

Adjusting to a Different Way of Parenting

The experiences and perspectives of mothers raising a child with cerebral palsy in New Zealand. An interpretative descriptive study

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Abstract

Cerebral palsy (CP) is a neurodevelopmental condition that has widely variable physical and non-physical challenges. Children with CP have long-term care requirements that exceed that of a typical child and, therefore, are more dependent on parents and caregivers for daily assistance. CP is the most common disability worldwide; yet, there is limited qualitative research exploring the experiences of parents and caregivers both internationally and in New Zealand. This research used interpretative descriptive methodology to explore the experiences and perspectives of parents and caregivers in New Zealand raising a school age child with CP. The intention of the research is to provide insight into this topic so that key stakeholders, such as the government, policy makers, and health professionals, can understand the experience and use it to provide services, supports, and practice changes that are evidenced based.

Purposive sampling was used to recruit the 15 participants, all of whom were mothers as they were the only caregiver to respond to the call for volunteers. Semi structured one on one interviews were conducted in person or via Zoom and transcribed through a transcription application (transcribe.com). Analysis of the data revealed an overarching concept of adjusting to a different way of parenting which is made up of three themes: a difficult start, rowing upstream, and winning but not as expected.

These themes represent the parenting journey that the mothers had taken. A difficult start covers a very influential time in the mother's life which often started with a complicated labour and led to many experiencing a rollercoaster of emotions. For many, this time in mothers' lives had a profound effect both on their physical health and their mental health and well-being. Overwhelmingly, this difficult start required them to adjust to a different way of parenting than they had envisaged. Rowing upstream represents the work and worries mothers experienced and reflects how much harder mothers felt it was parenting their child with CP. It includes the challenges and battles they faced with schools and government supports. These variables required mothers to adjust to a different way of parenting than expected. The final theme, winning but not as expected, represents the place where mothers arrived at in their parenting journey and consists of growth through gratitude and the discovery of a warm blanket of community support. All these experiences

led to mothers feeling positive about their parenting journey and that they were winning in life, just in a different way to what they had imagined and expected.

This study highlights a significant gap in qualitative disability research in New Zealand while also revealing the resilience and strength of mothers and their children as they navigate the challenges of disability. It has highlighted the inequities in the NZ health and education systems responsible for providing disability related support and care and uncovered the trauma mothers have experienced. These are important findings that both health and education professionals, policy makers, and disability support organisations should be made aware of. These research findings are intended to be shared widely to highlight the important issues that they have uncovered with a view to influence change.

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor used artificial intelligence tools or generative artificial intelligence tools (unless it is clearly stated, and referenced, along with the purpose of use), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

An application using artificial intelligence called Transcribe was used for transcribing the interviews which were conducted during the data collection process.

Signed:

Date: 29 November 2024

Co-authored Works

1. Smith, M., & Blamires, J. (2022). Mothers' experience of having a child with cerebral palsy. A systematic review. *Journal of Pediatric Nursing*, 64, 64-73. <https://doi.org/10.1016/j.pedn.2022.01.014>
2. Smith, M., Blamires, J., & Foster, M. (2022). The impact of policies and legislation on the structure and delivery of support services for children with cerebral palsy and their families in Aotearoa New Zealand: A professional perspective. *Nursing Praxis in New Zealand*, 38(3), 1-10. <https://doi.org/10.36951/001c.38925>

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Ethics Approval

Ethical approval was obtained from Auckland University of Technology Ethics Committee, reference number 22/343, in November 2022.

Glossary

ACC	Accident Compensation Corporation
AUT	Auckland University of Technology
CP	Cerebral Palsy
DSS	Disability Support Services
GMFCS	Gross Motor Function Classification System
ID	Interpretive Description
MoH	Ministry of Health
MoE	Ministry of Education
NASC	Needs Assessment Service Coordination
NICU	Neonatal Intensive Care Unit
NZ	New Zealand
NZCPR	New Zealand Cerebral Palsy Register
ORS	Ongoing Resourcing Scheme

New Zealand Terminology

Māori	Indigenous New Zealander
Pākehā	New Zealander of European descent
Pacifica People	People who have migrated from the Pacific Islands such as Samoa, Cook Islands, Tonga, Niue, and Fiji

Chapter One. Introduction

Study Overview

This thesis presents an interpretive descriptive (ID) study that explores the experiences and perspectives of primary caregivers (mothers) raising a school aged child with cerebral palsy (CP) in New Zealand (NZ). It is based on a series of 15 qualitative interviews. This chapter is presented in four parts, beginning with an overview of the structure of this thesis. The second part provides an overview of the study which includes an explanation of what CP is and how it presents. Part three explains why this research is important and relevant. The last part concludes the chapter by outlining the main objectives of the study and describing how it has been designed.

Organisation of Thesis

This thesis is organised into eight chapters.

- **Chapter One. Introduction** introduces the topic, the aims, and purpose of the research.
- **Chapter Two. Literature Review** presents a review of the literature in three parts. It covers the parents' experience of raising a child with CP drawing on international literature, the parents' experience of raising a child with a disability in NZ, and a review of the structure and delivery of support services for children living with CP and their families in NZ.
- **Chapter Three. Methodology and Methods**, explains the methodology and how the study has been designed to conduct the research.
- **Chapter Four. Introduction to the Findings**, describes the study participants and explains how the findings have been arranged into three distinct overarching themes.
- **Chapter Five. Theme One**, contains important contextual information about the mothers' difficult start to parenting their child with CP.
- **Chapter Six. Theme Two**, describes how many mothers felt like they were 'rowing upstream' against the current.
- **Chapter Seven. Theme Three**, presents the theme of winning but not as expected.

- **Chapter Eight. Discussion**, brings the themes together, the implications of their collective meaning, and how they can be used to influence current practice as well as future research.

Introduction

CP is a complex neurodevelopmental disorder and the leading cause of neurological impairment and physical disability in children globally (Sadowska et al., 2020; van Eyk et al., 2023). The underlying pathophysiology are lesions or anomalies to the developing brain that occur during the pre- or neo-natal period, and which result in a broad range of non-progressive, yet often evolving, motor impairments (Agarwal & Verma, 2012; Amatya & Khan, 2011). These motor impairments vary considerably and can manifest as weakness, spasticity, and poor co-ordination, all which can have a significant impact on a child's ability to carry out activities of daily living (Amatya & Khan, 2011). CP is not purely a physical disability, as is commonly described; it also encapsulates non-physical challenges that include epilepsy, perceptual disorders, and cognitive challenges which can significantly impact the life of the child and their family (Agarwal & Verma, 2012; Amatya & Khan, 2011; Rudebeck, 2020).

Children with CP have long term care requirements that are different to, and often exceed, the usual needs of typical children. As such, children with CP are dependent on parents and caregivers (most frequently mothers) for daily assistance (Elangkovan & Shorey, 2020). Many children with CP need help physically due to limitations with limb function which affects their ability to be independent with activities of daily living such as dressing, showering, walking, and participating in all aspects of life (Davis et al., 2010; Novak et al., 2013). Health care requirements and care management of a child with CP is, therefore, complex and involves a variety of multidisciplinary services within a health and education framework. Co-ordination of these services, together with advocacy on the behalf of the child, has a significant impact on both the physical and psychological health of a caregiver (Dambi & Jelsma, 2014).

The Physical Presentation of Cerebral Palsy

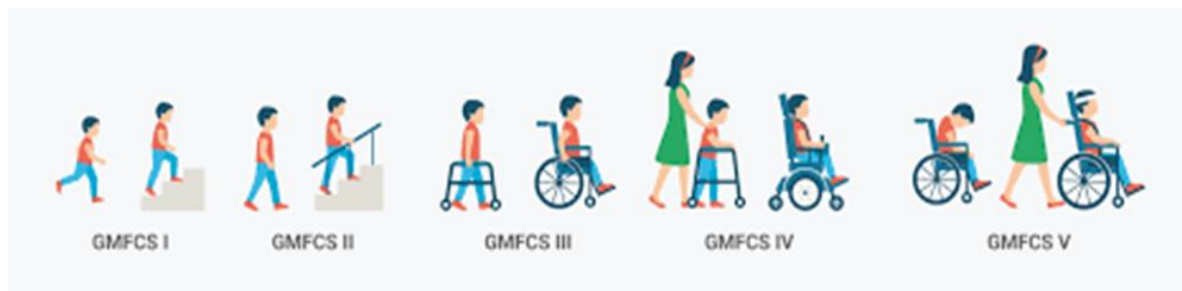
The physical presentation of CP related impairments can vary dramatically from one child to the next, and is often individually unique (Sadowska et al., 2020). While there are various

systems for classifying CP, in general, a diagnosis of CP describes the part of the body affected and the way it is affected. For example, quadriplegia (4 limbs affected), triplegia (3 limbs), diplegia (both legs), and hemiplegia (arm and leg) describe the parts of the body affected; while hypertonia/hyperkinesia, spasticity, dystonia, athetosis, ataxia or mixed, describe how that part of the body is affected (Jonsson et al., 2019; Morgan et al., 2021; Shevell et al., 2009).

Spastic CP, the most common type, is where the muscles in the limbs are stiff and tight (Blair, 2010). Children presenting with spasticity usually have their diagnosis described as spastic quadriplegia, spastic diplegia, and so forth (Michael-Asalu et al., 2019). The physical impairments are commonly further described using a universally recognised Gross Motor Function Classification System (GMFCS) (Palisano et al., 1997). Palisano et al. (1997) developed the GMFCS to define the different levels and stages of physical disability associated with CP. They did this by organising the physical disabilities into five stages from least severe (GMFCS 1) to most severe (GMFCS 5) (Figure 1). Each GMFCS level presents with different challenges for the person living with CP. GMFCS 1, the most common presentation (Blair, 2010), captures people living with CP who are independently ambulatory but may have some difficulty with speed, balance, and coordination. They might experience difficulties with everyday activities that require bilateral strength such as using a knife and fork or getting dressed. In these cases, it can be easy for an untrained eye to not recognise a person has CP as the condition may be subtle, such as having a slightly weaker arm or leg. GMFCS 2 presents as limitations with balance and endurance, a person may use a wheelchair for long distances or handheld supports such as walking sticks. People with GMFCS 3 often use walking frames for support or wheelchairs for traveling longer distances. They can sit and transfer with little or no support. Those with GMFCS 4 can sit and transfer with support, and will rely on a wheelchair with limited self-mobility but may be able to stand or walk for short distances with assistance (Paulson & Vargus-Adams, 2017). GMFCS 5 reflects people who live with the most significant physical disabilities which include impairments in all areas of motor function. People classified as GMFCS 5 are unable to maintain head and neck position and are reliant on others to provide care (Gray et al., 2010; S. M. Reid et al., 2011).

Figure 1.

The Gross Motor Classification System



Note. A figure depicting how physical disabilities within cerebral palsy are classified. From *What is Cerebral Palsy?: How is the severity of CP classified?* by R. D. Moen (n.d.). (<https://www.madeformovement.com/all-you-need-to-know-about-cerebral-palsy#scroll4>). Used with permission from R.D. Moen, Made for Movement.

The Hidden Challenges of Cerebral Palsy

While the GMFCS system is useful in describing physical disability, there is no single universal measure for indicating the many invisible impairments that may be associated with CP. While some people with CP may only be challenged by the physical aspects of CP, others endure the additional impact of cognitive challenges. These can include disorders such as epilepsy; sensory and perceptual disorders; learning, social, communication, executive functioning, and behavioural difficulties, all of which can significantly impact on the life of the child and their family (Agarwal & Verma, 2012; Amatya & Khan, 2011; Rosenbaum et al., 2007; Rudebeck, 2020). In addition they can present as behavioural manifestations such as shyness, depression, anxiety, aggression, problems socialising, hyper activity/inattention, and problems regulating emotions, all of which can lead to high levels of parental challenges and stress (Al-Dababneh & Al-Zboon, 2018; Brossard-Racine et al., 2012; Weber et al., 2016).

Early Diagnosis and Intervention

While CP cannot be cured, providing an early diagnosis (preferably before 6-months-old) allows parents and caregivers to access early interventions which can significantly positively impact on the quality of life for a child with CP (Morgan et al., 2021). Early intervention can optimise motor function, maximise neuroplasticity, minimise secondary complications, prevent deterioration, and improve parent/caregiver well-being (Novak et al., 2017). Therefore, the earlier the diagnosis is made and intervention received, the better for the

child and family (Novak et al., 2017). There are a range of early intervention treatments available to enable children to maximise their function, reduce spasticity, improve movement, support communication and behavioural skills (Faccioli et al., 2023; Novak et al., 2020; Sharma et al., 2023). These include specific repetitive exercises and activities that can be provided by professionals such as physiotherapists, occupational and speech therapists, and psychologists, along with treatment such as Botox injections and surgery provided by doctors (Faccioli et al., 2023; Novak et al., 2020; Spittle et al., 2015).

