they had to conform to the essential notions of single mother families but seemed to have embraced their current single status. Vera said: *The stress [of being in a relationship] that I was carrying on my shoulders has gone.* She elaborated on this:

> *I'm really enjoying my space, and I'm really enjoying what I'm doing and not having arguments or stressing because he was quite different in how he operated with money and things like that.*

Despite acknowledging the adjustment to cope with the demands of parenting alone, some of the mothers described that the physical presence of a partner does not automatically provide

emotional support but instead it can add more burdens on mothers who are parenting disabled child/children. Kate said that she preferred being a single parent: *Now I am where I am, my life is a whole lot easier, now I am single, because of the situation I personally was in.* For Kate, it was not without some adjustment and challenges when first moving from having two adults in the house helping with the children to parenting alone:

> *I think just to start off with it was really difficult despite that fact that I was in a bad relationship, there was somebody there, even though that somebody wasn't amazing, whereas I had to learn to be the stronger person that everyone would rely on.*

Once the initial adjustment period had settled, Kate recognised her abilities to parent alone: *I think that actually believing that I was strong enough to be that person that I didn't need another person, that I was quite capable of doing it on my own.*

Some of the participants considered that having no partner was better than having an unhelpful partner. The removal of the stress and burden of needing to care and think for a second adult was much more manageable and relaxing for Lucy:

> *I do feel that being a single mum is a lot easier than being in a relationship with someone who's not supportive, where you feel like you are in it on your own, yet you still have that adult person to clean up after and look after.*

Overall, mothers in this study demonstrated different coping strategies that they have employed to manage the stresses they experienced. Despite all of the challenges, almost all the mothers agree that overall their current life was better than when they were in a relationship.

Theme Four: Negotiating employment and care work

With the many additional responsibilities of single mothers with disabled children, not only have they experienced social isolation but increased responsibilities in caring. This has

affected their ability to work. Caring for a disabled child involves significant extra expenditure over a much longer period of time than for non-disabled children. Therefore, employment has proven to be challenging as the disabled child's needs remain the priority for these mothers. Despite this, employment was reported to be an aspiration for three of the six mothers in this research, and a reality for two others. For these two mothers who worked outside the home, paid employment or the ability to work was not only a way of addressing the financial barriers for accessing support services, it was also reported to increase self-esteem through having an identity outside of their caring/parenting role. Going out to work also helped to reduce the social isolation associated with being a single mother with a disabled child and to improve their mental health and their quality of life and happiness. In common with other mothers returning to work, employment forms a significant portion of regaining normalcy in life and making or reconnecting themselves to their previous social network and community. This was illustrated by Lucy: *Quality of life is definitely me having a social life and something that is for me, as well as my job. Also being able to provide for my kids.*

Finding affordable and accessible childcare has remained an ongoing problem for families with disabled children. One mother voiced her desire to set a good example to her children through financial independence, maintaining autonomy, and taking financial responsibility for her family's wellbeing. Kate articulated this thought by stating that:

> *I don't want them to think that I can live off the benefit for the rest of their life, I want them to say the benefit is there to help support me but look at all the things I can do rather than what they can't do, and I just want them to be really strong.*

Employment gives people, in part, a sense of purpose and value. Lara has identified with this and said: *I want to work, I want to be a valued member of society.* Vera spoke of similar

sentiment about her desire to give back to society, but voiced that her son, and his needs were still the priority:

> *I would be keen to do some part time work, probably teacher aiding, something to give back. But I need to find something that will fit in around my son, that's my biggest challenge.*

Similarly, Ruth said she had to prioritise her disabled child's needs and had wondered about alternate arrangements to traditional employment, such as being self-employed: *So it's flexible with my kids and the situation, I can do that out in the country, it's not an office job.* Although many of these single mothers acknowledged the social structural circumstances that prevented them from engaging in employment, their aspirations to employment or make some kind of contribution to society seemed to have shaped the way they expressed their reluctance to a resigned acceptance of the need to focus on care work.

Flexibility is a key component in employment. For many single mothers with a disabled child, this means employment during school hours, or before and after school care by suitably qualified and experienced carers would be required. As discussed earlier, this is neither affordable nor easily accessed. Lucy said:

> *I can't imagine what it would be like to be someone on a low income. Someone who wants to work and support their family, but not being able to afford proper childcare. That's the thing, you can't put these kids into after school or before school care, so there is no real allowance for that extra cost that goes on parents who are trying to pay for a nanny. That is one of the biggest barriers, as to why a lot of single mums wouldn't go out and work.*

For many of the single mothers in this study, employment was seen as an aspiration that would enhance their quality of life and help them find a sense of life purpose. Their stories revealed the context for their decisions on managing wage work and care work, which included overwhelming care demands of their disabled child/children and other family members, an inflexible labour markets, lack of information and support on returning to work and their rights while in work and insufficient public support for care. Caring for a disabled child is more likely to have non-reimbursed expenses for disability-related support and this further disadvantages mothers, particularly single mothers where their employment trajectories would be interrupted severely and indefinitely. Many of the mothers in the study have expressed that with sufficient access to support services and financial allowances that recognise the additional costs associated with raising a disabled child, a greater variety of employment opportunities could be available to them.

Summary

This chapter presented the results from interviews of six single mothers with a disabled child/children in Aotearoa New Zealand. The chapter began with a brief background of the single mothers who participated in this research. Following this, analysis of the data from the interviews resulted in four themes being identified: (1) social isolation and loneliness; (2) challenges accessing support services; (3) coping and contentment; and (4) negotiating employment and care work. Discussion of these four themes provided more insight into the experiences of single mothers with a disabled child/children in Aotearoa New Zealand. The following chapter will provide a discussion of the results, and provide links between the literature review, the theoretical underpinnings, and the data.

Chapter Six: Discussion

Introduction

The purpose of this study was to explore the experiences of single-mother led families with a disabled child in Aotearoa New Zealand, and in this chapter, key areas of focus from existing research and the findings of this study will be discussed. The themes identified in this study were: social isolation and loneliness; challenges accessing support services; coping and contentment; and negotiating employment and care work. The study showed that single mothers with a disabled child/children face an overwhelming combination of financial, emotional, practical and societal pressures and, without information and support; it is challenging for them to cope and they can become isolated. Through the participants' dialogue about the challenges they faced, it was evident that their narratives align with some of the existing research, which will be discussed in more detail in this chapter. The rich data elicited from this study also reflected other qualitative work in the field, providing further synthesis to address potential implications for the study and this will be illustrated in the subsequent sections.

The impact of social exclusion, loneliness and isolation

Results of this research have illustrated that single mothers with a disabled child/children often experience economic disadvantages, with five of the six mothers in this research reporting that things were hard financially. There are noticeable financial differences in the household incomes of single mothers, with single mothers having the lowest levels of household income when compared to other family types (Baker, 2002; Bromley et al., 2004; Cole et al., 2016; Emerson et al., 2006; Parish et al., 2012; Unger, Jones, Park, & Tressell, 2001). Within the Aotearoa New Zealand context, many one-parent families face economic difficulties, with only 46% of one-parent families having an income above 60% of the family median and only 31%

living in affordable housing (Superu, 2016). In relation to disabled children, 86% of disabled children, who lived in households earning less than $30,000 a year, were in one-parent families (Murray, 2018). Some of the mothers in this study talked about using credit cards for unexpected bills rather than asking for extra financial assistance from government departments, and others sought help from extended families for financial support. The majority of mothers interviewed in this research were under significant financial stress. Given the additional medical and disability related expenses, this has further compounded the financial stress. These findings continue to raise concerns that one-parent families with a disabled child/children are at greater risk of experiencing poverty, along with increasing risk of having poorer health and quality of life for both the parent (i.e., mothers) and the children (Emerson, 2004). Research has shown the link between poverty and social exclusion and isolation (Dahl, Fløtten, & Lorentzen, 2008).

In addition to economic disadvantages, social isolation is all too common in families with a disabled child/children (Goodley & Runswick-Cole, 2012; Heywood, 2010; Home, 2002). This experience of social isolation is consistent with the social model of disability, which states that it is society that disables the child, not the impairment (Goodley & Tregaskis, 2006) and that the responsibility for the creation of disability lies with the exclusionary structures and attitudes of society (Stace, 2013). This is also consistent with mothers in this research discussing the challenges they have faced when taking their children out into the community. Mothers voiced their concerns over the stress associated with the perceptions of their child's behaviour needing to conform to the norm. Research has indicated that parenting alone and caring for a disabled child/children, especially when there are associated behavioural problems, can create greater stress and emotional difficulties, contributing to further social isolation (Johnson, O'Reilly, & Vostanis, 2006; McConkey, 2005). Mothers in this study said this has caused them to distance

or isolate themselves, rather than expending the energy to try to manage the perceptions of others and manage the extra stress associate with the situation.