Cerebral Palsy in New Zealand

While data on people living with CP in NZ are limited, it is estimated that around 2 of every 1,000 babies born worldwide will develop CP and around 8,000-10,000 infants will be diagnosed each year (Oskoui et al., 2013). Based on the 2/1,000 ratio, and the Ministry of Health (MoH) population data, Research Officer Alexandra Sorhage of the NZCP Register (NZCPR) calculated that in NZ this equates to 2,490 children aged 19 years and under living with CP and an estimated 150 new cases being diagnosed each year (personal communication, August 27, 2021).

In NZ, children diagnosed with CP and their families are provided disability support through two distinct pathways. One pathway is through Accident Compensation Corporation (ACC) and the other is through disability support services (DSS). The ACC scheme provides no fault personal injury (caused by accident) cover for NZ residents and visitors. It includes support for medical treatment, rehabilitation, loss of income, and other ongoing costs. It is funded by the Government via taxes where services are purchased directly with (usually privately funded) health and disability providers (NZ Government, 2017). The DSS pathway is where CP related care, intervention, and rehabilitation is delivered by the NZ public healthcare system known as Te Whatu Ora Health NZ (previously District Health Boards) (Whaikaha Ministry of Disabled People, 2022b). This pathway is funded by the Ministry of Health (MoH), informed by the Disability Strategy and Action Plan (Office for Disability Issues, 2016) and provides whatever support and treatment is available within the public system. These two pathways dictate how treatment and interventions are structured and delivered to children living with CP and, subsequently, result in significant variation in service delivery (MoH, 2017; Whaikaha Ministry of Disabled People, 2022a). Research Officer Alexandra Sorhage of the NZCPR reports that 10% of children living with CP in NZ are

supported on the ACC pathway (personal communication, August 27, 2021). The remaining 90%, on the DSS pathway, are less likely to receive the care and treatment they need and are more reliant on their parents' ability to understand the system, ask the right questions, and have the financial means to access important non funded treatment (Williams, Alzahr, et al., 2021; Wynd, 2015). These pathways and the impact on children living with CP will be explored in greater detail in subsequent chapters.

There is evidence that the DSS pathway in NZ lacks coordination and has unexplained variations that affect children with CP across the Te Whatu Ora Health NZ districts (Smith et al., 2022). Those who are eligible to receive ACC funding, however, are likely to have better health and social outcomes (Bradley, 2022). This has led to a significant anomaly in the system resulting in the unequal and unfair distribution of resources depending on whether the aetiology of CP diagnosis has been caused through accident related injury or illness (Smith et al., 2022). Additionally, there are further inequities for Māori (NZ's Indigenous people) and Pacific children (whose families have migrated from the Pacific Islands and make up 9% of the population), for those who are socio-economically disadvantaged, and for those with poorer health literacy (Craig et al., 2016; Statistics New Zealand, 2024; Waitangi Tribunal, 2019). Launched in 2015, the NZCPR collects information on people living with CP to inform care pathways for prevention, diagnosis, management, and support. It captures approximately 55% of all children living with CP but only 26% of Māori children living with CP (Mackey et al., 2022). According to Alexandra Sorhage (Researcher Officer for the NZCP Register) there are approximately 1,500 Māori people in NZ living with CP of whom around 400 are 19 years of age or under year (personal communication, August 27, 2021). Māori children living with CP have a greater level of disability and are more likely to live in poverty and be admitted to hospital with a respiratory illness than their non-Māori counterparts (Sorhage et al., 2022). These factors add further layers of inequity for these children and their families as well as additional stress when faced with cultural barriers (such as having to access care through a largely westernised system), financial constraints, potentially lower levels of education, and the stigma of having a child with a disability.

While CP remains the most common childhood disability, both in NZ and globally, there is a concerning lack of local research into the experiences of those living with this condition and how they understand the support available to them. In NZ, not a lot is known

about the construct of families raising children with disabilities; however, the studies found echoed international trends reporting that that disability care in NZ (both paid and unpaid) is predominantly the role of mothers/women (Hitchcock et al., 2020; Tucker, 2004).

Rationale and Significance of the Study

Children with CP often live with impairments that are complex and chronic in nature. These result in long-term care needs that are different from, and go beyond, the usual requirements of typical children and result in them being more dependent on caregivers/parents for daily assistance (Elangkovan & Shorey, 2020). These impairments have an impact on the functional level and quality of life for the child and, in turn, can result in a significant physical, financial, and psychological health burden on the family (Elangkovan & Shorey, 2020). Hence, parents, and primary caregivers of children with CP often carry considerable multifaceted responsibilities that take time and energy (Chiluba & Moyo, 2017).

Health care requirements and care management of a child with CP requires navigation of a variety of multidisciplinary services within both health and education frameworks (Bourke-Taylor, Cotter, Lalor, et al., 2018; Elangkovan & Shorey, 2020; Hayles et al., 2015). For example, within health care and education settings families must navigate and communicate with different medical specialists, physiotherapists, occupational and speech therapists, along with specially trained teachers and support staff. Co-ordination of these people and corresponding services, together with advocacy on behalf of the child, influences both the physical and psychological health of the parent and/or primary caregiver (Dambi & Jelsma, 2014).

The international literature highlights that it is the mother who often takes on the role as the primary caregiver and that they experience significant impact on their time, freedom, and identity (Afonso et al., 2020; Mokhtari & Abootorabi, 2019; Singogo et al., 2015). They are also required to make adaptations and sacrifices to their lives in order to provide care for their child which affects their relationships (often marital) and well-being (Huang et al., 2012; Mokhtari & Abootorabi, 2019; Singogo et al., 2015). Along with mothers taking on the primary caregiver responsibilities, the literature illustrates that despite CP being the most common cause of disability in children globally, there are inadequate supports in place to maximise the child's potential and quality of life, and that if parents are

facing challenges, opportunities for the child may be compromised (Elangkovan & Shorey, 2020).

The literature relating to raising a disabled child in NZ echoes that of the international literature regarding caregivers' experiences (Gold, 2016; Lee, 2019). That is, the mother usually assumes the caregiver role and they find the health system overwhelming, unsupportive, and difficult to navigate (Gold, 2016; Lee, 2019; Williams, Alzaher, et al., 2021; Zhang & Li, 2021). Mothers experience social, physical, and financial barriers with impacts on their mental health and well-being (Gold, 2016; Hitchcock et al., 2020; Williams, Alzaher, et al., 2021; Zhang & Li, 2021). They report feeling lonely and isolated and identify the importance of receiving support from friends and family which leads to them feeling better equipped to cope (Tucker, 2004; Zhang & Li, 2021).

While there has been some research conducted relating to parents of disabled children in NZ, it is unknown how parents and/or primary caregivers specifically describe their experience of raising a child living with CP in NZ. There is a lack of local research about the experiences of living with CP; accessing healthcare services, disability supports, and information; and culturally appropriate care delivery models. Parents' experience is an important phenomenon to understand and conducting specific research in this space would make a significant contribution to understanding their experiences within the NZ context. It has potential to assist with obtaining a more meaningful picture of what their experience looks like and, in doing so, create new knowledge that can be used to inform and advance practice, theory, research, and policy. International literature supports further research, indicating that for improvements to happen, specific local studies are needed (Afonso et al., 2020; Hayles et al., 2015). The results of this study will be used to inform whether there is a need to change societal attitudes on inclusion and acceptance, develop interventions to support parents and caregivers, and improve strategies for rehabilitation and support for children living with CP in NZ. Findings will also be used to inform and educate health and education professionals and services about this important issue. Furthermore, gaining a deeper understanding of parents'/caregivers' experiences has the potential to positively influence the health outcomes and enhance the quality of life for both primary caregivers and children living with CP.

Study Objectives

The research question for this study is 'What are the experiences and perspectives of primary caregivers raising a school-aged child with cerebral palsy (CP) in NZ?' The research aim is to explore and understand the lived experiences and perspectives of primary caregivers in NZ who are raising a school-aged child with CP. The research objectives are:

1. To investigate how primary caregivers perceive, experience, and navigate their caregiving roles.
2. To explore and identify how disability services influence primary caregivers' experiences.

Given the limited understanding of the lived experience of raising a child with CP within NZ, a qualitative methodology was considered the most fitting approach. Thus, this qualitative study is designed to provide a platform for primary caregivers to share their stories, be heard, make a meaningful contribution, and have some influence in an area where they have historically had little or no choice over the way disability services are offered (Worcester et al., 2008). By capturing these narratives, the research findings are intended to be useful for informing government bodies, policymakers, health professionals, and other stakeholders, to foster a more inclusive and responsive support system for families living with CP in NZ.

The rationale for focusing on the school age range was because support services for children with CP and their families change once a child turns 5-years-old and starts school. For example up to age 5, children with developmental delays or disabilities may receive support from early intervention services (EIS) through the Ministry of Education (MoE), which includes specialists like speech-language therapists and early intervention teachers (Whaikaha Ministry of Disabled People, 2024) along with therapist input from the MoH. Then, once they turn 5-years-old, a large portion of care is transferred from the MoH to the MoE (MoE, 2021; MoH, 2012). At the other end of the school age perimeter, in NZ, the MoH does not mandate a specific age for transitioning children from paediatric to adult healthcare services. However, according to the Starship Children Hospital guidelines (Starship, 2019b), the process generally begins between ages 12 and 14, with the actual transfer often occurring around age 16. This timing is influenced by factors such as the young person's health stability and readiness for increased responsibility in managing their care (Starship, 2019b). Some paediatric disability health services might transfer children

who have been under their care for most of their lives later than this age, due to long standing relationships and fear that the adult services will not provide the same attention and care. The Ministry of Social Development (n.d.) supports transition out of school for children between the ages of 16 and 21 years.

Chapter Summary

This chapter has provided a brief overview of the thesis organisation and an overview of the study. It has introduced the topic of CP and parenting a child living with CP, and explained the relevance and importance of the research, as well as the aim of the study.

Chapter Two will be presented in three parts. The first part presents a review of the current international literature on parenting a child with CP. This is followed by a review of the NZ literature into parenting a child with a disability. The third part explores the impact of local policies and legislation on the structure and delivery of support services for children with CP and their families in NZ.

Chapter Two. Review of the Literature

This chapter reviews the existing literature surrounding primary caregivers' experiences of having a child with CP and how it relates to the NZ context. The literature review is presented in three parts. The first part describes primary caregivers' experience of having a child with CP and draws on the international qualitative literature. The second part, in the absence of any research from NZ on caregivers' experience of raising a child with CP, explores what is known about the experience of parenting a disabled child in NZ. Part three reviews the policies and legislation that impact the structure and delivery of support services for children living with CP and their families in NZ. These three separate but interconnected reviews inform the design of the research. Parts one and three have been revised, edited, and published in peer reviewed journals (Smith & Blamires, 2022; Smith et al., 2022). Links to these articles can be found in Appendices A and B.

The first part of this literature review was initially written as a standalone piece. Subsequently, a decision was made to develop the review into a publishable paper in collaboration with my academic supervisor. Although the same body of literature was examined in both versions, the analytical approach adopted for the published paper (Smith & Blamires, 2022) differed. Specifically, the published version was structured as a systematic review, incorporating the Preferred Reporting items for Systematic reviews and Meta-Analyses (PRISMA) framework and the Critical Appraisal Skills Programme (CASP) tool, whereas the initial version did not employ these methods. Additionally, while the original review considered the experiences of parents more broadly, the published paper focused exclusively on mothers. This refinement in scope was prompted by the identification of an existing publication (Elangkovan & Shorey, 2020) that addressed the experiences of parents raising a child with CP.

Part 1. Parents' Experience of Having a Child with Cerebral Palsy

The birth of a child is commonly a time of great joy and excitement. However, along with this joy and excitement comes a need for considerable resource, time, responsibility, and care (Elangkovan & Shorey, 2020; Kurtuncu et al., 2015). While parents are usually well prepared for the birth of a 'normal' baby, having a child who is diagnosed with CP is often unexpected (Milbrath et al., 2008) and brings with it an additional set of unique stressors

and demands because of a vast range of extra needs. These needs commonly cause additional stress, and emotional and financial burden to parents as they care for a child that requires lifelong attention and rehabilitation (Elangkovan & Shorey, 2020; Nyante & Carpenter, 2019; Rentinck et al., 2007).