Social contact is fundamentally important because humans are social creatures, and loneliness and social isolation contributes to negative health problems such as stress, anxiety, depression, heart disease, and high blood pressure (Hawkley & Cacioppo, 2010; Ministry of Social Development, 2016b). In Aotearoa New Zealand, loneliness is more likely to be felt by females, by those with the lowest level of material wellbeing and who earn under $30,000, and by single parents (Ministry of Social Development, 2016b). Mothers in this research talked about social isolation and stated the challenges they faced in trying to socialise. Two of the mothers specifically commented on not having friends or not being invited to other people's homes or events. Having a disabled child/children can potentially influence a mother's maternal health status (Burton, Lethbridge, & Phipps, 2008) as they tend to have a higher prevalence of physical health problems and significant feelings of constant worry, being overwhelmed, and high levels of stress (Skinner, Slattery, Lachicotte, Cherlin, & Burton, 2002). Research comparing mothers with and without disabled children found that mothers with disabled children have lower levels of happiness, self-esteem, and self-efficacy (Emerson et al., 2006). Raising a disabled child/children can also affect siblings in the family. Research by Johnson et al. (2006) into maternal experiences found that mothers recognised that siblings are often affected by the disabled child/children. Some of the mothers in this research talked about activities revolving around the disabled child/children and how it had a negative impact on their other children. This was consistent with other literature reporting parental strain derived from caring for the disabled child/children who placed restrictions on everyday family life (Kenny & McGilloway, 2007). Siblings can play a significant role in offering both physical and emotional support to their parents. Although none of the mothers spoke in detail about

siblings looking after the disabled child/children, research in this area suggests that as a result of difficulties in accessing formal support services, parents with a disabled child/children may reply upon siblings for informal support, which could be useful in terms of maintaining employment and day-to-day activities (Shearn & Todd, 2000; Todd & Jones, 2003).

Socioeconomic mobility with child disability

A focus on mothers with a disabled child/children is warranted considering recent disability trends globally and in Aotearoa New Zealand. Disabled children have a high prevalence of residence in one-parent households (Cohen & Petrescu-Prahova, 2006; Murray, 2018), which can be linked to greater exposure to poverty (Hogan, 2012; Murray, 2018). Families across the economic spectrum face various challenges, including lack of childcare, fewer supports, role-strain, lower employment levels, increased medical expenses, when caring for a disabled child/children, and low-income families are more vulnerable to these challenges (Stabile & Allin, 2012; Swenson & Lakin, 2014). Mothers and women are typically the primary caregivers of a disabled child/children (Cohen & Petrescu-Prahova, 2006) and often experience greater difficulties gaining or maintaining employment. Factors influencing workforce participation choices of mothers of a disabled child/children are more complex than those of other mothers (Porterfield, 2002). Mothers with a disabled child/children are motivated to gain employment as a way to lessen feelings of isolation (Glendinning, 1983; Kazak, 1987; Shearn & Todd, 2000), however, they are often the first to reduce or curtail employment because of lack of specialised child care, insufficient workplace flexibility or societal demands that they maintain their maternal role at home (Curle, Bradford, Thompson, & Cawthron, 2005; Segal, 2001). Research by Cole et al. (2016) also reported that the employment choices of single mothers with a disabled child/children are strongly linked to the confidence that the mother has in the school to care for her disabled child/children. The findings of the current research are congruent

with that, with the two mothers who are in paid employment expressing the confidence that they have in their child's school and the teachers. Three of the mothers who wanted to be in paid employment, but were not, stated that future employment needed to fit around their care responsibilities. Several studies have also found that sufficient childcare or school care helps parents with a disabled child/children from having to miss work or risk their jobs (Brennan & Brannan, 2005; Rosenzweig, Brennan, Huffstutter, & Bradley, 2008). This is particularly more essential when the disabled child requires extensive and ongoing care and supervision.

Mothers in the current study who were in paid employment discussed the need to balance paid employment with the numerous medical and disability related appointments that their disabled children attended. Cole et al. (2016) researched the ways that single mothers in paid employment, who have a disabled child/children, manage to combine appointments with paid employment, and suggest that service providers need to be flexible in their appointment scheduling. Paid employment was described as more than just providing money for the family but something purposeful and meaningful for a single mother to reclaim her sanity and identify other than the challenges of raising a disabled child/children (Cole et al., 2016).

Research suggests that education levels of mothers with a disabled child/children has an impact on their labour force participation, with mothers with higher education levels being more likely to be in paid employment (Porterfield, 2002). It is suggested that the higher potential earnings of mothers with higher levels of education meant that they could purchase quality childcare (Breslau, Salkever, & Staruch, 1982; Porterfield, 2002). One of the mothers in this research described herself as a mid to high-income earner, and used her higher income to employ a nanny who could provide specialised childcare for her children. However, it may be more difficult for a mother of a disabled child/children to pursue education than work because in

addition to issues such as needing adequate childcare, there are also costs associated with schooling, including tuition, books and supplies that can make it less feasible. Low-income mothers may struggle to pay for education. Coupled with normal societal expectations regarding caregiving responsibility on women, Hogan (2012) argued that this increases pressure on single mothers not to work and hence to rely on welfare.

Another factor to consider is that mothers with higher levels of education are considered to have better skills and knowledge to 'work the system'; being able to advocate for their child was described as more than half the battle of getting appropriate services for their disabled child/children (Porterfield, 2002). One mother in the current study who was in paid employment stated that she knew what her and her child's rights were and fought for them. Although some mothers expressed high hopes and exhibit resilience to make ends meet regarding the importance of employment and education, the reality is that they continue experiencing a myriad of challenges in dealing with everyday life and societal expectations of their roles and responsibilities that thwart their active pursuits of improving their socioeconomic mobility to improve the quality of life and wellbeing of their families.

Lack of information and support

Experiencing a battle for resources and support from professionals has constantly been highlighted as one of the major barriers for families with a disabled child/children, with many parents left feeling tired and stressed at the amount of energy needed to access support (Howie-Davies & McKenzie, 2007; Johnson et al., 2006). Research conducted in Aotearoa New Zealand reported that luck, rather than professional service provision, was often the main reason for families finding support services that are helpful to them and their disabled child/children (Stace, 2011). Families with a disabled child/children describe the process of

securing support services or funding for support services as long, slow, time consuming, complicated and the root of a lot of anxiety and frustration (Brett, 2002; Dowling & Dolan, 2001; Heywood, 2010; Jarrett et al., 2014; McKeever & Miller, 2004). The experiences of the single mothers in this research reported similar occurrences, due to the time-consuming nature of accessing services and the complexities of this process. They also felt extremely frustrated at not being made aware of what support and services were available to them. This is consistent with research into the experience of single mothers with a disabled child/children accessing support services, who experience those services as fragmented, and only respond when requested to for help in times of crisis (Cigno & Burke, 1997).

Previous research shows that single mothers with a disabled child/children receive less financial, practical and emotional support than partnered mothers (Bromley et al., 2004), which is problematic given that partner support is not available in one-parent families, therefore, support received from external sources is even more important to single parents (Cigno & Burke, 1997; Cole et al., 2016). Even if they qualified for support and assistance, mothers in this research, as also reported in other research, indicated that they have found professionals insensitive to their emotional concerns, unhelpful when they must fight for resources, or were blamed for their children's behaviours by professionals who considered the disorder as related to poor parenting (Johnson et al., 2000; Podolski & Nigg, 2001; Russell, 2017).

Mothering, women's caring, and disabled children

The good mother ideology, where 'mother' is a social and cultural construct to be self-sacrificing, completely child-centred, heterosexual/married, and emotionally involved, is incongruous with being a single mother (Levine, 2008). This is portrayed in the stigma associated with being a single mother. In this research, mothers identified ways that they felt

the stigma and discrimination of being a single mother. These negative stereotypes ranged from a lack of appreciation of how challenging the job of raising a disabled child/children is, which they are doing as a single parent, through to feeling that because they were a single mother, they were disregarded as being a worthwhile person. The feelings that mothers had of negative stereotypes being directed towards them were perceived in subtle ways, rather than being explicit or direct, with slight shifts in the tone of conversations or the sense that they needed to justify themselves as not fitting the stereotype of being a single mother. Single mothers are often perceived as different from "ordinary" women, as well as being constructed as a problematic Other (Patterson, 2004). Mothering while receiving welfare payments was seen as undermining rather than contributing to society (Breheny & Stephens, 2009). The so-called 'state of father-absence' in their relationships continues to marginalise single mothers in the historically and socially reinforced judgements that contend children are significantly disadvantaged in single-mother led families. It was evident from the data that the stereotypes around being a single mother continue to be felt by the mothers in this research.

Families with a disabled child/children carry the physical and emotional caring burden (Brett, 2002; Dowling & Dolan, 2001; Green, 2007), and care remains very much gendered, with disability care being a lifelong role and responsibility for many mothers of a disabled child/children (Home, 2002; Stace, 2013). Mothers in this research expressed their concern about what would happen to their disabled child/children when they were no longer able to care for them. This awareness by the mothers of their child's reliance on them for care is the reality that eventuates from disabled children being primarily cared for at home by their own families. Although the mothers did not specifically assert that they would be caring for their disabled child/children for their lifetime, the declaration of their concern about their child's future does attest to the acknowledgement that they had the responsibility for taking their

child's future into strong consideration. The concerns from these mothers align with existing research identifying parents' worries about future provision for their children (Johnson et al., 2006; Kenny & McGilloway, 2007). Policy and welfare reforms often disregard caregivers as they are largely unsupported, unrecognised, and unpaid (Stace, 2013). This gendered caregiving, when coupled with the good mother ideology and single mother status (Levine, 2008), further reinforces the financial hardships and stigma experienced by single mothers with a disabled child/children.