A review on parenting and caregiver experiences highlighted the complex and multifaceted reality of caring for a child with CP (Elangkovan & Shorey, 2020). In that review, mothers made up most of the participant group (184 out of the 226 participants); and, although the intention was not to focus specifically on the experience of mothers, the authors acknowledged a dichotomy between the roles of mothers and fathers (Elangkovan & Shorey, 2020). Other studies have demonstrated that mothers of children with disabilities experience higher stress than fathers and are at greater risk of anxiety, depression, lower psychological well-being, and decreased health (Crettenden et al., 2018; Resch et al., 2012; Rudebeck, 2020). Despite the obvious and evident burden that mothers carry with regard to looking after a child with CP, it was deemed important to provide a foreground for this study utilising a broad approach and to consider not only mothers but all caregivers' experiences.

Once the decision was made to look broadly at all caregivers' experience, consideration was given to the types of research the review would include. An initial search of Google Scholar revealed some articles using qualitative approaches and an abundance of articles using quantitative approaches. In brief, quantitative research has its roots in positivism and uses numbers (e.g., percentages or averages) to explain a phenomenon and make sense of the world. It believes that there is one truth or reality (Claydon, 2015). Many of the quantitative studies found included those that used standardised quality of life tools to survey vast numbers of parents. These studies provided generalised information indicating a significant negative impact on physical, mental, and emotional well-being amongst mothers of children with CP (Ahmadizadeh et al., 2015; Ones et al., 2005; Ström et al., 2012). Two of these studies did comparisons with mothers of children who did not have a disability (Ahmadizadeh et al., 2015; Ström et al., 2012) and the tools used indicated the mothers of children with CP were significantly worse off and needed more psychological support and help. For example, Ones et al. (2005) revealed that mothers of children with CP had a mean score on the Beck Depression Inventory of 18.30 (indicating a higher prevalence of depression) compared to 7.34 among mothers of non-disabled children.

Although these quantitative approaches provide important information about children with CP and their families, they do not allow for the rich meaningful description and subjective stories that I sought to provide the scaffolding for my research. It was, therefore, decided to focus more specifically on the qualitative literature. Qualitative research takes place in a natural setting where data are collected face to face by the researcher themselves rather than relying on instruments from others (Creswell, 2013). Inquiry is conducted in such a way as to not disturb the natural phenomenon and multiple forms of data are generally used including interviews, focus groups, and observations (Creswell, 2013). The aim is to capture the meaning and experience of the participant and to understand their reality (Cypress, 2015). This is based on more interpretivism and the notion of multiple realities within qualitative research, where the existence of something may depend on one's perspective, and language is used to explain and make sense of that existence (Claydon, 2015). For these reasons, and in line with the aim of the first review (to understand individual parents' experiences more deeply), a qualitative literature review was most appropriate.

Method

Aim

The aim of this part of the literature review was to explore the subjective experiences and individual realities of caregivers raising a child with CP. The question that informed this review was: What are the perception and experiences of caregivers raising a child with CP?

Design

The review was guided by Bettany-Saltikov and McSherry's (2016) approach to undertaking a systematic qualitative literature review in nursing. A qualitative synthesis method was used through which the findings from qualitative studies were aggregated, integrated, and/or interpreted utilising Braun and Clarke's (2019) reflective thematic analysis approach. Braun and Clarke's (2019, 2022) reflexive thematic analysis is a flexible approach to analysing qualitative data by identifying, analysing, and interpreting patterns (themes) within it.

Inclusion and Exclusion Criteria

Qualitative research studies published in English were used if they reflected the experiences of parents of school age (5-16 years) children with CP. Studies were excluded if they used quantitative research, included children with multiple disabilities, focused only on parents of pre-school aged children or focused on specific aspects of parenting a child with CP for example articles specifically about home therapy programmes, as I wanted to approach the topic from a broader lens.

Search Strategy

Electronic databases (Medline via OVID, SCOPUS, Google Scholar, EBSCO Health, and CINAHL [Cumulative Index to Nursing and Allied Health Literature] via EBSCO) were systematically searched for qualitative literature in April and May 2021. The search terms used were participants (parent* or caregiver* or mother* or father* or guardian*), phenomena of interest (experience* or perception* or attitude* or view* or feeling* or emotion* or 'everyday life' or 'daily life' or 'living with'), and context (Cerebral Palsy or CP). The search was limited to qualitative studies published in English from 2000 to 2021 that explored the experience of caregivers of children living with CP between the ages of 5 and 16 years, and that used a qualitative methodological study design. To ensure rigour of the literature search process¹, an Auckland University of Technology (AUT) librarian was consulted who confirmed that a thorough and comprehensive search had been conducted. An AUT postgraduate literature review workshop was also attended.

Data Extraction and Analysis

Once the search of the databases was complete and articles that met the criteria were identified, a data extraction table was created (Table 1). This table included authors, publication year, country, research aim/question, methodological design and data collection, sample and sample size, and any relevant findings. While utilising the data extraction table, data were examined and analysed using Braun and Clarke's (2012)

¹ This search strategy was formulated by Meg Smith and is included in the following publication which can be found in Appendix A: Smith, M., & Blamires, J. (2022). Mothers' experience of having a child with cerebral palsy. A systematic review. *Journal of Pediatric Nursing*, 64, 64-73. <https://doi.org/10.1016/j.pedn.2022.01.014>

approach to thematic analysis as a framework. This process involves six steps: familiarisation with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the final findings. Reflexivity, or self-awareness, is central to this approach. Therefore, I continually reflected on my own perspectives and biases throughout the analysis (Braun & Clarke, 2012, 2019).

Findings

A comprehensive search of the literature resulted in 17 qualitative articles relevant to the topic of a parent's experience of raising a child living with CP. Table 1 summarises the characteristics of the included studies.

The data collection method utilised in the research articles was predominately interviews. All the articles included the term 'parents' to describe their participants as opposed to caregivers or guardians. Mothers ($n=204$) were more commonly interviewed than fathers ($n=37$). Some articles also included very small numbers of grandparents, carers, or other family members (e.g., cousins). The literature was not clustered in one region of the world but spread over 10 countries representing a wide variety of cultures, resources, and wealth. There were no studies from NZ. The included studies were conducted in Australia ($n=3$) (Davis et al., 2010; Davis et al., 2009; Hayles et al., 2015); Brazil ($n=2$) (Afonso et al., 2020; Milbrath et al., 2008); Taiwan ($n=2$) (Huang et al., 2012; Huang et al., 2010); India ($n=2$) (Nimbalkar et al., 2014; Vadivelan et al., 2020); Iran ($n=2$) (Alaee et al., 2014; Mokhtari & Abootorabi, 2019); Canada ($n=2$) (A. Reid et al., 2011; Whittingham et al., 2013); and one each from Zambia (Singogo et al., 2015), Saudi Arabia (Mohamed Madi et al., 2019), Spain (Fernandez-Alcantara et al., 2015), and Ghana (Nyante & Carpenter, 2019). The studies used a range of qualitative methodological approaches including hermeneutic phenomenology ($n=3$), interpretative descriptive ($n=1$), grounded theory ($n=5$), critical ethnography ($n=1$), and qualitative descriptive ($n=7$).

Table 1².*Characteristics of the Studies Included in the First Review*

Authors and year published	Country of origin	Research question/aim	Methodological design and data collection	Sample and sample size	Findings relevant to the review
Afonso, T., da Costa Silva, S. S., & Pontes, F. A. R. (2020)	Brazil	To explore past experiences and future expectations arising from mothering a child with CP.	Semi demographic inventory, GMFCS interviews. Grounded theory, interviews.	13 mothers	1) importance of acquired learning 2) the maturation processes 3) the suffering experienced 4) the perceptions about happiness and the challenges to be overcome Mothers perceived themselves accomplished with the construction of intense learning about the care required in CP Future – feeling relates to the perception of the child’s lack of adaptive competence Past – a set of experiences leads to a maturation process which tolerance and patience are evident.
Alaee, N., Shahboulaghi, F. M., Khankeh, H., & Mohammad Khan Kermanshahi, S. (2014)	Iran	To explore the needs and challenges of parents in caring and supporting their child with CP.	Semi structured interviews.	12 mothers 5 fathers	Four subcategories in the category of social challenges 1) inadequate facilities and services 2) unsupportive interactions 3) limitation of parents’ social relations, 4) social seclusion of the child and parent Three subcategories in the category of psychoemotional challenges 1) intrapersonal conflicts 2) being worried 3) sense of loneliness
Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., Davern, M., & Reddiough, D. (2009)	Australia	To explore impact of caring for a child with CP: Quality of life (QOL) for mothers and fathers.	Grounded theory, semi-structured interviews.	24 mothers 13 fathers	1) no differences in parental QOL among subgroups (i.e., mothers and fathers, age groups, GMFCS levels) 2) parental QOL ranged across a wide spectrum 3) caring for a child with CP affects a parent’s physical well-being, social well-being, freedom and independence, family well-being, and financial stability 4) parents indicated that they often feel unsupported by the services they access

² This table was formulated by Meg Smith and is included in the following publication: Smith, M., & Blamires, J. (2022). Mothers’ experience of having a child with cerebral palsy. A systematic review. *Journal of Pediatric Nursing*, 64, 64-73. <https://doi.org/10.1016/j.pedn.2022.01.014> (Appendix A).

Authors and year published	Country of origin	Research question/aim	Methodological design and data collection	Sample and sample size	Findings relevant to the review
		To explore if impact changes from childhood to adolescence.			
Davis, E., Shelly, A., Waters, E., Mackinnon, A., Reddihough, D., Boyd, R., Kerr Graham, H. (2008)	Australia	To identify domains of QOL for adolescents with CP from adolescent and parent perspectives to guide the development of an adolescent version.	Grounded theory, semi-structured interviews.	21 mothers 2 fathers 17 adolescents	15 QOL domains were identified including; 1) health issues in adolescence 2) participation 3) education 4) specific CP-related issues (pain and discomfort, communication) 5) family issues practical issues (financial resources) 6) changes associated with adolescence (sexuality, independence)
Fernandez-Alcantara, M., Garcia-Caro, M. P., Laynez-Rubio, C., Perez-Marfil, M. N., Marti-Garcia, C., Benitez-Feliponi, A., Berrocal-Castellano, M., & Cruz-Quintana, F. (2015)	Spain	To identify feelings of loss in parents of children with infantile CP.	Grounded theory, semi-structured interviews.	24 parents 15 mothers 9 fathers	Parents experience; 1) loss of the ideal child (more complex in the first stage of diagnosis and when CP is more severe), shock, hope, traumatic experience 2) acceptance of child

Authors and year published	Country of origin	Research question/aim	Methodological design and data collection	Sample and sample size	Findings relevant to the review
Hayles, E., Harvey, D., Plummer, D., & Jones, A. (2015)	Australia	How do parents living in a rural area of Australia experience health care for their children with CP? What do parents think are important aspects of their child's health care? How do parents want their healthcare needs met?	Grounded theory, focus group interview.	11 mothers 2 fathers	Parents experience health care for their child as a process of 1) making the most of their body and their life 2) learning as you go 3) navigating the systems meeting needs through partnership 4) being empowered or disempowered 5) finding a balance Suggestions made on how to modify the system to improve experience.
Huang, Y. P., Kellett, U. M., & St John, W. (2010).	Taiwan	CP: Experiences of mothers after learning their child's diagnosis.	Hermeneutic phenomenology, interviews.	15 mothers	Four shared meanings revealed; 1) feeling out of control and powerless 2) mistrusting health professionals 3) release and confirmation 4) feeling blame for not following traditional practices
Huang, Y. P., Kellett, U. M., & St John, W. (2011).	Taiwan	To study Taiwanese mothers' challenging experiences when a disabled child is born into their families in the	Hermeneutic phenomenology, interviews.	15 mothers	Shared meanings revealed four modes of being concerned; (1) experiencing burden as a sole primary caregiver (2) managing the challenges by balancing demands (3) being marginalised by others (4) encountering limited or no professional support

Authors and year published	Country of origin	Research question/aim	Methodological design and data collection	Sample and sample size	Findings relevant to the review
		context of Chinese culture.			
Milbrath, V. M., Cecagno, D., Soares, D. C., Amestoy, S. C., & Heckler de Siqueira, H. C. (2008).	Brazil	What is the adaptive processes experienced by a woman motivated by the birth of a child with CP?	Descriptive exploratory.	6 mothers	Two key themes; 1) experiencing being a woman-mother of a child with CP 2) supporting networks necessary to the woman-mother of a child with special needs
Mohamed Madi, S., Mandy, A., & Aranda, K. (2019)	Saudi Arabia	To explore the perceptions of disability among Saudi mothers and to understand the implication of the meaning for the mothers of children with disability.	Critical ethnographic, focus groups and follow-up interviews.	6 mothers	Three primary themes were identified that specifically influenced and affected the mothers' experiences; 1) culture and religion 2) motherhood and disability 3) community stigma and discrimination
Mokhtari, M., & Abootorabi, F. (2019)	Iran	Lived experiences of mothers of	Hermeneutic phenomenology, interviews.	8 mothers	Themes identified; 1) feelings 2) self-expectation 3) levels of relations 4) levels of support