Research has also shifted from a socio-political to an individual mother focus. Knight (2013) observes how research into families with a disabled child/children has changed since the 1970s, reflecting changing societal attitudes, paradigms, and research methodologies. Early research had a psychopathological view of the family, that then moved to a stress and coping focus on the 1980s and 1990s, then to a resilience model in the 2000s, and from here the focus on family/mother adaptation and transformation (Knight, 2013). This recent focus on adaptation and transformation seeks to portray the positive aspects of raising a disabled child/children, and ways that parents, and especially mothers, find meaning and personal transformation while doing this (Knight, 2013). Emerson et al. (2006) and Knight (2013) suggest that this individual focus risks losing sight of the political and social context of raising a disabled child/children, and places the research focus back on the individual/mother, rather than at the socio-political level. In relation to this research, the political and social context of raising a disabled child/children is recognised through identifying policy developments, as well as acknowledging the social constructs of the single parent and of disability.

Crafting and recrafting identities as single mothers of a disabled child/children

Raising a disabled child/children takes place within a political and social context. Mothers in the current study craft and recraft their ways of being, identities and families according to their own terms and views, to challenge the dominant discourse on how traditional family, motherhood and parenting is constructed. Single mothers, rather than seeing themselves through the lens of the negative stereotypes, recraft their identity as 'mother-presence' rather than father-absence, and prefer their single-parent status over being in an unhealthy or unsatisfying relationship (Levine, 2009). The societal perception that being a single mother is something negative is, in the view of mothers in this research, a misconception that they are resisting as they work to define themselves, their families and their children as typical, to make decisions around caring responsibilities that reflect their own needs and preferences, and to be respected for their knowledge, skills, and strengths as 'valid' mothers. Overall, mothers in this research saw their lives now, as a single mother, as more desirable than their partnered life. Their stories coincide with Levine's (2009) research on single mothers of disabled children that advocate the status and strengths of single mothers to honour their role as single-parents, rather than the notion of "fatherlessness".

It is undeniable that existing literature has provided evidence to indicate that mothering a disabled child/children entails additional tasks and challenges, e.g., managing their child's diagnoses, adapting the social and environment to facilitate the development of their children, and dealing with societal perceptions (Home, 2012; Levine, 2009). In addition, single mothers assume these additional responsibilities in a more challenging situation, making them more vulnerable to poorer health, greater concerns and worries, and increased stress to deal with other family commitments (Grant & Whittell, 2000; Levine, 2009; Schormans & Brown, 2004). While single mothers in the current study have described difficulties and challenges, they have also shown to be resilient and have confidence in themselves as primary caregivers.

These mothers reported that having a disabled child/children had brought about a positive change in their attitudes and approaches to life, which is consistent to Kenny and McGilloway's (2007) research. Mothers in this research project identified themselves as the experts on their own disabled child/children, understanding what is best for their child with respect to their needs. As they recognised themselves as the expert and were actively engaged in decision making, they also put boundaries in place to manage their role as a single parent of a disabled child/children. These boundaries included stipulating when the numerous medical appointments were scheduled, a boundary that was not negotiable. Similar to the single mothers of disabled children in Levine's (2009) research, they trust their judgement and knowledge of their child. In doing this, these mothers move from passive recipients of knowledge and advice, to being actively engaged in decision making processes about their child, and able to challenge situations if necessary. As professionals, it is important to acknowledge and challenge the legacy of professionals being seen as the experts and how this has disempowered single mothers and viewed their knowledge of their disabled child/children as inferior. Single mothers with a disabled child/children in the current research and also in other existing research have demonstrated that they are learning and evolving in their journey as they learn skills such as advocacy or notice new ability to savour good times (Segal, 2001) and also bring personal growth or reveal inner strengths (Levine, 2009).

Summary

This chapter has provided a discussion on the focus areas, which came from the relationship between the interviews of single mothers related to their experiences raising a disabled child/children, and the literature. The focus areas for discussion in this chapter were: the impact of social exclusion and isolation; socioeconomic mobility; lack of information and support; the changing context of family and women's caring; and mothers crafting and recrafting their

identities as single mothers of disabled children. The following chapter will conclude the research by offering a summary of findings, and present discussion on implications and recommendations on social work practice and future research based on the outcomes of the study.

Chapter Seven: Conclusion and Recommendations

Introduction

This research has explored the experiences of single-mother led families with a disabled child/children in Aotearoa New Zealand. Existing research into the experiences of single mothers in Aotearoa New Zealand have explored areas such as welfare reform in relation to single mothers (Patterson, 2004), resilience in single parents (Waldegrave et al., 2011), and the experiences of single mothers transitioning from welfare to work (Baker, 2002). Other research on families with a disabled child/children or children in Aotearoa New Zealand has provided valuable insights into their experiences on poverty, parental peer advocacy, activism, issues relating to education system, and family wellbeing (Ballard et al., 1997; Bell et al., 2013; Child Poverty Action Group, 2015; Good et al., 2017; IHC, 2016; Murray, 2018; Tiso & Stace, 2015). However, there seems to be a dearth of literature and research about the space where these two spheres overlap: being a single mother with a disabled child/children within the Aotearoa New Zealand context. This research aimed to provide insight into that space.

Methodology

This research employed a qualitative approach, and utilised semi-structured interviews with six mothers to explore their experiences as single mothers with a disabled child/children. The use of qualitative methods was deemed as an appropriate tool for enabling researcher to examine and explain issues and events from the perspective of the participants through their own lens (Crabtree & Miller, 1999). The number of mothers interviewed was limited to six as this was seen as an adequate number to elicit the research data required to complete the research using a qualitative approach. The topics covered in the interviews included supports, networks and resources that the mothers and families have or use, experiences of accessing support services,

considering what quality of life meant for the mothers and their family, coping mechanisms, and future considerations. A thematic analysis of the interviews was carried out (Braun & Clarke, 2006), which was compared with relevant literature and research material.

Benefit of conducting this research

While there is a substantial body of literature that explores how families adapt within the context of disability as stated in earlier chapters, they are mostly concentrated on two-parent family system. Despite existing evidence that indicates that single mothers are more likely to raise disabled children on their own, and are exposed to long-term poverty, stigma and discrimination due to their status, their experiences have received minimal attention in both social science and disability (Levine, 2009). Findings of this research further confirm that mothers of disabled children occupy a liminal position because they are often not disabled but they can experience disablism due to the constraints within their children's lives (Ryan & Runswick-Cole, 2008). This study was underpinned by a growing concern of the limited documentation and analysis of the experiences of single mothers with a disabled child/children given the increasing number of disabled children who are currently and will be living in one-parent families, both overseas and in Aotearoa New Zealand.

Summary of the key findings

Findings from this research show that there are financial, emotional, practical and societal challenges that single-mother led families with a disabled child/children face. Financially, almost all of the mothers in the current research reported that they were struggling, and in addition to this there were barriers to pursuing current or future employment. Two of the six mothers were in paid employment; however, one of them said that she was not any better off

financially, being in paid employment, as the nature of her work meant that she was only paid when she worked during the school term. Three of the four mothers who were not currently in employment had aspirations to eventually return to employment, although their care responsibilities for their disabled child/children needed to take priority over any potential employment.

Emotionally, social isolation and loneliness were key features for these mothers and their families. Two of the mothers stated that they have no friends, and all of the mothers outlined barriers to them and their children being able to socialise and integrate fully and meaningful in their community. These barriers to being able to socialise included some of the followings: the negative perceptions of others about their child's behaviour, stigma and discrimination of their single status and being a disabled family, a lack of appropriate transport and accessibility, lack of communication from professionals on service provision and mothers not being recognised and acknowledged of being the expert of their disabled child/children's ability and characteristics to be included in planning and consultation.

Practical challenges faced included needing to attend numerous medical and therapy-related appointments and staying on top of referrals, while also managing the day to day tasks of running a household and parenting. Another practical challenge was accessing support using their Ministry of Health Carer Support allocation due to the need to recruit, train and provide top-up funding. Societal challenges were the stereotypes that the mothers felt were associated with being a single mother. Although they acknowledged that the societal perception of being a single mother is a negative one, in the view of mothers in this research, that was a misconception that they were resisting as they worked to define themselves, their families and their children as normal, to make decisions around caring responsibilities that reflect their own

needs and preferences, and to be respected for their knowledge, skills, and strengths as 'valid' mothers.

Another key finding from this research was the lack of a readily available database of support agencies, and the relationships with service providers and professionals. Mothers outlined their experience of finding out about support agencies by accident, the passive nature of support agencies, and their frustrations in dealing with some service providers and professionals. A need that was identified was a disability navigator service that provided options around supports that were available and how to access them. Given that single parents are carrying the parenting load of two parents, so have limited time and energy to research and follow up with agencies, this is especially important.

Despite these challenges and frustrations, mothers in this research overwhelmingly preferred their current single-parent status to their previous experience of being in a relationship. Mothers valued themselves as experts in their own and their child's lives. These mothers were actively engaged in decision making processes about their child, and able to challenge situations if necessary, including putting in boundaries. As outlined previously, while they were aware of the negative stereotypes of being a single mother, they chose not to live down to these expectations, but rather, crafted and recrafted their and their family's identities according to their own terms and views. Rather than defining themselves through the lens of the negative stereotypes and father-absence, they redefined their identity as 'mother-presence'.

Implications and recommendations for social work practice

Implications and recommendations for social work practice, in relation to the research, are outlined below. The findings relate specifically to the experience of being a single mother with a disabled child/children.

As social workers, we are trained to take into consideration the context of a person's environment, when working with a person. This ecosystem perspective seeks to understand the relationship between the person and their social environment (Kondrat, 2002). This is especially important when working with single mothers, given they have no spousal support. The use of an ecosystem ecomap provides a visual representation of the supports and interactions that people have with individuals or organisations, and any support gaps that may exist (Payne, 2014). Taking an ecosystems perspective provides social workers with an opportunity to advocate for change at a community or political level (Payne, 2014), given their knowledge of what support is available and whether this sufficiently supports single mothers raising disabled children.