Authors and year published	Country of origin	Research question/aim	Methodological design and data collection	Sample and sample size	Findings relevant to the review
		children with CP in Iran.			Conclusions: Mothers are uncertain about the future. Facilities for rehabilitation and treatment (insufficient and inadequate) and levels of satisfaction with caring systems (dissatisfaction with government agencies/satisfaction with private treatment centres).
Nimbalkar, S., Raithatha, S., Shah, R., & Panchal, D. A. (2014)	India	To explore the psychosocial problems faced by the parents of children with CP in rural and urban settings.	Focus groups.	1 grandmother 1 father 11 mothers	Psychosocial problems experienced by the parents identified as; 1) disturbed social relationships 2) health problems 3) financial problems 4) moments of happiness 5) worries about future of the child 6) need for more support services 7) lack of adequate number of trained physiotherapists
Nyante, G. G., & Carpenter, C. (2019)	Ghana	The experience of carers of children with CP living in rural areas of Ghana who have received no rehabilitation services.	Descriptive phenomenology, semi-structured interviews.	12 carers 8 mothers 1 father 2 grandmothers 1 cousin	Two themes; 1) developing personal beliefs to support the caregiving role (3 subthemes) 2) demands that shape the experience of caring (3 subthemes)
Reid, A., Imrie, H., Brouwer, E., Clutton, S., Evans, J., Russell, D., & Bartlett, D. (2011)	Canada	If I knew then what I know now: Parents' reflections on raising a child with CP.	Interpretive description, interviews.	7 mothers 2 fathers	1) results informed the development of tips for parents and children to enhance their family's experience and interactions with healthcare providers, educators, and others 2) parents elaborated upon what was helpful and what could be changed to improve their children's and family's experiences through support, advocacy, and education at different levels

Authors and year published	Country of origin	Research question/aim	Methodological design and data collection	Sample and sample size	Findings relevant to the review
Singogo, C., Mweshi, M., & Rhoda, A. (2015)	Zambia	Explore the challenges experienced by mothers caring for children with CP in Zambia.	Exploratory, interviews.	16 mothers	Themes; 1) physical challenges 2) social isolation 3) perceived causes of CP 4) physical access challenges 5) marital problems 6) challenges with the health care system
Vadivelan, K., Sekar, P., Sruthi, S. S., & Gopichandran, V. (2020)	India	To explore the burden of caregivers of children with CP: An intersectional analysis of gender, poverty, stigma, and public policy.	Exploratory, interviews-thematic content analysis.	10 mothers	Stressors identified; 1) physical-aches/pains, abusive husband, lack of community support-accessibility barriers 2) emotional-guilt blame-emotional abuse-worry 3) social-blame, discrimination, lack of inclusive spaces, lack of social support groups 4) financial-unable to work, lack of job options, insufficient welfare support 5) informational-lack of knowledge about caregiving options
Whittingham, K., Wee, D., Sanders, M. R., & Boyd, R. (2013)	Canada	Sorrow, coping and resiliency: Parents of children with CP share their experiences.	Focus groups and web based cross sectional survey (adapted burke questionnaire on chronic sorrow).	6 mothers 2 fathers 94 parents completed the survey	1) some parent found diagnosis distressing while others found it a relief 2) at times, parents found medical and allied health intervention particularly challenging 3) authors concluded that the chronic sorrow theory is a useful way of understanding experiences of parents of children with CP 4) parents may experience delayed intense chronic sorrow symptoms following a triggering event and this is normal

The total number of parents and caregivers across all studies was 257. The level of education was often not reported but among those studies that did report on this variable there was wide variation ranging from no education at all to level one tertiary education. Some of the studies (Afonso et al., 2020; Davis et al., 2010; Davis et al., 2009; Fernandez-Alcantara et al., 2015; A. Reid et al., 2011) reported on disability using the GMFCS (Palisano et al., 1997) as described in Chapter One. This five-level classification system describes the gross motor function of children and youth with CP based on their self-initiated movement including sitting, walking, and wheeled mobility. Level one reflects a lower level of physical disability while the highest level of the GMFCS (five) and is designated for those living with the most severe mobility issues (McDowell, 2008). In this review, where the study reported disability status of the child with CP, there was a wide spread of disability with GMFCS scores ranging from 1 to 5.

Key Themes

The findings from this review are organised into eight themes: coming to terms with CP, financial challenges, emotional burdens, health and education systems challenges, social isolation and support, physical challenges, environmental barriers, and spiritual guidance. The first two themes—coming to terms with CP and financial challenges—represent parents' experiences. The second, third, and fourth themes (emotional burdens, healthcare systems challenges, social isolation and support) reflect the experiences of parents and, more specifically, the experiences of mothers as the primary caregiver. The last three themes (physical challenges, environmental barriers, and spiritual guidance) reflect only mothers' experiences as that is how it was presented in the literature reviewed.

While some of the studies did include fathers (Alaee et al., 2014; Davis et al., 2010; Davis et al., 2009; Fernandez-Alcantara et al., 2015; Hayles et al., 2015; Nimbalkar et al., 2014; Nyante & Carpenter, 2019; A. Reid et al., 2011; Whittingham et al., 2013), all studies represented mothers either as the majority or exclusively, and provided evidence to demonstrate that mothers were most commonly the primary caregiver.

Coming to Terms with the Diagnosis of Cerebral Palsy

This first theme presents synthesised findings from 10 of the 17 articles reviewed (Afonso et al., 2020; Davis et al., 2010; Hayles et al., 2015; Huang et al., 2012; Huang et al., 2010;

Milbrath et al., 2008; Mokhtari & Abootorabi, 2019; A. Reid et al., 2011; Vadivelan et al., 2020; Whittingham et al., 2013). Parenting a child with CP is seen as a challenge that has an additional set of stressors on top of the usual parenting stresses (A. Reid et al., 2011; Vadivelan et al., 2020). On receiving their child's diagnosis, families are required to make swift and unexpected adjustments to their lives and change the way they structure and organise themselves in order to cater to their child's higher caregiving demands (Davis et al., 2010; Milbrath et al., 2008). This unexpected news results in a wide range of emotions being experienced, including shock, refusal to accept, anger, fear, guilt, worry, and uncertainty (Fernandez-Alcantara et al., 2015; Huang et al., 2010; Milbrath et al., 2008; Mokhtari & Abootorabi, 2019; A. Reid et al., 2011; Vadivelan et al., 2020). The magnitude of these emotions can relate to the severity of the child's disability (Fernandez-Alcantara et al., 2015). Parents reported feeling a keen loss for their ideal child (Fernandez-Alcantara et al., 2015; Huang et al., 2010).

There's a different kind of grief because you recognise that things are never going to be the way you planned them to be. And the things that you may have planned for you and your spouse are no longer going to be that way either. (Parent of Greta, cited in A. Reid et al., 2011, p. 174)

However, not all the literature reviewed reported on negative and challenging perspectives, with some conveying positive experiences (Davis et al., 2009; Hayles et al., 2015; Mokhtari & Abootorabi, 2019). The presence of both good social support and relationships with health professionals was highlighted as an important influencing factor for adjusting and coping with the diagnosis of CP (Hayles et al., 2015; Huang et al., 2012; Huang et al., 2010; Mokhtari & Abootorabi, 2019; A. Reid et al., 2011; Whittingham et al., 2013). Hayles et al. (2015) reported that parents found a balance through a process of "continuous evaluation, prioritisation and management of the needs of a child with CP in the context of all the other challenges" (p. 1147) in their life. This is influenced by parents' understanding of the challenges faced and the impact on the whole family (Hayles et al., 2015). Studies reveal that health professionals must be equipped to provide parents with emotional support and information when they are informed of the diagnosis and throughout the child's upbringing so that the parent is able to work through inevitable obstacles related to their child's disability (Fernandez-Alcantara et al., 2015; Huang et al., 2010; Whittingham et al., 2013). Family adaptation and the child's inclusion within society are

identified as important and the adaptive aspects depend on the characteristics of the parent, the disability, and existing resources (Afonso et al., 2020).

Financial Challenges

Financial demands related to raising a child with CP was a significant cause of stress and pressure for parents in India, Ghana, Iran, and Australia (Alaee et al., 2014; Davis et al., 2010; Nimbalkar et al., 2014; Vadivelan et al., 2020). Parents in these countries reported heavy health related expenses which they were required to self-fund (Alaee et al., 2014; Davis et al., 2010; Nimbalkar et al., 2014; Vadivelan et al., 2020). These costs included privately funded equipment and therapy, doctors' appointments, medications, spiritual interventions, and transport to attend appointments (Nimbalkar et al., 2014). Mothers, in particular, reported having to make significant sacrifices in order to be able to meet these financial needs (Nimbalkar et al., 2014). "We might eat less but we shall fulfil all that is required by him" (Nimbalkar et al., 2014, p. 3). Sometimes such sacrifice resulted in mothers having to leave paid employment so they could adequately care for their child and attend day time hospital appointments which impacted negatively both the family's finances as well as their own identity (Davis et al., 2010; Nimbalkar et al., 2014).

Emotional Burden

This theme first highlights the emotional burden of parents raising a child with CP, followed by the specific emotional burdens that mothers experienced as the primary caregiver of their child. It was evident from the literature that parents carry a significant emotional burden and experience a high level of stress due to the constant and continuous work involved with caring for their child with CP which, in turn, affects their well-being (Davis et al., 2009; Nimbalkar et al., 2014). Parents who experience stress report that it has a negative impact on all aspects of their lives (Alaee et al., 2014; Davis et al., 2010; Davis et al., 2009; Nimbalkar et al., 2014). Parents can experience negative emotions such as anger, tiredness, frustration, grief, and a sense of sadness for the lost parenting opportunities and idealised child. Parents worried about the uncertainty of the future and who would take care of their child in their absence but were resigned to accepting they had no control over this (Nimbalkar et al., 2014; Whittingham et al., 2013).

He's getting bigger, he's getting heavier. What's going to happen when he leaves school? What role is my five-year-old going to inherit at some point with his brother? I can't help but worry about those things. (Whittingham et al., 2013, p. 1450)

They reported feelings of helplessness when they did not see improvements in their child; for example, achieving milestones (Nimbalkar et al., 2014). At other times parents reported feeling positive and satisfied with their child's learning and achievements, and enjoyed celebrating their child milestones and the mastering of new skills (Davis et al., 2009; Nimbalkar et al., 2014). Australian parents said they felt inspired by their children and admired the resilience and courage they showed (Davis et al., 2009).

The literature did provide some advice for emotionally burdened parents and others in their lives. For example, A. Reid et al. (2011) recommended parents prioritise self-care to ensure they had the internal resources and capacity to provide the care required for their child. While Whittingham et al. (2013) proposed the use of positivity and internal management skills as effective coping strategies for parents which included being proactive with asking for help from professionals with developing goals and plans. Whittingham et al. also highlighted that health professionals should be aware that parents can feel intense grief and sorrow at any time during their journey which may trigger these strong emotions.

Overwhelmingly, the literature highlights how it is most often the mother who takes on the majority of the caregiving responsibility of the child, equating to a heavy burden (Huang et al., 2012; Milbrath et al., 2008; Vadivelan et al., 2020). Mothers will experience the most change and, therefore, have the biggest alteration to their daily lifestyle as well as biggest sacrifices to accommodate the needs of her child (Davis et al., 2010; Milbrath et al., 2008). Thus, mothers are also the family member who experience the most diverse range of emotions (Davis et al., 2010; Hayles et al., 2015; Mohamed Madi et al., 2019; Mokhtari & Abootorabi, 2019; Nimbalkar et al., 2014; Nyante & Carpenter, 2019; Singogo et al., 2015; Vadivelan et al., 2020). Mothers from Iran and Australia reported feelings of happiness, joy, and satisfaction (Davis et al., 2010; Hayles et al., 2015; Mokhtari & Abootorabi, 2019); while mothers from Ghana, Iran, Brazil, India, Saudi Arabia, and Taiwan reported feeling apathy, sadness, grief, self-blame, shame, guilt, regret, and stress. These feelings often evolved from feelings of humiliation and a personal failure that came from not delivering a 'healthy baby' and the belief that this misfortune was a punishment from God (Milbrath et al., 2008; Mohamed Madi et al., 2019; Mokhtari & Abootorabi, 2019; Nimbalkar et al., 2014; Nyante &

Carpenter, 2019; Singogo et al., 2015; Vadivelan et al., 2020). These mothers felt blamed for their child's CP and experienced negative attitudes from their husbands, family, friends, people within their communities, and health professionals, which affected their ability to accept the CP diagnosis (Huang et al., 2010; Milbrath et al., 2008; Mohamed Madi et al., 2019; Mokhtari & Abootorabi, 2019; Nyante & Carpenter, 2019; Vadivelan et al., 2020).

My mother-in-law blamed me for not having a healthy child. Society blames the mother. In the beginning my mother and my aunt told me to admit him to a disabled centre and to leave him till he became independent, but I refused. (M6, cited in Mohamed Madi et al., 2019, p. 7)

Mothers from Ghana, Saudi Arabia, and Taiwan also experienced negative societal attitudes with their children being labelled as animals, seen as incomplete, or regarded as a disruption to ancestry, which was described as bringing shame and disgrace to a family (Huang et al., 2012; Mohamed Madi et al., 2019; Nyante & Carpenter, 2019). In these situations, mothers often rejected the diagnosis of CP, choosing instead a more acceptable term such as brain atrophy and preferring to believe that their child would 'catch up' (Mohamed Madi et al., 2019). Milbrath et al. (2008) reported that these feelings of guilt led mothers to fully dedicating their life to caring for their child.

Mothers reported marital problems such as frequent fighting with their husband (due to the husband's family interfering or blaming each other for their child's CP), the husband becoming an alcoholic, the mother being a victim of domestic abuse or being rejected by her husband (Mohamed Madi et al., 2019; Mokhtari & Abootorabi, 2019; Nyante & Carpenter, 2019; Singogo et al., 2015; Vadivelan et al., 2020). In these studies, the husband often left to start a new family elsewhere (Milbrath et al., 2008; Singogo et al., 2015; Vadivelan et al., 2020). In contrast, studies from India and Brazil revealed that married life had not been significantly impacted for mothers, with mothers from Brazil feeling supported to care for their child by their husband, family, friends, and members of the community (Milbrath et al., 2008; Nimbalkar et al., 2014). However, mothers in Taiwan felt pressured by their husbands to have a 'normal' son so they could regain their reputation (Huang et al., 2012).

In addition to feeling complex internal emotions regarding their child with CP, Taiwanese and Indian mothers also reported that they felt stressed and sorry for their other children who were frequently expected to help with caregiving of their sibling with CP, as

well as taking on more responsibility around the house while not receiving as much parental attention (Huang et al., 2012; Nimbalkar et al., 2014; Vadivelan et al., 2020). Indian mothers felt this stress more acutely when the healthy sibling reacted in a jealous and angry way to the situation (Nimbalkar et al., 2014; Vadivelan et al., 2020).

Health and Education System Challenges

Health and education system challenges were experienced broadly by parents across the studies and more acutely by mothers. Parents from Canada, Ghana, Iran, and Australia found the health system difficult to navigate and were unsatisfied with support they received (Alaee et al., 2014; Hayles et al., 2015; Nyante & Carpenter, 2019; A. Reid et al., 2011). One study reported that this difficulty was due to the complex nature of a “multitude of systems with different, eligibility, accessibility, availability, policies, procedures and funding that needs to be navigated” (Hayles et al., 2015, p. 1144).

We don't know who to approach to get the care that we're requiring. It all comes from us and we don't know what exactly we need. And how long to wait before we should be getting some direction on what we should be doing... It's really difficult. (Hayles et al., 2015, p. 1145)

Hayles et al. (2015) discovered that the more parents knew about their child's needs and the services available, the easier it was to find them appropriate care and learn more about their needs and vice versa. Parents of children that were less physically disabled reported that their children had even less access to services because they were not considered a priority (Hayles et al., 2015; A. Reid et al., 2011). Several studies revealed that parents were frustrated with receiving inaccurate, insufficient, and inconsistent information, and wanted improved access to services (Alaee et al., 2014; Hayles et al., 2015; Nyante & Carpenter, 2019; A. Reid et al., 2011). For example, they reported receiving information 'by chance' from health professionals and that they had to be proactive and work hard to get their child access to the care they felt they needed (Davis et al., 2010; Hayles et al., 2015; Nyante & Carpenter, 2019; A. Reid et al., 2011). They also wanted health professionals to be more honest with them, give accurate and individualised information, develop a plan of care, and treat them as an equal team member (Hayles et al., 2015; Whittingham et al., 2013).

Parents reported that inadequate information and support led to difficulties with balancing the needs of the child and the family. They realised that their ability to meet their child's needs was dependent on them competently managing these multiple needs, and good working relationships with health professionals and health services. When this did not happen, parents felt unheard, disempowered, and dissatisfied (Hayles et al., 2015; Huang et al., 2012). Hayles et al. (2015) found that regardless of their child's age or level of disability, parents had to deal with an ongoing cycle of evolving needs. Each healthcare interaction was a cumulative effect of their subsequent experiences which resulted in a 'learning as you go' situation. Parents' learning happened in two ways, through receiving information and through experience.

With regards to mothers' experience of healthcare systems, the literature uncovered that Iranian, Indian, and Taiwanese mothers found government rehabilitation facilities and disability services (including obtaining information specific to their child) to be insufficient and inadequate. As a result, many lost trust and faith in the public system and turned to private facilities (Alaee et al., 2014; Huang et al., 2012; Mokhtari & Abootorabi, 2019; Nimbalkar et al., 2014; Vadivelan et al., 2020). Mothers in Zambia and Taiwan found the health system challenging because of the negative attitude of health professionals (who lacked empathy and willingness to communicate), a lack of provision of assistive devices, and lack of help with transport to and from appointments (Huang et al., 2012; Singogo et al., 2015). Taiwanese mothers reported they did not feel listened to which left them feeling confused, angry, and disempowered. In the Chinese culture, mothers are expected to be subservient and compliant, and doctors do not acknowledge the significance of the parent's experience or knowledge (Huang et al., 2012). Mothers in Brazil said better treatment for their children was needed (Alfonso et al., 2020).

Three studies (from India, Brazil and Taiwan) reported that mothers felt there was a lack of appropriate education and training facilities for their children (Afonso et al., 2020; Huang et al., 2012; Nimbalkar et al., 2014). Taiwanese mothers reported feeling powerless and worried about the lack of a disability friendly environment at school for their children (Huang et al., 2012).

Social Isolation and Support

The literature uncovered both positive and negative experiences with regards to social support for parents who reported being affected by the loss of friendship with friends not understanding the situation (Nimbalkar et al., 2014; Whittingham et al., 2013).

People constantly surprise me... when (my child with CP) was born prematurely, my best friend drifted away. On my assessment, she couldn't cope with the disappointment of me not having the pregnancy and the child that she wanted me to have. And so she just drifted away because there was no connection anymore, that was a total surprise. (Mother, cited in Whittingham et al., 2013, pp. 1450-1451)

Parents from Canada and Australia embraced the opportunity for social support and built informal networks with like-minded parents, describing them as a positive and powerful place where they could seek support, share information, solve problems, and receive guidance (Hayles et al., 2015; A. Reid et al., 2011).

There'd be a group of parents sitting on the side and we'd start talking, "oh did you hear about this?" Or "Did you know that you could do that?" we teach each other because nobody's teaching us. (Hayles et al., 2015, p. 1144)

Conversely, parents in Iran reported feeling a lack of social support networks and a range of challenges including a lack of public awareness and social stigma, isolation, stress, and worry (Alaee et al., 2014). The literature revealed mothers from Zambia, Ghana, India, Iran, Saudi Arabia, and Australia reported feeling unsupported by key people, socially rejected, discriminated against, isolated, and experienced difficulties in maintaining their own interests and social connections (Davis et al., 2009; Mokhtari & Abootorabi, 2019; Nimbalkar et al., 2014; Nyante & Carpenter, 2019; Singogo et al., 2015; Vadivelan et al., 2020).

I have not had so much contact with my friends and neighbours as I stay indoors with my child most of the time. I am afraid of being laughed at or other people not accepting my child the way she is, it would hurt. I also don't want anyone to blame me for the condition. (M15, cited in Singogo et al., 2015, p. 3)

Mothers reported feeling as though their lives had become very different since having their child with CP. They found when socialising they could only make depressing contributions to conversations which, ultimately, resulted in them either withdrawing socially or limiting their socialising to a few close family members (usually their own

mothers or other female family members) and/or other mothers of children with CP (if they knew any) with whom they could feel safe and supported (Davis et al., 2010; Mokhtari & Abootorabi, 2019; Nimbalkar et al., 2014; Singogo et al., 2015). Mothers reported having a reduced ability to participate in social gatherings that required leaving their house (including attending important events such as weddings). Instead, guests were invited to their home and conversations occurred around the child's therapy and cares being carried out (Nimbalkar et al., 2014). Mothers in Saudi Arabia stopped going out of their house to avoid public discrimination (Mohamed Madi et al., 2019). Mothers found it hard to go on holidays and felt like they had lost some of their previous freedom (Davis et al., 2009). Many mothers longed for the resumption of their previous lives that they viewed as a lost period due to caring for their child with CP (Alfonso et al., 2020).

Many mothers did not know where to go for support or information and they overwhelmingly lacked knowledge as to what CP was and how to care for a child with CP (Nyante & Carpenter, 2019; Vadivelan et al., 2020). In all countries there was widespread ignorance about CP. Overall, the consistent lack of understanding and support from friends and families and government services, came out as a major cause of both psychological and physical stress for mothers who felt alone and solely responsible for meeting all aspects of their child's needs (Mokhtari & Abootorabi, 2019; Vadivelan et al., 2020). Social networks play a crucial role in supporting mothers with their ability to cope and adapt, and are also beneficial to other family members (Alfonso et al., 2020; Milbrath et al., 2008; A. Reid et al., 2011). Some mothers, for example those from Taiwan (in accordance with their Chinese culture), are taught that it is not acceptable to ask for help or to complain about their situation. They are expected to ensure they maintain harmony within the family unit as it is deemed more important than serving their individual needs (Huang et al., 2012). This expectation creates a culture where mothers are often afraid to ask for support.

Mothers' Physical Challenges

Mothers in Zambia, Ghana, Iran, India, and Australia suffered significant physical ailments related to caring for their child with CP, such as shoulder and back pain as well as generalised body aches (Nimbalkar et al., 2014; Vadivelan et al., 2020). These were reported to be a direct result of activities such as lifting, carrying, and physically caring for their child (Mokhtari & Abootorabi, 2019; Nimbalkar et al., 2014; Nyante & Carpenter, 2019; A. Reid et

al., 2011; Singogo et al., 2015; Vadivelan et al., 2020). Mothers in India reported walking long distances, carrying their child to and from appointments as they did not have a vehicle (Nimbalkar et al., 2014). The lack of access to equipment, such as hoists and wheelchairs, was commonly reported in Zambia, Ghana, and Iran, creating more physical demands for these mothers and reducing their quality of life (Mokhtari & Abootorabi, 2019; Nyante & Carpenter, 2019; Singogo et al., 2015). Other tasks, such as changing nappies, bathing, and dressing children who had spasticity and musculoskeletal issues became increasingly more demanding as the child grew bigger and heavier, and required mothers to be physically strong (Davis et al., 2010; Nyante & Carpenter, 2019; Vadivelan et al., 2020).

Sometimes when I am bathing her, she would be struggling with me. She is now stronger than I am. If she is doing something and I tell her not to do it, she can struggle with me until we both fall (Nyante & Carpenter, 2019, p. 819).

Mothers' Environmental Barriers

Mothers in Taiwan, Saudi Arabia, India, and Zambia reported environmental barriers that inhibited their child's ability to be an active participant in their community (Huang et al., 2011; Mohamed Madi et al., 2019; Singogo et al., 2015; Vadivelan et al., 2020). Barriers included poor design of public facilities such as a lack of ramps, lifts, and sidewalks; lack of inclusive spaces and disability friendly transport (Huang et al., 2012; Mohamed Madi et al., 2019; Singogo et al., 2015; Vadivelan et al., 2020).

When we go to town, it is a problem as most shops do not have ramps for wheelchairs. Hardly any of the lifts on the tall buildings work. That is the same at the big hospitals. The lifts don't work most of the time. (M1, cited in Singogo et al., 2015, p. 4)

These barriers, which left mothers feeling angry and frustrated, were cited as a key driver in creating isolation and segregation (Huang et al., 2012; Mohamed Madi et al., 2019) and led to children having limited involvement in activities outside the home and in society.

Mothers' Spiritual Guidance

In the absence of information about CP, mothers in Brazil, India, Ghana, and Saudi Arabia looked for answers and meaning to their situation through spiritual and religious support. This helped them cope with the demands of caring for their child, process negative

emotions, and make sense of why their child had CP (Mohamed Madi et al., 2019; Nimbalkar et al., 2014; Nyante & Carpenter, 2019). Some mothers attributed their child's CP to divine intervention, perceiving it as an act of God. They sought divine guidance from influential community religious leaders in achieving developmental milestones. Others experienced conflicting messages; while some were encouraged to accept CP as part of God's plan, with hopes for their child's potential future significance, others encountered beliefs framing CP as a misfortune or curse, attributed to an 'evil eye' cast upon the child (Mohamed Madi et al., 2019; Nyante & Carpenter, 2019).