It is essential that social workers have an awareness of stereotypes and biases towards single mothers. Mothers in this research were cognisant of the stereotypes and stigma of being a single mother and felt the biases against them. As social workers, we need to be aware of our own perceptions of single mothers, and especially of any negative biases towards single mothers. According to Breheny and Stephens (2009), some healthcare professionals in Aotearoa New Zealand have the view that single mothers are the contravening social norms by not being in a two-parent family, and there is the perception that single mothers receiving welfare payments are living an undeservedly easy life. Findings from this study also call for the fundamental transformation of perceptions of single mothers and disability. In conjunction with how social model of disability has challenged that disability is related to pathology, it is also important to

challenge the patriarchal nature of the social, economic and structural system that marginalises not just motherhood but especially single mothers. Social workers need to be strong advocates for diversity to move away from the traditional notion of family based on able-bodied, two-parent and heterosexual formation to emphasis on wholeness, inclusivity, strengths, empowerment and resilience of what family brings regardless of the marital, race, gender and sexuality basis.

Mothers in this research identified the need for a disability navigator service, and fortunately Aotearoa New Zealand is headed that way with the roll out of the Enabling Good Lives scheme (Enabling Good Lives, n.d.). This links to research on the experiences of low-income women accessing social service support, which suggests that low-income women do not know what they are eligible for; to what extent and under what terms; feel confusion about eligibility from not well-defined criteria; feel that there is a lack of consistency with available support; and feel invisible (Lavee, 2017). These experiences are consistent with some of the experiences of mothers in this research, especially not knowing what support is available and what they are eligible for. Therefore, it is important that social workers are aware of organisations and services that single mothers with disabled children are able and eligible to access, and actively support and follow up referrals to these services.

Limitations of the research

Six research participants were sought, and while this number was in no way representative of all single mothers who have a disabled child/children, it did provide information that was useful in gaining more of an understanding of this research area. The participants also represented a narrow ethnicity band, with only one participant identifying as Māori. This demographic is not representative of the diverse population of single mothers in NZ, particularly those of Māori

and Pasifika peoples. Despite these limitations, given that there is no other research specifically relating to this topic in Aotearoa New Zealand, it is hoped that this research will provide a foundation to call for more research in this specific area that will be added to the current shallow pool of research knowledge.

The small sample size had the potential to attract only mothers who feel they have the time and energy to participate in the research project, skewing the results to only reflect the experiences of mothers who do have the time, energy and more resilience to be involved. If these mothers have the time and energy to be involved in this research, this may be an indication that they also have distinctive internal or external factors at play in other areas of their lives. This means that the results of this research are the commonalities of mothers who have a similar set of unique internal or external factors in their lives, which are not generalisable to the experience of other single mothers with a disabled child or children in a more oppressed and vulnerable situation. Parenting a disabled child/children and being a single mother has many challenges, and mothers who may have less support or feel overwhelmed by this may not feel they can be involved in a research project. The recruitment process could have also introduced bias, with those recruited through the specific organisation mentioned in Chapter Four having that agency as a support, and those recruited through snowballing having enough social contact with others to be named as a potential participant.

As this was insider research with potential biases, strategies were used to mitigate potential biases. Supervision was utilised throughout the research, and there were clear expectations and boundaries of me as the researcher rather than as a social worker. Credibility indicators of dependability and transferability were used also to avoid biases. Triangulation took place through using data from overseas research on this subject area and combining this with the data

obtained from the interviews (Flick, 2015). And lastly, authenticity was enhanced by focusing on the participants' narratives as their true accounts.

Conclusion

The aim of this chapter was to provide a summary of the research project, outline the key findings, provide recommendations for social workers, and present limitations. Single mothers with a disabled child/children in Aotearoa New Zealand face many challenges and experience many frustrations. These challenges and frustrations align with the social model perspective of disability; it is predominantly society that is disabling these families with disabled children. Key findings from this research confirmed existing literature: single mothers with a disabled child/children often experience economic disadvantages; in addition to economic disadvantages, social isolation is all too common in families with a disabled child/children; balancing care responsibilities is challenging; and there is a battle for resources and support from professionals.

Despite these challenges and frustrations, mothers chose to craft and recraft their and their family's identities according to their own terms and views, as well as defining themselves through their mother presence. Given that approximately 30% of disabled children in Aotearoa New Zealand live in a one-parent family (Murray, 2018), there is scope for the experiences of these families to be highlighted. Limitations of this research and future implications have been outlined to encourage further research into understanding the experiences of single-mother led families with a disabled child/children in Aotearoa New Zealand.

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Appendix A

Ethics approval letter

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

8 October 2015

COPY FOR YOUR
INFORMATION

Jane Lee

▮▮▮▮▮▮▮

Dear Jane

Re:　HEC: Southern B Application – 15/54
　　　Single-mother led families with a child with disability in Aotearoa NZ

Thank you for your letter dated 26 September 2015.

On behalf of the Massey University Human Ethics Committee: Southern B I am pleased to advise you that the ethics of your application are now approved. Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Dr Rochelle Stewart-Withers, Chair
Massey University Human Ethics Committee: Southern B

cc　Dr Polly Yeung　　　　　　　Dr Martin Sullivan
　　School of Social Work　　　　School of Social Work
　　PN371　　　　　　　　　　**PN371**

　　Dr Kieran O'Donoghue, HoS
　　School of Social Work
　　PN371

Appendix B

Letter requesting permission

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

To whom it may concern,

My name is Jane Lee and I am studying towards a Master of Social Work through Massey University.

As part of my study, I wish to undertake research on understanding the experiences of single mothers who have a child with a disability. I am writing to request your assistance in circulating my recruitment flyers to potential participants.

I wish to conduct interviews with six mothers. Selection of participants will be based on the following criteria: (1) single mothers living in the greater Wellington region who (2) have a child with a disability aged between 5 and 12 years old; (3) the child with a disability would qualify the mother to receive either a Work and Income child disability allowance or carer support through a Needs Assessment and Service Coordination (NASC) agency; (4) speak and understand English without needing to use an interpreter; and/or (5) single mothers who have shared care arrangements will be included.

I would be grateful if you would consider placing the attached advertisement in your newsletter or on your noticeboard.

If you have any questions, please contact me.

You can also contact my research supervisors:
Dr Polly Yeung & Dr Martin Sullivan
School of Social Work
Massey University
06-3569099 ext 83514 or ext 83525
P.Yeung@massey.ac.nz
m.j.sullivan@massey.ac.nz

Thank you for your assistance.

Kind regards,

Jane Lee

Information sheet

Single-mother led families with a child with disability in Aotearoa NZ

INFORMATION SHEET

Introduction

My name is Jane Lee and I am interested in exploring the experiences of single mothers raising a child with disability in Aotearoa NZ. While this research is being undertaken to fulfil the requirements of a Master of Social Work, I have also been a single mother, and one of my children has moderate to severe autism.

Purpose of the study

Approximately 10% of children in Aotearoa New Zealand live with disability, and 28% of these disabled children live in a one parent family. Currently, the vast majority (around 83%) of one-parent families are headed by women. Within the Aotearoa NZ context, relatively little is known about the experiences of single-mother led families with a child with disability. This research will expand knowledge in this area.

Invitation to the study

I would like to invite six single mothers to take part in a one hour individual interview who:

- have a child with disability aged between 5 and 12 years old;
- currently reside in the greater Wellington region;
- the mother receives either a Work and Income child disability allowance or carer support through a Needs Assessment and Service Coordination (NASC) agency;
- speak and understand English without needing to use an interpreter;
- single mothers who have shared care arrangements will be included.

Priority will be given to the first six mothers who respond and meet the criteria for participation. If you agree to participate in the research, we will arrange a time and venue to conduct the interview, which suits us both. Before the start of the interview, you will be asked to sign a consent form. I will send you the interview questions for you to think about before the interview. The interview will be digitally recorded and transcribed by me. If you feel distressed or uncomfortable during the interview, I will offer you a break, the option to stop or withdraw from the interview and/or to phone a support person of your choice

to come and sit with you. A list of support services would be made available for you at the end of the interview, which you can contact if you wish. You will be sent the transcript to review to ensure it accurately captures your views.

All information you provide will be kept confidential and only I will have access to the data. The recording of the interview will be offered back to you or be deleted upon research completion. Confidentiality is assured as names of individuals, locality and regions will be omitted from the report. On completion of the research, I will email or post you a summary of the findings.

Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study up until the release authority form is signed;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the research findings when it is concluded;
- ask for the recorder to be turned off at any time during the interview.

Project Contacts
If you have further questions or feel that this research topic has caused you any discomfort, you can contact me, my research supervisor or paper coordinator at the below contact details.

Student Researcher	Research Supervisor	Research Supervisor
Jane Lee	Dr. Polly Yeung School of Social Work Massey University Palmerston North 06 356 9099 xtn 83514 p.yeung@massey.ac.nz	Dr. Martin Sullivan School of Social Work Massey University Palmerston North 06 356 9099 xtn 83525 m.j.sullivan@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 15/54. If you have any concerns about the conduct of this research, please contact Dr Rochelle Stewart-Withers, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x 83657, email humanethicsouthb@massey.ac.nz

Organisation consent form

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

Single-mother led families with a child with disability in AotearoaNZ

CONSENT FORM - ORGANISATION

I have read the Information Sheet and have had the details of the study explained to me.

My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree to participate in recruiting for this study under the conditions set out in the Information Sheet.