I understand it (caring) in the sense that the bible has told us that when we give birth and we do not cater for the child it is a curse, that being responsible for the child's needs attracts Gods blessings. (Nyante & Carpenter, 2019, p. 819)

Discussion of Part 1: Parents' Experience of Having a Child with Cerebral Palsy

CP is the most common cause of physical disability and neurological impairment in children in the world. Considering this fact, it is surprising that there is such a limited amount of qualitative research studying the experience of parents. The 17 studies, across 10 countries over 13 years, described a wide variation in both wealth and culture; however, there were consistent themes and similar experiences reported. This is particularly the case with regards to emotional burden, navigating health care systems, and experiencing social isolation and changes to support networks.

Emotional Burden

A child living with CP is more physically and psychosocially vulnerable than their neurotypical peers. As a result, parents (particularly mothers) assume a greater caregiving burden, often acting as advocates, coordinators of care, and emotional supports. This responsibility includes navigating complex systems to access services and ensure their child's quality of life, while mitigating the impact of their impairment (Davis et al., 2010; Liu et al., 2023). This is also the case for parents of children with other disabilities (Abeasi et al., 2024; Celik & Kara Uzun, 2023; Muller-Kluits & Slabbert, 2018; Woodgate et al., 2015). Findings of this review suggest that caregivers (especially mothers) carry complex and evolving emotional burden shaped by grief, uncertainty, love, and societal judgment. This sustained emotional labour places them at heightened risk of anxiety, depression, stress, and compromised

physical and psychological well-being (Elangkovan & Shorey, 2020; Nyante & Carpenter, 2019; Rentinck et al., 2007; Rudebeck, 2020). These findings align with research on both CP and other disabilities which highlight the prolonged demands of caregiving and its negative impact on parents' daily lives and mental health (Dlamini & Chang, 2025; Kouter et al., 2022; Muller-Kluits & Slabbert, 2018; Reichman et al., 2008). Such findings raise serious concerns about systemic failures to adequately support those who provide care to vulnerable children. These concerns demand global attention and policy responses aimed at more effectively addressing caregiver needs.

Although some studies in this review included fathers, mothers overwhelmingly emerged as the primary caregivers and central figures in the caregiving narrative. This pattern is consistent with findings across other health conditions (Cantero-Garlito et al., 2020; Chu et al., 2022; Ntre et al., 2022). The gendered nature of caregiving imposes a disproportionate physical, emotional, and social toll on mothers. This finding invites critical reflection on how entrenched gender roles, cultural expectations, and healthcare systems contribute to and sustain inequitable caregiving responsibilities.

This review also reveals that parenting a child with CP profoundly reshapes family life, a finding echoed across diverse cultural and socioeconomic contexts (Alaee et al., 2014; Dlamini & Chang, 2025; Rudebeck, 2020). The consistency of these experiences globally points to structural and systemic inadequacies that transcend national wealth or healthcare capacity, as highlighted in other studies (Ostojic et al., 2024; Smith et al., 2022). These persistent challenges continue to be acknowledged in the literature; yet, they remain largely unaddressed in practice. Beyond emotional tolls, families often face financial and logistical challenges that exacerbate health inequities and contribute to the disproportionately high rates of caregiver mental health challenges across the disability spectrum (Abeasi et al., 2024; Celik & Kara Uzun, 2023; Dlamini & Chang, 2025; Muller-Kluits & Slabbert, 2018). Nevertheless, there remains a significant lack of psychosocial, emotional, and financial support to alleviate these burdens (Dlamini & Chang, 2025; Ostojic et al., 2024).

While prior research often focuses on the clinical management of CP, far fewer studies explore the lived realities of caregiving, particularly through a qualitative lens. However, an emerging body of research documents heightened psychological distress among families of children with disabilities (including CP) during the COVID-19 pandemic, as they faced service disruptions, loss of routine, and increased caregiving demands. This

includes countries such as Iran (Farajzadeh et al., 2021), Australia (Masi et al., 2021), and America (Sutter et al., 2021). These challenges span disability types and geographic contexts, revealing an intensified burden on already stretched caregivers.

Challenges with Navigating Health Systems

This review highlights the challenges families face when navigating complex, often fragmented, health systems that can lead to or exacerbate caregiver distress. Parents described encountering inconsistent or inaccurate information, disrespectful and dismissive attitudes, and lack of an individualised approach from health professionals that contributed to negative healthcare experiences which are consistent with other studies (Elangkovan & Shorey, 2020; Pelentsov et al., 2015; Ryan & Salisbury, 2012). In particular, parents reported feeling overwhelmed by challenges such as long wait times, poor communication, contradictory advice, proactively having to seek information, and the ongoing need to self-advocate to access appropriate care (Elangkovan & Shorey, 2020; Pelentsov et al., 2015; Ryan & Salisbury, 2012). Navigating complex systems can significantly impact parents' emotional well-being and family life. Many participants in this review and other studies (Askeland et al., 2025; McCann et al., 2012) describe their caregiving role as akin to full-time employment, involving extensive administrative tasks and coordination of healthcare professionals. This finding aligns with existing broader disability literature, which both reports mothers feeling compelled to act as de facto case managers for their children and critiques the growing shift of care coordination responsibilities onto families (Badawi et al., 2020; Dlamini & Chang, 2025; Whittingham et al., 2013; Woodgate et al., 2015). These findings suggest that many health systems are not always designed with the needs of families in mind and can unintentionally create additional barriers rather than alleviate them (Pelchat et al., 2009). Similar concerns have been raised in other contexts (Aduagna et al., 2020; Kuper et al., 2024) reinforcing the urgent need for more equitable and responsive systems for all. Emphasis should be placed on ensuring health professionals recognise the significant time and effort parents invest in caring for a child with CP, and how this responsibility impacts them along with other aspects of family life and well-being.

Despite these challenges, many parents reported gaining a sense of confidence and control as they acquired knowledge and skills to manage their child's care more effectively. Health professionals play a pivotal role in this process by equipping parents with the

information, tools, and emotional support needed to navigate complex medical, social, and financial systems (Alaee et al., 2014). Effective communication, advocacy support, accessible information, and genuine emotional connection should all be acknowledged as essential components of this partnership.

As reflected in both this review and other studies (Beauchamp et al., 2022; Kaplan & Celik, 2023; Nimbalkar et al., 2014), systemic inequities further compound challenges for parents from minority or low-income backgrounds. Barriers such as linguistic differences, cultural misunderstandings, and limited financial resources can hinder access to adequate care and support (Adugna et al., 2020; Beauchamp et al., 2022; Kaplan & Celik, 2023). Conversely, parents with greater financial means and strong support networks were more likely to access supplementary services and resources, thereby enhancing the health and well-being of both the child and the broader family (Goudie et al., 2014; Wallace-Watkin et al., 2023). This disparity raises important concerns about equity and fairness within national health and support systems (Smith et al., 2022).

Social Isolation and Support

In this review social isolation, stigma, and a lack of support were commonly reported experiences by mothers caring for their child with CP. This finding is supported by wider literature which reveals that these experiences often result in a profound sense of exclusion from broader social and community life (Celik & Kara Uzun, 2023; Inan Budak et al., 2018; Pelentsov et al., 2015; Vadivelan et al., 2020). Misconceptions about disability, rooted in limited public knowledge and cultural beliefs, continue to fuel discrimination and social withdrawal, leaving many mothers feeling marginalised, misunderstood, and solely responsible for their child's care. While peer support networks and community-based connections have been shown to offer substantial emotional and practical benefits, including reassurance, shared knowledge, and coping strategies (Bray et al., 2017; Celik & Kara Uzun, 2023; Postma et al., 2024), these opportunities are not universally accessible. This review found that only mothers in Canada and Australia reported access to informal support networks that allowed for mutual problem-solving and information exchange. In contrast, mothers from countries such as Iran, Zambia, Saudi Arabia, and India described experiences of social rejection, discrimination, and isolation, often linked to cultural stigma, systemic neglect, and the invisibility of their caregiving labour which is consistent in other

literature (Gupta et al., 2012; Torres & Ohajunwa, 2025). This disparity points to the importance of context. The value of social support is well-documented, but its accessibility and form are heavily shaped by cultural norms, socioeconomic status, and national infrastructure. For example, in Taiwanese and Chinese contexts, cultural expectations to maintain familial harmony may discourage mothers from seeking help or speaking openly about their struggles (Huang et al., 2012). These findings underscore the need for culturally responsive models of support that recognise the diverse ways caregiving is experienced and managed across different societies. Moreover, the emotional and physical toll of caregiving is compounded when support systems, whether familial, social, or governmental, are absent or insufficient. As evidenced in this review, many mothers lacked access to accurate information about CP, leading to heightened anxiety, uncertainty, and feelings of helplessness. Without social networks or reliable sources of support, caregiving can become an isolating and overwhelming experience.

Importantly, this review also highlights the often-invisible emotional labour involved in caregiving. Mothers not only perform the practical tasks of care but also shoulder the burden of navigating social judgment, maintaining family stability, and managing their own identity in the face of significant life changes. In this context, psychosocial support systems (both formal and informal) are critical. Such systems should acknowledge the hidden dimensions of caregiving and create safe, inclusive spaces where mothers can share experiences, seek support, and build resilience.

Finally, the experiences described by mothers in this review illustrate how they actively sought meaning and coping strategies within their caregiving journeys. Whether through informal peer networks, familial relationships, or cultural narratives, many mothers drew on a range of internal and external resources to adapt to their roles. This suggests the importance of developing support structures that not only meet immediate needs but also nurture long-term resilience, tailored to each family's social and cultural environment.

Summary

This review suggests the main variables that influence the impact of a child's impairment on daily life were: the parents' capacity to adapt (Alaee et al., 2014); the parents' ability to provide the required time and resources; the availability of government and private structures and systems (Rudebeck, 2020); the parents' ability to navigate, understand, and

manage often complex and confusing structures and systems; and the level of personal support that is received (Alaee et al., 2014). Overall, there is clear evidence that parents are required to make huge adjustments to cater for their child's needs, they experience significant impacts and additional stress on all aspect of their life (Davis et al., 2010), and they are being continually let down by the system put in place to support them.

Limitations Part 1

This review was limited to qualitative literature published in English that focused primarily on the experiences of parents raising a school age child with CP. It excluded literature that included children with multiple disabilities, children younger than 5-years-old or that focused on a specific aspect of CP such as therapy programmes as I wanted to approach the topic from a broader lens. While studies reported on a mix of mothers, fathers, other family members (i.e., grandparents and cousins) and even carers, this review focused on the findings of the studies that reflected the experiences of mothers (because mothers are predominantly represented in the literature), and to a lesser extent fathers as well as the collective experiences of parents.

Conclusion of Part 1: Parents' Experience of Having a Child with Cerebral Palsy

This review highlights the enduring challenges faced by parents, particularly mothers, raising children with CP, noting little change in their experiences over the years. The greatest challenges stem not from the child's impairment but from systemic failures, socially constructed barriers, and inadequate support and fragmented services, all which place significant emotional, financial, and logistical strain on families (Alaee et al., 2014; Davis et al., 2010; Nimbalkar et al., 2014; Vadivelan et al., 2020). Parents must often act as expert case managers, with better outcomes linked to stronger support networks and financial resources (Hayles et al., 2015; Nyante & Carpenter, 2019).

This first literature review was relevant for informing my research as it provided useful information and context on the experience of parents raising a child with CP. It is clear from the literature that it is a challenging role for parents, and they experience significant burden of care. However, as no literature could be found on the primary caregiver's experience of raising a child living with CP in NZ, a broader literature search exploring primary caregivers' experience of raising a child with a disability in NZ was undertaken (July

2022) to understand the local context. This is important as NZ is a unique country with distinct cultural diversity and nuances that may not be captured in research outside NZ. Therefore, understanding parents' experiences of raising a child with a disability broadly similar to CP could provide more context and relevant information to inform this study. Part two of this chapter explores what is known about the experience of parenting a disabled child in NZ.

Part 2. Primary Caregivers' Experiences and Perspectives of Having a Child with a Disability in New Zealand: A Narrative Review of the Literature

As no qualitative literature could be found specifically on the primary caregiver's experience of raising a child living with CP in NZ, it was decided to take a different approach and look more broadly at primary caregivers' experience of raising a disabled child in NZ. It was rationalised that although raising a child with CP would have specific differences from raising a child with another disability, this approach would add another piece of important scaffolding that could inform the development of the research questions for the current study. The intention of this part of the literature review was to gain a wider understanding of the experiences of parents and caregivers who were raising a child with any type of disability within NZ.

Background

There are an estimated 236.3 million children worldwide living with some type of disability (Olusanya et al., 2022). The last nationwide disability survey by StatsNZ stated there were 95,000 (11%) children living with a disability in NZ (Statistics New Zealand, 2014); the most common disability being CP. Other common disabilities in children are epilepsy, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), intellectual disability, autism spectrum disorder, and attention-deficit/hyperactivity disorder (Olusanya et al., 2022). Becoming a parent is generally a happy time; however, this happiness can be overshadowed by the unexpected and upsetting diagnosis of a disability (Elangkovan & Shorey, 2020; Kurtuncu et al., 2015). Parenting a child with a disability has an additional set of unique stressors (on top of the usual parenting stresses) and responsibilities that comes with caring for a child who requires lifelong support (Gold, 2016; Lee, 2019; Oskram, 2020; Tucker, 2004; Zhang & Li, 2021). These

stressors include financial, emotional, and physical burdens; lack of both formal and informal support; and relationship challenges (Gold, 2016; Lee, 2019; Oskram, 2020; Tucker, 2004; Zhang & Li, 2021). There is consistency across the international literature revealing that regardless of the type and aetiology of a disability, it is likely to have a detrimental effect on both the child and their family (Rosenbaum et al., 2007; Rudebeck, 2020). However, there remains an absence of local NZ literature about the experience of raising a child with any type of disability.

Method

Aim

The aim of part two, in line with the first part of the literature review, was to understand individual parents' experiences more deeply. However, part two focuses on the experience of parents in NZ raising a child with a disability that shares aspects of similarities to CP. The question that informed this review was: What are the perceptions and experiences of caregivers raising a child with a disability in NZ?

Design

This review was guided by Sukhera's (2022) approach to undertaking a qualitative narrative literature review. This narrative review presents a thematic analysis of the qualitative studies found describing the experience of caregivers raising a child with a disability in NZ. A qualitative synthesis method was used through which the findings from qualitative studies were synthesised and interpreted (Sandelowski et al., 2007; Sukhera, 2022). Only one article specific to CP in NZ (Williams, Alzaher, et al., 2021) was found (and included) and it focused solely on one aspect of the experience: receiving a diagnosis.

Inclusion and Exclusion Criteria

Narrative reviews do not usually have strict inclusions and exclusion criteria; however, Sukhera (2022) highlighted that boundaries are required. This literature search was limited to studies conducted in NZ, published in English, exploring the experiences of a caregiver raising a child with a disability using a qualitative methodological study design. Studies were excluded if they only explored parents' experiences of home therapy programmes or other specific rehabilitation interventions and/or reported on research outside NZ. This was because these experiences were

deemed to be too specific and the intention of the review was to capture a broader understanding of caregivers' experience in general.

Search Strategy

The electronic databases for this second review were searched in July 2022 and included Medline via OVID, SCOPUS, Google Scholar, EBSCO Health, and CINAHL via EBSCO. The following disabilities: downs syndrome, muscular dystrophy, spina bifida, were deemed to be appropriate as they are all common child disabilities that include an element of physical disability comparable with CP. The search terms were participants (parent* or caregiver* or mother* or father* or guardian* or famil* or foster*); phenomena of interest (experience* or perception* or attitude* or view* or feeling* or emotion* or 'everyday life' or 'daily life' or 'living with'); and context ("cerebral palsy" or CP or disabilit* OR "chronic illness" OR "down syndrome" OR "muscular dystroph*" OR "spina bifida").

Due to the small number of articles found, and in line with the more invisible disabilities that are consistent with CP, a second search of the literature was conducted and included under context (autis* OR Asperger OR "attention deficit hyperactive disorder" OR ADHD OR "invisible disability"). Alongside this, a search was conducted of theses in the AUT thesis database and NZ research.org.nz. To ensure rigour of the literature search process, following the above search, an AUT librarian was consulted who confirmed that a thorough and comprehensive search had been conducted. While narrative reviews are not required to include every piece of relevant literature (Sukhera, 2022), a thorough search of the literature resulted in nine qualitative research studies relevant to the topic of a caregiver's experience of raising a child who is living with a disability in NZ.

Data Extraction and Analysis

Data extraction and analysis followed the same process as per part one of this literature review. Data were entered into a data collection table (Table 2). The data were then analysed using Braun and Clarke's (2012, 2019) six steps thematic analysis method.

Table 2.*Characteristics of the Studies Included in the Second Review*

First author and year	Geographical location	Research question/aim	Methodological design and data collection	Sample and size	Findings relevant to the review
Fitzgibbon, G. (2006) Master's thesis	Auckland	To investigate the impact of resilience on the experience of parents raising a disabled child.	Interpretivist participatory	3 mothers	Parents who took part in this small research project felt they were resilient because of what they did to help themselves and how they felt about themselves. Making sense of their different lives, looking after themselves, and taking control of their lives in a strong and positive manner was what made them feel resilient.
Gold, J. (2016) Doctoral thesis	Wellington	To explore parent experiences and coping responses when raising children with Asperger syndrome.	Narrative inquiry qualitative	26 parents	Four key themes around challenges were identified: the challenges associated with Asperger syndrome (e.g., their child's difficult behaviour); challenges arising from a lack of understanding and acceptance in the community that led to stigma and social withdrawal; challenges interacting with health and education services, such as a long medical diagnostic process and inadequate support at school; and challenges to family dynamics that resulted in increased tension between family members. Parents successfully adopted positive coping strategies including developing resources, and planning ahead.
Hitchcock, B., Hocking, C., & Jones, M. (2020)	Christchurch	The perceptions and concerns of mothers raising a child with developmental coordination disorder.	Interpretative description	9 mothers	Thematic analysis of data from semi-structured phone interviews revealed mothers' awareness of delayed motor skills evident in children's daily activities. This increasingly impacted the child's academic achievement as well as their social and emotional well-being. Mothers used strategies to support participation, however, limited knowledge of Developmental Coordination Disorder amongst health and education professionals meant advocating for their child's needs to be understood and addressed. The findings are in keeping with international studies
Lee, J. (2019)	Wellington	To produce insights into the understanding of single-mother led families with a disabled child/children and their	Interpretative approach	6 mothers	Findings showed that there are financial, emotional, practical, and societal challenges that single-mother led families with a disabled child/children face. Another key finding was the lack of a readily available database of support agencies, and the relationships with service providers and professionals.

First author and year	Geographical location	Research question/aim	Methodological design and data collection	Sample and size	Findings relevant to the review
Master's Thesis		journey dealing with the challenges and opportunities of caring for their child.			Despite 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.
Oskram, J. (2020) Doctoral thesis	Whanganui & Palmerston	To explore self-care and well-being for parents of children with high-needs disabilities and the development of a psychoeducational resource.	Mixed methods	25 parents	Findings suggested that despite caregiving challenges, there are effective self-care strategies which parents use to mitigate risks and improve well-being. Four main themes were identified; use of formal supports and resources, informal relationships, values, and goals and time. Each theme identified one area of selfcare that parents discussed as being useful for maintaining their sense of well-being. All participants believed the booklet provided helpful information regarding selfcare, the language was clear and easy to understand and they would recommend the booklet to other parents of children with special needs.
Topia, M. (2015) Master's thesis	Auckland	To examine the lived experience of mothering a young child with severe multiple disability.	Hermeneutic phenomenology	4 mothers	Findings showed that mothering a young child with severe multiple disability encompasses interconnected 'being' and that the transition experienced in mothering is not sequential. Rather, a mother can exist in multiple realities at any moment, shifting back and forth in the context of being a mother. The findings also recognise the duality of burden and joy experienced in mothering. Being a mother is a constant, a role that will only cease in death. Coming to acquiescence in the lived experience of mothering a young child with severe multiple disability, a mother comes to recognise the 'joy' in spite of the burden, despite the unique journey, and towards acceptance in her own version of 'being a mother'.
Tucker, P. (2004)	Auckland	To examine the experience of parents caring for a child who experiences disability and has high care needs in	Qualitative	5 mothers	All five mothers could be described as having developed competency and parental strength because they had the support and means to become involved in all aspects of their child's life from the very early days. They also shared information with parents in similar circumstances and, in some

First author and year	Geographical location	Research question/aim	Methodological design and data collection	Sample and size	Findings relevant to the review
Master's thesis		order to establish the influences that have built parental strength.			circumstances, they moved into working with a parent support organisation to provide other parents with support,
Williams, S. A., Wilson, N. et al. (2021)	NZ	To survey the family experience surrounding diagnosis and early management of infants with CP in NZ. A secondary aim was to identify areas of strengths and areas for improvement in health service delivery around diagnosis and early management, from the family perspective.	Mixed methods	57 people	Common themes impacting on families' experience in the diagnosis and health service delivery journey related to provision of information and the style of communication, with both direct and ongoing communication styles common for greater family satisfaction. Overall, families desired the diagnosis experience to be informative and timely, with early follow up support and assistance with health sector navigation.
Zhang, K. C., & Li, Q. (2021)	North Island	This paper draws on findings from a qualitative study on low-income families' experiences of early childhood inclusive education in NZ. Parents participating in this study came from different religious backgrounds, and represented diverse ethnicities.	Qualitative	30 parents	Results showed that though the majority of the families appreciated the flexible time and structures of the early childhood programmes their children attended, parents were concerned about the lack of intervention services for their children. In addition, these low-income families reported that they had limited access to early interventions and resources. The findings also highlighted the importance of the use of positive coping methods (e.g., maintaining a positive outlook and seeking social support), and the role faith plays in family life.

Findings

Of the nine studies found, three were published articles (Hitchcock et al., 2020; Williams, Alzahrer, et al., 2021; Zhang & Li, 2021) and six were theses (Fitzgibbon, 2006; Gold, 2016; Lee, 2019; Oskram, 2020; Topia, 2015; Tucker, 2004). The three articles were published in 2020 (Hitchcock et al., 2020) and 2021 (Williams, Alzahrer, et al., 2021; Zhang & Li, 2021). One did not specify methodology other than they used a qualitative approach (Zhang & Li, 2021), one used interpretative description (Hitchcock et al., 2020), and the other mixed methods (Williams, Alzahrer, et al., 2021). Of the six theses reviewed, four were for a master's degree (Fitzgibbon, 2006; Lee, 2019; Topia, 2015; Tucker, 2004) and explored mothers' experiences, and two from doctoral degrees (Gold, 2016; Oskram, 2020) that explored parents' experiences. Three of the studies were about parenting children with significant disabilities who were described as having a severe disability or high needs (Oskram, 2020; Topia, 2015; Tucker, 2004). One researched single mothers (Lee, 2019). All were qualitative in approach and specified as follows; narrative inquiry (Gold, 2016), interpretative (Lee, 2019), interpretivist participatory (Fitzgibbon, 2006), hermeneutic phenomenology (Topia, 2015), qualitative (Tucker, 2004), and mixed methods (Oskram, 2020). No published journal articles could be found reporting on thesis findings. However, Lee (2019) had contributed to a Child Poverty Action Group publication regarding children with disabilities needing greater income support (Neuwelt-Kearns et al., 2020).

Studies predominantly used interviews for data collection and covered a variety of disabilities including Asperger's Syndrome (Gold, 2016), dyspraxia (Hitchcock et al., 2020), intellectual disabilities (Zhang & Li, 2021), and CP (Williams, Alzahrer, et al., 2021). Studies took place in specific geographical locations within NZ. Three studies were based in Auckland (Fitzgibbon, 2006; Topia, 2015; Tucker, 2004), two in Wellington (Gold, 2016; Lee, 2019), and one each in Christchurch (Hitchcock et al., 2020), Whanganui and Palmerston (Oskram, 2020), North Island (Zhang & Li, 2021), and across NZ (Williams, Alzahrer, et al., 2021). All studies included parents and/or caregivers, and mothers were more commonly interviewed than fathers.

Key Themes

The thematic analysis revealed five overarching themes reflecting the experiences and perspectives of parents raising a child with a disability in NZ. These five themes are

parenting burden; coping mechanisms and self-care strategies; financial challenges; healthcare and education experiences; support networks.