Signature: .... **Date:** ....

Full Name - printed ....

Flyer

Are you a single mother?

Do you have a child at primary or intermediate school who has a disability?

Would you like to take part in research about what it is like being a single mother with a child with a disability?

Hello,

My name is Jane Lee and I am a research student completing my Master of Social Work degree at Massey University. I am interested in finding out more about the experiences of single mothers who have a child with a disability.

I would like to invite single mothers living in the greater Wellington region to take part in a one hour interview who:

- have a child with a disability aged between 5 and 12 years old;
- currently reside in the greater Wellington region;
- qualify to receive either a Work and Income child disability allowance or carer support through a Needs Assessment and Service Coordination (NASC) agency;
- speak and understand English without needing to use an interpreter;
- single mothers who have shared care arrangements will be included.

Your involvement and identity will be kept confidential.

My research supervisors are:

Dr. Polly Yeung, School of Social Work, ph: 06-3569099 xt 83514; p.yeung@massey.ac.nz

Dr. Martin Sullivan, School of Social Work, ph: 06-3569099 xt 83525; m.j.sullivan@massey.ac.nz

If you are interested, please phone, text or email me, and I will send you more information about the research.

Jane Lee

Interview schedule

Interview Schedule

Introduction
Thank you for agreeing to take part in this research. I am interested in your experiences, so don't feel you need to give me an answer that you think I might want to hear. If I ask you a question and you aren't sure what I mean, please ask me to be clearer or explain it better to you. There are no right or wrong answers to the questions I will ask you.

Family Background
Tell me about you, your family and your child with impairment.
Who is in your family, ages?

Tell me about a typical day.
Listen for personal, material and cultural daily experiences, and how these relate to the mother, the child with impairment, and the family, for example, meal times, morning routines, school, meeting up with friends or family, homework, spending time together as a family.

What about things that happen on a weekly, monthly or yearly basis? Tell me about these.
Listen for personal, material and cultural experiences, for example friends coming to play, birthday celebrations, health/hospital appointments, Work and Income appointments, parent/teacher interviews, family holidays, weekend activities.

Tell me about the supports, networks and resources that you and your family have or use.
What works well for you? What challenges have you faced and how did you overcome them?

What are your hopes and dreams for you, your child with impairment, and your family?
What kind of supports, networks and resources do you and your family need to achieve these hopes and dreams?

Tell me about your experiences of accessing social service support for you, your child with impairment, and your family.
What service, waiting list, responsiveness of service, people providing service, experience for child, mother and family.

What about some questions like "What has worked well for you?" "What challenges you have faced and how did you overcome them?" "What are your hopes and dreams for you, your child with disabilities and your families" "What kind of supports, mechanisms and resources will you need to achieve those hopes and dreams?" "What does quality of life mean for you and your family?" "What strategies do you use to manage your roles, your emotions and your child's developments and behaviours?"

Summing up
Those are the end of my questions. Is there anything else that you would like to talk about that we haven't covered? Do you have any questions for me?
Remind the participant that I will be transcribing our interview for them to review.

Participant consent form

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

Single-mother led families with a child with disability in AotearoaNZ

PARTICIPANT CONSENT FORM - INDIVIDUAL

I have read the Information Sheet and have had the details of the study explained to me.

My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being sound recorded.

I wish/do not wish to have my recordings returned to me.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: ....   **Date:** ....

Full Name - printed ....

Transcript release authority

MASSEY UNIVERSITY
COLLEGE OF HEALTH
TE KURA HAUORA TANGATA

Single-mother led families with children with impairment in AotearoaNZ

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature: .... **Date:** ....

Full Name - printed ....

Human ethics application

Human Ethics Application

FOR APPROVAL OF PROPOSED RESEARCH/TEACHING/EVALUATION INVOLVING HUMAN PARTICIPANTS

(All applications are to be typed and presented using language that is free from jargon and comprehensible to lay people)

SECTION A

1   Project Title   Single-mother led families with a child with impairment in AotearoaNZ.

Projected start date for <u>data collection</u>   1 October 2015

Projected end date   28 February 2017

(In no case will approval be given if recruitment and/or data collection has already begun).

2   Applicant Details *(Select the appropriate box and complete details)*

ACADEMIC STAFF APPLICATION (excluding staff who are also students)

Full Name of Staff Applicant/s

School/Department/Institute

Campus *(mark one only)*   **Albany** [ ]   **Palmerston North** [ ]   **Wellington** [ ]

Telephone   **Email Address**

STUDENT APPLICATION

Full Name of Student Applicant   Jane Weheora Faith Lee

Employer (if applicable)

Telephone   ▮▮▮▮▮   **Email Address**   ▮▮▮▮▮▮▮

Postal Address   ▮▮▮▮▮▮▮▮▮▮▮▮▮▮

Full Name of Supervisor(s)   Dr Polly Yeung and Dr Martin Sullivan

School/Department/Institute   School of Social Work

Campus *(mark one only)*   **Albany** [ ]   **Palmerston North** [x]   **Wellington** [ ]

Telephone   *06 3569099*   **Email Address**   p.yeung@massey.ac.nz extn 83514
m.j.sullivan@massey.ac.nz extn 83525

GENERAL STAFF APPLICATION

Full Name of Applicant	
Section	
Campus *(mark one only)*	**Albany** ☐ **Palmerston North** ☐ **Wellington** ☐
Telephone	**Email Address**
Full Name of Line Manager	
Section	
Telephone	**Email Address**

---

3 Type of Project *(provide detail as appropriate)*

Staff Research/Evaluation:		Student Research:		If other, please specify:
Academic Staff	☐	Specify Qualification	MSW	
General Staff	☐	Specify Credit Value of Research	120	
Evaluation	☐	(e.g. 30, 60, 90, 120, 240, 360)		

---

4 Summary of Project

Please outline in no more than 200 words in lay language why you have chosen this project, what you intend to do and the methods you will use.

(Note: All the information provided in the application is potentially available if a request is made under the Official Information Act. In the event that a request is made, the University, in the first instance, would endeavour to satisfy that request by providing this summary. Please ensure that the language used is comprehensible to all.)

Using the social model of disability, the argument is made that families with a child with impairment are also disabled, but it is society that disables the family, not the child (Dowling & Dolan, 2001). The concept of the disabled family views the family with a child with impairment holistically, and uses this as the basis from which to analyse the personal, material and cultural challenges encountered by these families (Goodley, 2011).

Approximately 10% of children who live in AotearoaNZ have a disability, and 28% of these children live in a one parent family (IHC, 2011). Currently, the vast majority (around 83%) of one-parent families are headed by women (Ministry of Social Development, 2012). Within the AotearoaNZ context, relatively little is known about the experiences of single-mother led families with a child with impairment and this research will expand knowledge in this area.

Six mothers will be interviewed, and the research will utilise qualitative semi-structured interviews and a thematic analysis will be conducted.

---

5 List the Attachments to your Application, e.g. Completed "Screening Questionnaire to Determine the Approval Procedure" (compulsory), Information Sheet/s (indicate how many), Translated copies of Information Sheet/s, Consent Form/s (indicate of how many), Translated copies of Consent Form/s, Transcriber Confidentiality Agreement, Confidentiality Agreement (for persons other than the researcher / participants who have access to project data), Authority for Release of Tape Transcripts, Advertisement, Health Checklist, Questionnaire, Interview Schedule, Evidence of Consultation, Letter requesting access to an institution, Letter requesting approval for use of database, Other (please specify).

Completed *Screening Questionnaire to Determine the Approval Procedure*
Appendix A: Information Sheet - 1
Appendix B: Consent Form - 1
Appendix C: Authority for Release of Transcripts
Appendix D: Advertisement
Appendix E: Interview Schedule
Appendix F: Organisation Request letter

Applications that are incomplete or lacking the appropriate signatures will not be processed. This will mean delays for the project.

Please refer to the Human Ethics website (http://humanethics.massey.ac.nz) for details of where to submit your application and the number of copies required.

SECTION B: PROJECT INFORMATION

General

6 **I/We wish the protocol to be heard in a closed meeting (Part II).**   Yes [ ]   No [✓]

(If yes, state the reason in a covering letter.)

7 **Does this project have any links to previously submitted MUHEC or HDEC application(s)?**   Yes [ ]   No [✓]

If yes, list the MUHEC or HDEC application number/s (if assigned) and relationship/s.

8 **Is approval from other Ethics Committees being sought for the project?**   Yes [ ]   No [✓]

If yes, list the other Ethics Committees.

9 **For staff research, is the applicant the only researcher? NA**   Yes [ ]   No [ ]

If no, list the names and addresses of all members of the research team.

Project Details

10 **State concisely the aims of the project.**

To research the experiences of single mothers raising children with impairment, to find out if and how the disabling society and process of accessing social services recreates the child as a disabled child and the family as a disabled family.

11 **Give a brief background to the project to place it in perspective and to allow the project's significance to be assessed.** *(No more than 200 words in lay language)*

International research into mothers of disabled children is emerging (Read, 1991; Green, 2007; Ryan & Runswick-Cole, 2008; Sousa, 2014), along with research into the experiences of single mothers who have a disabled child (Gottlieb, 1998; Levine, 2009). Recently, research has been conducted into the concept of stigma on the lives of families with children with impairment (Green, 2003), and the impact of disablism on the psycho-emotional well-being of families with a child with impairment (Jarrett, Mayes & Llewellyn, 2014).

Studies into the experiences of single parents in Aotearoa New Zealand have explored areas such as welfare reform (Patterson, 2004), resilience (Waldegrave, King, Maniapoto, Tamasese, Parsons & Sullivan, 2011), and the experiences of single mothers in transition from welfare to work (Baker & Tippin, 2002). The Christchurch Health and Development Study examined the associations between exposure to single parenthood in childhood and later mental health, educational, economic, and criminal behaviour outcomes (Fergusson, Boden & Horwood, 2007).

Although the likelihood of a child with impairment being raised by a single mother is high, there has not been research into the experiences of single-mother led families with children with impairment in Aotearoa New Zealand.

12 Outline the research procedures to be used, including approach/procedures for collecting data. Use a flow chart if necessary.

Ethics application approved.

Advertisement for research participants.

Selection of six research participant who satisfy selection criteria.
Information sheet and consent form provided.

Time and place for interview agreed.
Interview schedule provided and consent form signed.

Semi-structured interviews completed and audio recorded.
Participant forms and interview and audio information securely stored.

Interviews transcribed and securely stored. Transcription provided to participants.

Does the participant wish to change anything on the transcription? If yes, changes made.

'Authority for release of transcripts' signed.
Complete data analysis.

Research findings written up and summary provided to participants.

13 Where will the project be conducted? Include information about the physical location/setting.

Participants will be recruited from the greater Wellington region. The interviews will take place either in the participant's home or at a mutually agreed public space such as a community house or church.

14 **If the study is based overseas:**

   i) **Specify which countries are involved;**

   ii) **Outline how overseas country requirements (if any) have been complied with;**

   iii) **Have the University's Policy & Procedures for Course Related Student Travel Overseas been met?**
   (Note: Overseas travel undertaken by students – refer to item 5.10 in the document "Additional Information" on the MUHEC website.)

15 **Describe the experience of the researcher and/or supervisor to undertake this type of project?**

The student researcher completed 179.702 Advanced Research Methods paper in 2011.

The student's supervisors are Dr Polly Yeung and Dr Martin Sullivan.

Dr Yeung's research interests are successful aging, citizenship participation, and social work education. Dr Yeung's areas of expertise are Welfare and Community Services; Social Work; and Studies In Human Society.

Dr Sullivan's research interests are the social and political aspects of disability. Dr Sullivan has recently completed a four year, Health Research Council funded project on the first two years following spinal cord injury (SCI). Dr Sullivan's areas of expertise are Sociology and Disability Studies.

16 **Describe the process that has been used to discuss and analyse the ethical issues present in this project.**

Supervision has been used to discuss and analyse the ethical issues present in this project.

I need to recognise the power relationships involved in this research due to the participants being single parents of children with impairments and belonging to a socially vulnerable group. I need to also be aware of any class and/or educational disparities between myself and the research participants, and I have a responsibility to recognise my own cultural location (MUHEC, 2012).

The major ethical principles that need to be given consideration are: respect for persons; harm minimisation to participants, researchers, institutions and groups; informed and voluntary consent; respect for privacy and confidentiality; avoidance of conflict of interest; and social and cultural sensitivity to the age, gender, culture, religion, social class of the participants (MUHEC, 2012).

Participants

17 **Describe the intended participants.**

Six single mothers who reside in the greater Wellington region, who have a child with impairment aged between 5 and 12 years old. The mother would qualify for either a Work and Income child disability allowance or carer support through a Needs Assessment and Service Coordination (NASC) agency. Single mothers who have shared care arrangements will be included. English will be spoken and understood by the participants without the need for an interpreter.

18 **How many participants will be involved?**

Six

What is the reason for selecting this number?

(Where relevant, attach a copy of the Statistical Justification to the application form)

This is an accepted number of participants for a master's level research project. While this number will not be representative of all single mothers who have a child with impairment, it will provide information-rich data that will be useful in gaining more of an understanding of this research area.

19 **Describe how potential participants will be identified and recruited?**

Recruitment of potential participants will be through giving organisations working with parents of children with impairment a flyer to distribute, advertising the research to the parents. Those parents interested in participating will be invited to contact the student researcher directly.

20 **Does the project involve recruitment through advertising?** Yes ✓ No ☐

(If yes, attach a copy of the advertisement to the application form)

21 **Does the project require permission of an organisation (e.g. an educational** Yes ✓ No ☐
institution, an academic unit of Massey University or a business) to access
participants or information?

      ii) **attach a copy of the draft request letter(s) to the application form, e.g. letter to Board of**
      Trustees, PVC, HoD/I/S, CEO etc (include this in your list of attachments (Q5).

(Note that some educational institutions may require the researcher to submit a Police Security Clearance.)

22 **Who will make the initial approach to potential participants?**

Potential participants will contact the researcher directly by text message, email or telephone.

23 **Describe criteria (if used) to select participants from the pool of potential participants.**

The first six applicants who satisfy the selection criteria will be selected. The selection criteria are: (1) single mothers living in the greater Wellington region who (2) have a child with impairment aged between 5 and 12 years old; (3) the child with impairment would qualify the mother to receive either a Work and Income child disability allowance or carer support through a Needs Assessment and Service Coordination (NASC) agency; (4) speak and understand English without needing to use an interpreter; and/or (5) single mothers who have shared care arrangements will be included.

24 **How much time will participants have to give to the project?**

The total amount of time is estimated to be one hour and thirty minutes, 15 minutes to read and sign consent forms, one hour for interviewing, and 15 minutes to review the transcript.

Data Collection

25 **Does the project include the use of participant questionnaire/s?** Yes ☐ No ✓

(If yes, attach a copy of the Questionnaire/s to the application form and include this in your list of attachments (Q5))

If yes: **i)** **indicate whether the participants will be anonymous (i.e. their** Yes ☐ No ☐
      identity unknown to the researcher).

      ii) **describe how the questionnaire will be distributed and collected.**

      (If distributing electronically through Massey IT, attach a copy of the draft request letter to the
      Associate Director Service Delivery, Information Technology Services to the application form.
      Include this in your list of attachments (Q5) – refer to the policy on "Research Use of IT
      Infrastructure").

      (Note: All requests for IT related aspects of ethics committee approvals can be directed through
      the IT service desk in the first instance – the request will be registered and on a response timeline,
      with the Associate Director dealing with the request).

26 **Does the project involve observation of participants? If yes, please describe.** Yes ☐ No ✓

27 **Does the project include the use of focus group/s?** Yes ☐ No ✓

(If yes, attach a copy of the Confidentiality Agreement for the focus group to the application form)

If yes, describe the location of the focus group and time length, including whether it will be in work time. *(If the latter, ensure the researcher asks permission for this from the employer).*

28	**Does the project include the use of participant interview/s?**	**Yes** ✓	**No**	

(If yes, attach a copy of the Interview Questions/Schedule to the application form)

If yes, describe the location of the interview and time length, including whether it will be in work time. *(If the latter, ensure the researcher asks permission for this from the employer)*

The interviews will take about an hour, at a mutually agreed upon time and place.

29	**Does the project involve sound recording?**	**Yes** ✓	**No**	
30	**Does the project involve image recording, e.g. photo or video?**	**Yes**	**No** ✓	

If yes, please describe. *(If agreement for recording is optional for participation, ensure there is explicit consent on the Consent Form)*

31	**If recording is used, will the record be transcribed?**	**Yes** ✓	**No**	

If yes, state who will do the transcribing.

Jane Lee – researcher

(If not the researcher, a Transcriber's Confidentiality Agreement is required – attach a copy to the application form. Normally, transcripts of interviews should be provided to participants for editing, therefore an Authority For the Release of Tape Transcripts is required – attach a copy to the application form. However, if the researcher considers that the right of the participant to edit is inappropriate, a justification should be provided below.)

32	**Does the project involve any other method of data collection not covered in Qs 25-31?**	**Yes**	**No** ✓	

If yes, describe the method used.

33	**Does the project require permission to access databases?**	**Yes**	**No** ✓	

(If yes, attach a copy of the draft request letter/s to the application form. Include this in your list of attachments (Q5). <u>Note</u>: If you wish to access the Massey University student database, written permission from Director, National Student Relations should be attached.)

34 **Who will carry out the data collection?**

Jane Lee – researcher

SECTION C: BENEFITS / RISK OF HARM (REFER CODE SECTION 3, PARA 10)

35 **What are the possible benefits (if any) of the project to individual participants, groups, communities and institutions?**

While there is no direct benefit to the participants, it is hoped that the research will provide single mothers who have a child with impairment a platform to share and give voice to their experiences.

This research will also provide information to social workers and other health and social service practitioners working with single parents who have a child with impairment.

36 **What discomfort (physical, psychological, social), incapacity or other risk of harm are individual participants likely to experience as a result of participation?**

The mothers may feel frustrated, angry or annoyed when relaying their experiences, and also possibly experience a bout of chronic sorrow.

37 **Describe the strategies you will use to deal with any of the situations identified in Q36.**

I will provide a listening ear to the participants. If the strong emotions persist, I will stop/pause the interview and provide the participants with a list of counsellors, including low-cost and telephone options, which they can contact. I will also offer to make the referral for them, if they would prefer this. I will ensure there is informed consent, voluntary participation, confidentiality protection and the right to stop the interview or decline answering any questions prior to commencing or during the interview.

38 **What is the risk of harm (if any) of the project to the researcher?**

Some of the interviews may take place in the participants' homes, which could be a risk of harm to me.

39 **Describe the strategies you will use to deal with any of the situations identified in Q38.**

For safety reasons, if the interview takes place at the participant's home, I will advise my husband of the address, and let him know when I have arrived at the address, and again when I leave. If I arrive at the address and do not feel comfortable about going inside, I will not go inside. I will contact the participant to reschedule for another time at a public space. If at any stage during the interview I feel concerned about my safety, I will tell the participant that I am feeling unwell and I will leave. I will contact the participant to reschedule for another time at a public space. I am a social worker by profession, and have many years of experience going into client's homes alone, therefore I am confident that I will be able to keep the risk of harm to me to a minimum.

40 **What discomfort (physical, psychological, social) incapacity or other risk of harm are groups/communities and institutions likely to experience as a result of this research?**

None is anticipated.

41 **Describe the strategies you will use to deal with any of the situations identified in Q40.**

NA

42 **Is ethnicity data being collected as part of the project?**   Yes [ ]   No [✓]

If yes, please describe how the data will be used.

(Note that harm can be done through an analysis based on insufficient sample or sub-set numbers).

43 **If participants are children/students in a pre-school/school/tertiary setting, describe the arrangements you will make for children/students who are present but not taking part in the research.**

(Note that no child/student should be disadvantaged through the research)

SECTION D: INFORMED & VOLUNTARY CONSENT (Refer Code Section 3, Para 11)

44 **By whom and how, will information about the research be given to potential participants?**

Once potential participants have contacted me for further information about the research, I will post or email them an information sheet (Appendix…) and a consent form (Appendix…)

45 **Will consent to participate be given in writing?**   Yes [✓]   No [ ]

(Attach copies of Consent Form/s to the application form)

If no, justify the use of oral consent.

46 **Will participants include persons under the age of 16?**   Yes [ ]   No [✓]

If yes: i)   indicate the age group and competency for giving consent.

	ii) indicate if the researcher will be obtaining the consent of parent(s)/caregiver(s).	Yes		No	

(Note that parental/caregiver consent for school-based research may be required by the school even when children are competent. Ensure Information Sheets and Consent Forms are in a style and language appropriate for the age group.)

47	**Will participants include persons whose capacity to give informed consent may be compromised?**	Yes		No	✓

If yes, describe the consent process you will use.

48	**Will the participants be proficient in English?**	Yes	✓	No	

If no, all documentation for participants (Information Sheets/Consent Forms/Questionnaire etc) must be translated into the participants' first-language.

(Attach copies of the translated Information Sheet/Consent Form etc to the application form)

SECTION E: PRIVACY/CONFIDENTIALITY ISSUES (REFER CODE SECTION 3, PARA 12)

49	**Will any information be obtained from any source other than the participant?**	Yes		No	✓

If yes, describe how and from whom.

50	**Will any information that identifies participants be given to any person outside the research team?**	Yes		No	✓

If yes, indicate why and how.

51	**Will the participants be anonymous (i.e. their identity unknown to the researcher?)**	Yes		No	✓

If no, explain how confidentiality of the participants' identities will be maintained in the treatment and use of the data.

No identifying features will be included in the thesis or published data.

52	**Will an institution (e.g. school) to which participants belong be named or be able to be identified?**	Yes		No	✓

If yes, explain how you have made the institution aware of this?

---

53 **Outline how and where:**

i) the data will be stored, and

(Pay particular attention to identifiable data, e.g. tapes, videos and images)

The interviews will be audio recorded, and once the interviews have been completed, the recording, transcripts and data will be stored on a password protected external hard drive, stored in a locked desk in my home that only I will have access to.

ii) Consent Forms will be stored.

(Note that Consent Forms should be stored separately from data)

The paper-based consent forms will be stored in a separate locked filing cabinet in my home that only I will have access to.

54 **i)** **Who will have access to the data/Consent Forms?**

The research team: Jane Lee – researcher, and the supervisors, Dr Polly Yeung and Dr Martin Sullivan

ii) **How will the data/Consent Forms be protected from unauthorised access?**

The data will be kept on a password protected external hard drive, stored in a locked desk in my home. The consent forms will be stored in a separate locked filing cabinet in my home that only I have access to.

55 **How long will the data from the study be kept, who will be responsible for its safe keeping and eventual disposal? (Note that health information relating to an identifiable individual must be retained for at least 10 years, or in the case of a child, 10 years from the age of 16).**

(For student research the Massey University HOD Institute/School/Section / Supervisor / or nominee should be responsible for the eventual disposal of data. Note that although destruction is the most common form of disposal, at times, transfer of data to an official archive may be appropriate. Refer to the Code, Section 4, Para 24.)

Personal information will only be kept for as long as it is necessary to complete the research and to allow for academic examination, challenge or peer review. Once this has taken place all electronic data will be permanently deleted and all paper data will be burned. I will be responsible for the safe keeping and eventual disposal of the data.

SECTION F: DECEPTION (Refer Code Section 3, Para 13)

56 **Is deception involved at any stage of the project?** Yes [ ] No [✓]

If yes, justify its use and describe the debriefing procedures.

SECTION G: CONFLICT OF ROLE/INTEREST (Refer Code Section 3, Para 14)

57 **Is the project to be funded or supported in any way, e.g. supply of products for testing?** Yes [ ] No [✓]

If yes: **i)** **state the source of funding or support:**
- **Massey Academic Unit**
- **Massey University (e.g. MURF, SIF)**
- **External Organisation (provide name and detail of funding/support)**

ii) **does the source of the funding present any conflict of interest with regard to the research topic?**

iii) **identify any potential conflict of interest due to the source of funding and explain how this will be managed?**

58 **Does the researcher/s have a financial interest in the outcome of the project?** Yes [ ] No [✓]

If yes, explain how the conflict of interest situation will be dealt with.

59 **Describe any professional or other relationship between the researcher and the participants? (e.g. employer, employee, work colleague, lecturer/student, practitioner/patient, researcher/family member). Indicate how any resulting conflict of role will be dealt with.**

No professional or other relationship between the researcher and the participants.

SECTION H: COMPENSATION TO PARTICIPANTS (Refer Code Section 4, Para 23)

60 **Will any payments, koha or other form of compensation or acknowledgement be given to participants?** **Yes** [ ] **No** [✓]

If yes, describe what, how and why.

(Note that compensation (if provided) should be given to all participants and not constitute an inducement. Details of any compensation provided must be included in the Information Sheet.)

SECTION I: TREATY OF WAITANGI (REFER CODE SECTION 2)

61 **Are Maori the primary focus of the project?** **Yes** [ ] **No** [✓]

If yes: Answer Q62 – 65

If no, outline: i) what Maori involvement there may be, and

ii) how this will be managed.

Given the research involves voluntary recruitment, some single mothers who identify themselves as Maori may show interest in the research and choose to participate. The researcher will discuss any questions that should arise regarding Maori ethnicity with her supervisors. In addition, I will ask participants if they would like to start with a karakia and/or mihi.

62 **Is the researcher competent in te reo Maori and tikanga Maori?** **Yes** [ ] **No** [ ]

If no, outline the processes in place for the provision of cultural advice.

63 **Identify the group/s with whom consultation has taken place or is planned and describe the consultation process.**

(Where consultation has already taken place, attach a copy of the supporting documentation to the application form, e.g. a letter from an iwi authority)

64 **Describe any ongoing involvement of the group/s consulted in the project.**

65 **Describe how information resulting from the project will be shared with the group/s consulted?**

SECTION J: CULTURAL ISSUES (Refer Code Section 3, Para 15)

66 **What ethnic or social group/s (other than Maori) does the project involve?**

One-parent families with children with impairment.

| 67 | Are there any aspects of the project that might raise specific cultural issues? | Yes | | No | ✓ |

If yes, explain.   Otherwise, proceed to Section K.

| 68 | Does the researcher speak the language of the target population? | Yes | ✓ | No | |

If no, specify how communication with participants will be managed.

69   Describe the cultural competence of the researcher for carrying out the project.

(Note that where the researcher is not a member of the cultural group being researched, a cultural advisor may be necessary)

I have prior experience of being a single mother, and I have two children with impairments. My training as a social worker has given me skills in cultural competence.

70   Identify the group/s with whom consultation has taken place or is planned.

(Where consultation has already taken place, attach a copy of the supporting documentation to the application form)

71   Describe any ongoing involvement of the group/s consulted in the project.

72   Describe how information resulting from the project will be shared with the group/s consulted.

73   If the research is to be conducted overseas, describe the arrangements you will make for local participants to express concerns regarding the research.

SECTION K: SHARING RESEARCH FINDINGS (Refer Code Section 4, Para 26)

74   Describe how information resulting from the project will be shared with participants and disseminated in other forums, e.g. peer review, publications, and conferences.

(Note that receipt of a summary is one of the participant rights)

I will offer the research participants a one-page summary of my research findings upon completion and grade finalised. The research will form the basis of my Master's thesis. I may also develop a manuscript to have my research findings published in a peer-reviewed academic journal such as ANZASW Social Work Review or possibly Disability & Society.

SECTION L: INVASIVE PROCEDURES/PHYSIOLOGICAL TESTS (Refer Code Section 4, Para 21)

| 75 | Does the project involve the collection of tissue, blood, other body fluids; physiological tests or the use of hazardous substances, procedures or equipment? | Yes | | No | ✓ |

If yes, are the procedures to be used governed by Standard Operating Procedure(s)? If so, please name the SOP(s). If not, identify the procedure(s) and describe how you will minimise the risks associated with the procedure(s)?

76   **Does the project involve the use of radiation (x-ray, CT scan or bone densitometry (DEXA))?**   **Yes** [ ]   **No** [✓]

     If yes, has the Massey Licensee been contacted and consulted?   **Yes** [ ]   **No** [ ]

     (A copy of the supporting documentation must be provided with the ethics application, i.e. relevant SOP, participant dose assessment calculation sheet and approval of the dose assessment from the relevant authority). NOTE: See "Additional Information for Researchers" (Item 4.2) document for further detail.

     (If yes to Q75 and/or Q76, complete Section L; otherwise proceed to Section M)

77   **Describe the material to be taken and the method used to obtain it. Include information about the training of those taking the samples and the safety of all persons involved. If blood is taken, specify the volume and number of collections.**

78   **Will the material be stored?**   **Yes** [ ]   **No** [ ]

     If yes, describe how, where and for how long.

79   **Describe how the material will be disposed of (either after the research is completed or at the end of the storage period).**

     (Note that the wishes of relevant cultural groups must be taken into account)

80   **Will material collected for another purpose (e.g. diagnostic use) be used?**   **Yes** [ ]   **No** [ ]

     If yes, did the donors give permission for use of their samples in this project?   **Yes** [ ]   **No** [ ]
     (Attach evidence of this to the application form).

     If no, describe how consent will be obtained. Where the samples have been anonymised and consent cannot be obtained, provide justification for the use of these samples.

81   **Will any samples be imported into New Zealand?**   **Yes** [ ]   **No** [ ]

     If yes, provide evidence of permission of the donors for their material to be used in this research.

82   **Will any samples go out of New Zealand?**   **Yes** [ ]   **No** [ ]

     If yes, state where.

     (Note this information must be included in the Information Sheet)

83   **Describe any physiological tests/procedures that will be used.**

84   **Will participants be given a health-screening test prior to participation?**   *(If yes,*   **Yes** [ ]   **No** [ ]
     attach a copy of the health checklist)

Reminder: Attach the completed Screening Questionnaire and other attachments listed in Q5

SECTION M: DECLARATION (*Complete appropriate box*)

ACADEMIC STAFF RESEARCH

DECLARATION FOR ACADEMIC STAFF APPLICANT

I have read the Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants. I understand my obligations and the rights of the participants. I agree to undertake the research as set out in the Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants.   My Head of Department/School/Institute knows that I am undertaking this research.   The information contained in this application is to the very best of my knowledge accurate and not misleading.

Staff Applicant's Signature ....   Date: ....

STUDENT RESEARCH

Declaration for Student Applicant

I have read the Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants and discussed the ethical analysis with my Supervisor. I understand my obligations and the rights of the participants. I agree to undertake the research as set out in the Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants.

The information contained in this application is to the very best of my knowledge accurate and not misleading.

Student Applicant's Signature ....   Date: ....

Declaration for Supervisor

I have assisted the student in the ethical analysis of this project.   As supervisor of this research I will ensure that the research is carried out according to the Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants.

Supervisor's Signature ....   Date: ....

Print Name ....

GENERAL STAFF RESEARCH/EVALUATIONS

Declaration for General Staff Applicant

I have read the Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants and discussed the ethical analysis with my Line Manager. I understand my obligations and the rights of the participants. I agree to undertake the research as set out in the Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants. The information contained in this application is to the very best of my knowledge accurate and not misleading.

General Staff Applicant's Signature ....   Date: ....

DECLARATION FOR LINE MANAGER

I declare that to the best of my knowledge, this application complies with the Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants and that I have approved its content and agreed that it can be submitted.

Line Manager's Signature ....   Date: ....

Print Name ....

TEACHING PROGRAMME

Declaration for Paper Controller

I have read the Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants. I understand my obligations and the rights of the participants. I agree to undertake the teaching programme as set out in the Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants.   My Head of Department/School/Institute knows that I am undertaking this teaching programme. The information contained in this application is to the very best of my knowledge accurate and not misleading.

Paper Controller's Signature ....   Date: ....

DECLARATION FOR HEAD OF DEPARTMENT/SCHOOL/INSTITUTE

I declare that to the best of my knowledge, this application complies with the Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants and that I have approved its content and agreed that it can be submitted.

Head of Dept/School/Inst Signature .... Date: ....

Print Name ....

Appendix J

Response to ethics committee

26th September 2015

Dear Patsy,

Thank you for sending me the comments provided by the Ethics Committee regarding my research ethics application. I want to take this opportunity to thank the Committee for providing useful comments to help fine-tune my application. My responses to the Committee's feedback are listed below:

- The committee discussed Q16 of the Screening Questionnaire to determine the Approval procedure and suggests that participants could be considered as vulnerable.

On reflection, I acknowledge that the participants could be considered as vulnerable.

- In relation to the researcher having the lived experience of raising children with mild disability as indicated in the Introduction Sheet the committee just wishes to highlight that while we acknowledge that qualitative research is very much about the co-construction of knowledge, from an ethics perspective please keep in mind the value of reflecting on positionality; acknowledging subjectivities and behaving reflexively. We reiterate the importance to let the findings speak for themselves.

I will keep in mind the value of reflecting on positionality; acknowledging subjectivities and behaving reflexively. I will use a journal to keep my reflection during the research processes to enhance rigor and trustworthiness. In addition, I will use supervision sessions to discuss and unpack any potential bias or subjectivities derived from interviews.

 SECTION B

Q21

- Please provide a copy of the permission letters from organisations, when received.

These will be provided and will also attach them in my thesis's appendices.

SECTION C

Q37/INFORMATION SHEET

- The committee noted that as the study is being undertaken in the applicants role as a researcher (rather than a therapist), caution should be used in regards to referral to counsellors (this shifts the student researcher into a clinical/social work role). Might someone else be able to refer a participant; or is the response to Q37 intended to note the researcher will facilitate the process? If so, some rephrasing is advised. In addition, who will pay for the cost of counselling even if it is low cost (if it is the participant, this must be made clear in the information sheet).

Q37 has been rephrased in the information sheet:

If you feel distressed or uncomfortable during the interview, I will offer you a break, the option to stop or withdraw from the interview and/or to phone a support person of your choice to come and sit with you. A list of support services would be made available for you at the end of the interview, which you can contact if you wish.

SECTION E

Q55

- Note: In the case of supervised student research, the HoS/supervisor (or nominee) is responsible for the eventual disposal of the data.

This has been rephrased to read:

Personal information will only be kept for as long as it is necessary to complete the research and to allow for academic examination, challenge or peer review. Once this has taken place hard copies of the consent form and transcripts will be sent to the supervisors for eventual disposal and all electronic data will be transferred from the main computer to discs and sent back to supervisors for eventual disposal of the data.

SECTION J

Q68

- Note: Unless the researcher knows the potential participants, the committee noted that the researcher may, or may not speak the language of the target population.

I have revised this to read:

I do not know the potential participants, so I may or may not speak the language of the target population. However, the information sheet and selection criteria specifies that participants speak and understand English without needing to use an interpreter. While participants may not speak English as a first language, their ability and comprehension will be at a level that no extra support will be needed.

SECTION H

Q60

- Is koha being offered? The committee suggests this would be a good gesture.

My response:

I will apply to the Graduate Research Fund (GRF) to offer Koha of either a $20 supermarket gift card or a $20 petrol voucher.

INFORMATION SHEET

- Refer to Q37 above – include relevant details in the information sheet.
- Page 1, paragraph 4, sentence 3 – committee suggests removal of this sentence ("I am aware of the childcare arrangements that you may need …") as it may be perceived as an offer to pay for childcare.
- Page 1, paragraph 5, sentence 1 should read "All information you provide will …"
- Please include the committee approval statement, as follows: This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 15/54. If you have any concerns about the conduct of this research, please contact Dr Rochelle Stewart-Withers, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x 83657, email humanethicsouthb@massey.ac.nz
- Please submit a copy of the revised information sheet

Q37. The information sheet now includes:

If you feel distressed or uncomfortable during the interview, I will offer you a break, the option to stop or withdraw from the interview and/or to phone a support person of your choice to come and sit with you. A list of support services would be made available for you at the end of the interview, which you can contact if you wish.

Page 1, paragraph 4, sentence 3: the sentence "I am aware of the childcare arrangements that you may need…" has been removed.

Page 1, paragraph 5, sentence 1 now reads "***All information you provide will…***"

The copy of the revised information sheet is attached.

Thank you for your feedback regarding my ethics application and I hope that I have addressed all revisions required.

Jane Lee

Appendix K

Support services

Family Works Hutt Valley

Street address: 4 Exchange Street, Upper Hutt

Telephone: 04 439 4900

Website: http://www.psc.org.nz/

Barnardos Hutt Valley

Street address: 29 Waterloo Road, Lower Hutt

Telephone: 04 801 1710

Website: http://www.barnardos.org.nz/office/wellington-cityhutt-valley

Lower Hutt

Barnardos Wellington

Street address: 181 Vivian St, Te Aro, Wellington 6011, New Zealand

Telephone: (04) 385 7560

Website: http://www.barnardos.org.nz/

Lower Hutt Women's Centre

Street address: 186 Knights Road, Lower Hutt

Telephone: 04 569 2711

Website: http://www.lhwc.org.nz/

Skylight Counselling and Support Groups

Street address: 143-145 Riddiford St, Newtown, Wellington 6021, New Zealand

Telephone: (04) 920 9967

Website: http://skylight.org.nz/

Wesley Wellington Counselling

Street address: 75 Taranaki St, Te Aro, Wellington 6011, New Zealand

Telephone: (04) 384 7695

Website: http://www.wesleychurch.org.nz/