Parenting Burden

As with the international literature review (part 1), this review also highlighted that parenting a child with a disability is seen as a challenge that is quite different from parenting a child without a disability. There is an additional set of stressors on top of the usual parenting stresses that require significant lifestyle adaptations (Gold, 2016; Lee, 2019; Oskram, 2020; Tucker, 2004; Zhang & Li, 2021). Also consistent with part one, this literature review highlighted that mothers often assumed the role of primary caregiver and take on the subsequent burdens that come with the role. Mothers experienced hard physical work, loneliness, loss of income, and additional financial stressors (Gold, 2016; Hitchcock et al., 2020; Lee, 2019; Oskram, 2020). The caregiving role also impacted their mental health, family dynamics and relationships, as well as quality of life (Gold, 2016; Lee, 2019; Topia, 2015; Tucker, 2004; Williams, Alzaher, et al., 2021). Mothers of severely disabled children reported going through a 'mothering journey' while they came to accept the burden of being a mother (Topia, 2015). Stages of this journey include "being visible" (Topia, 2015, p. 61), "being challenged" (p. 76), and "being acquiescent" (p. 101). The findings of several of the studies revealed that parents experienced anger, grief, hopelessness, and felt overwhelmed (Fitzgibbon, 2006; Lee, 2019; Oskram, 2020; Topia, 2015). Mothers also reported feeling challenged by strong emotions such as regret and guilt for not meeting self-imposed parenting expectations (Topia, 2015).

I feel guilty that I fail as a mother if I don't do her stretching programme every day or therapy based programmes every day and that's a burden on me that I have to deal with... I know they are really important in helping to keep her well but I just find that such a drag some days. The time and energy it takes when putting her in equipment... is so time consuming and it drives me to distraction some days. People have no idea. (Topia, 2015, p. 68)

Coping Mechanisms and Self-care Strategies

Parents adopted self-care and coping strategies in direct response to the constant challenge they faced with balancing the additional demands of parenting a disabled child (Oskam,

2020). The literature reported on a large variety of strategies being utilised by parents including adopting a positive outlook on life (Fitzgibbon, 2006; Gold, 2016; Lee, 2019; Zhang & Li, 2021); establishing clear routines and boundaries (Gold, 2016; Lee, 2019; Oskam, 2020); taking control and being proactive (Fitzgibbon, 2006; Gold, 2016); building formal supports and resources (Oskam, 2020); maintaining informal relationships (Oskam, 2020; Zhang & Li, 2021); considering values, goals, and balancing time (Oskam, 2020); managing appointments (Lee, 2019); seeking support in faith (Zhang & Li, 2021), managing difficult emotions, and finding ways to mentally switch off (Lee, 2019; Oskam, 2020).

What I find meaningful... My family, they mean the world to me. So being there for them and being able to be there for them. Being happy, I say that like I'm not but I am. I think it is an emotional wellbeing... Enjoying the little things, despite everything I've got going on, there are some good things in my life (Aroha, cited in Oskam, 2020, p. 98)

Mothers used crying, mindfulness exercises, psychosocial support, or purposeful distraction to manage difficult emotions (Oskam, 2020). Another important coping strategy was establishing boundaries which included asking for medical appointments to be grouped together, and being open and honest with their children about their emotions (Lee, 2019). Seeking support through faith had a positive effect on general health and well-being; however, when faith led to feelings of blame and punishment this could have negative effects (Zhang & Li, 2021). Many parents highlighted how the successful adoption of coping strategies was instrumental in supporting them to maintain their well-being and gave them a sense of control, acceptance, awareness, appreciation, and achievement (Fitzgibbon, 2006; Gold, 2016; Lee, 2019; Oskam, 2020; Topia, 2015). This led them to a space where they could feel positive, competent, resilient, overcome their own challenges, be themselves, and appreciate what they had (Fitzgibbon, 2006; Topia, 2015; Tucker, 2004). Parents reported to finding strength in being their child's parents, gaining new abilities (such as public speaking and writing), and a sense of self confidence (Topia, 2015).

I think cuddles are probably the best thing. I never tire of the opportunities to sit and cuddle. She loves that too. Seeing her smile and laugh is the best thing because that is what she can really do well, so if we can find an activity that she really loves, then that's rewarding. (Topia, 2015, p. 99)

However, Oskram (2020) revealed that supporting mothers with coping mechanisms and selfcare strategies are often not considered by formal disability services which tended to focus solely on the child's well-being.

Financial Challenges

Financial challenges were cited as a significant cause of stress for families who made sacrifices to pay privately for services, non-funded medication, and equipment (Hitchcock et al., 2020; Lee, 2019). Several mothers said they lost income as they either could not work or worked less hours to support their child (Hitchcock et al., 2020; Lee, 2019; Williams, Alzahr, et al., 2021; Zhang & Li, 2021). Mothers rated paid employment as important for both alleviating their financial pressures and their mental health; however, some struggled with finding appropriate childcare so they could go to work (Lee, 2019).

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. (Lee, 2019, p. 62)

Some mothers reported that they struggled to pay for what they considered prohibitive babysitting costs which led to them feeling isolated and unsupported.

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. (Lee, 2019, p. 50)

Healthcare and Education Experiences

Some parents were dissatisfied with their healthcare experiences (Gold, 2016; Williams, Alzahr, et al., 2021; Zhang & Li, 2021). Parents reported that doctors lacked compassion and had poor interpersonal skills which contributed to negative experiences (Williams, Alzahr, et al., 2021). Single mothers found it hard to ascertain what support was available and often found out information by chance or through informal networks (Lee, 2019). Many parents found the health system overwhelming, unsupportive, and difficult to navigate due to factors such as long diagnostic process, inadequate resources and interventions, and a lack of service integration and coordination (Gold, 2016; Hitchcock et al., 2020; Lee, 2019; Williams, Alzahr, et al., 2021; Zhang & Li, 2021).

There were so many opportunities for medical professionals to inform us that our son was high risk of having CP however this information was never passed on to us. I know doctors can't look into the future, but giving a parent an idea in what to expect would be helpful. Your whole world turns upside down at diagnosis stage.

(Participant 53, cited in Williams et al., 2021, p. 9)

Mothers revealed feeling tired and frustrated about having to fight for support that was often inadequate and suggested that a disability navigation service would be helpful (Lee, 2019).

Some parents also expressed dissatisfaction with the education system (Gold, 2016; Zhang & Li, 2021). Parents revealed they felt unsupported citing inadequate resources, interventions, and services (Hitchcock et al., 2020; Lee, 2019; Zhang & Li, 2021). While other parents expressed dissatisfaction with teachers' lack of disability knowledge and inability to understand how best to support disabled children and their families (Gold, 2016; Hitchcock et al., 2020). Some reported feeling very upset when their child was excluded from attending school because of their disability (Topia, 2015). They felt they had to fight to be heard and to get their child's needs met by disability services (Fitzgibbon, 2006; Gold, 2016; Oskram, 2020). "He can't fight for his own rights, he can't fight for what he needs or wants. But I can" (Fitzgibbon, 2006, p. 47).

Support Networks

Parents in several studies reported the value of support groups, and described them as a place where they were able to gain expert knowledge and support from other parents within the disabled community (Gold, 2016; Oskram, 2020; Topia, 2015). Research revealed the significant positive benefits of support from a wider community (which spanned friends, cultural, religious and work place networks) and led to practical and emotional support, guidance and advice, and a sense of belonging (Fitzgibbon, 2006; Gold, 2016; Oskram, 2020; Topia, 2015; Tucker, 2004).

They knew where I was coming from and I could understand where they were coming from and it was just being there and talking over coffees and getting to meet everybody else and getting together regularly was really good for me. (Fitzgibbon, 2006, p. 42)

When mothers felt supported by wider family, friends, and professionals, they were able to meet the parenting challenges presented to them and be fully engaged in the process of caring for their child's special needs (Tucker, 2004). Some parents felt that an important aspect of support was getting assistance from friends and family to help address the lack of understanding and acceptance from the community (Gold, 2016). Conversely, other mothers said they felt forgotten about and believed people had deliberately distanced themselves (Topia, 2015). Some mothers admitted they had withdrawn socially because of a lack of awareness, understanding, and acceptance of their child's disability from friends and society (Gold, 2016; Lee, 2019). A significant deterrent to leaving the house was the social perception of their child's behaviours as being inappropriate (Lee, 2019; Gold). Parents felt they needed support from friends and family to help reduce the isolation that raising a disabled child can bring (Zhang & Li, 2021).

Discussion of Part 2: Primary Caregivers' Experience and Perception of Having a Child with a Disability in New Zealand

The findings of this review into parents' experiences of raising a child with a disability in NZ is consistent with much of the international literature into parenting a child with CP and other disabilities. This was particularly the case with regards to emotional burden, health system challenges, and support. The review also emphasised the importance of coping mechanism and self-care strategies for mothers.

Emotional Burden

This review revealed parents raising a child with a disability experience emotional burden, additional stress and significant lifestyle changes, a finding that aligns with international literature which reports that parents of children with disabilities experience added stress, negative health outcomes, and emotional burden (Abeasi et al., 2024; Brekke & Alecu, 2023; Broll et al., 2025). The widespread nature of this finding is concerning and, as with the findings of the first review, it continues to raise serious concerns about systemic failures to adequately support those who provide care to vulnerable children. These concerns demand global attention and policy responses aimed at more effectively addressing caregiver needs

Additionally, this review reveals that disability care in NZ (both paid and unpaid) is predominantly the role of mothers/women and that the caregiving burdens

disproportionately fall on mothers. This finding aligns with previous studies (Cantero-Garlito et al., 2020; Chu et al., 2022; McCann et al., 2012; Ntre et al., 2022). As with the discussion in the first part of this review the gendered nature of caregiving imposes a disproportionate physical, emotional, and social toll on mothers, and invites critical reflection on how entrenched gender roles contribute to and sustain inequitable caregiving responsibilities. Despite there being considerable evidence to support this inequity, change is still to happen.

Health System Challenges

Mothers in NZ found the health system overwhelming, unsupportive, and difficult to navigate due to factors such as long diagnostic process, inadequate resources and interventions, and a lack of service integration and coordination. These negative experiences align with findings from other studies as well as the first part of the review which highlighted that parents often felt overwhelmed by challenges such as long wait times, poor communication, contradictory advice, proactively having to seek information, and the ongoing need to self-advocate to access appropriate care (Elangkovan & Shorey, 2020; Pelentsov et al., 2015; Ryan & Salisbury, 2012). These widespread experiences suggest that system design and delivery (as opposed to the child or disability) drives much of the caregiver stress and that the need for integrated child and family-centered services is urgent.

Coping Mechanism, Self-Care Strategies and Support

Many mothers in this review developed a range of personal coping mechanisms to navigate the complex realities of raising a child with a disability. This is consistent with international research which reveals that despite the challenges that come with parenting a child with a disability, most parents are able to effectively adopt positive coping strategies to support their mental health and well-being such as prayer, searching for information on the diagnosis, and seeking support (Abeasi et al., 2024; Bourke-Taylor, Cotter, Johnson, et al., 2018; Celik & Kara Uzun, 2023). Along with coping strategies, this review highlighted both the challenges and importance of support networks. Parents reported not feeling understood by their friends, family, and community which is consistent with other international studies (Celik & Kara Uzun, 2023; Mohamed Madi et al., 2019). Formal and informal support networks were identified as being important, with the makeup of informal

supports sometimes changing with the loss of friendships due to stigma associated with disability. Again, this finding is consistent with international literature which discusses how parents (mainly mothers) reshaped their social support network due to people in their lives distancing themselves because of their child's disability and becoming friends with other parents of children with disabilities (Celik & Kara Uzun, 2023; Inan Budak et al., 2018).

Both coping mechanism and support networks are identified as being essential to parental well-being; however, they are often unsupported or overlooked by formal disability services, which tend to prioritise the child's needs over the holistic well-being of the entire family. Involved professionals should understand how parents cope with stress and what strategies they adopt to cope, including consideration of cultural factors that may impact strategies. By understanding these variables professionals will be better equipped to tailor support for parents aimed at reducing stress, enhancing wellbeing, and strengthening parents' capacity to support their child.

Summary

The burden of care, particularly for mothers, seems to be a global phenomenon and deserves to be addressed. Additionally, the perception of being misunderstood by social networks (Mohamed Madi et al., 2019) and the intersection of financial, environmental, healthcare, and systemic challenges (Vadivelan et al., 2020; Williams, Alzaher, et al., 2021) highlight the persistence of socially constructed barriers rather than impairment-related limitations. This situation requires urgent redress. There is considerable work ahead to ensure that caregivers of vulnerable children are adequately supported to maximize their child's opportunities and outcomes, and support systems are appropriately holistic and family focused.

Limitations of the review of Part 2: Primary Caregivers' Experience and Perception of Having a Child with a Disability in New Zealand

This review was limited to qualitative literature published in English that focused primarily on the experiences of parents raising a child with a disability in NZ. Due to the limited available literature, the inclusion criteria used included a wide range of disabilities which led to generalising findings across a group of parents that could be experiencing quite different challenges depending on their child's disability. Inclusion criteria also led to studies being

included that focused on specific aspects of disability such as diagnosis and experiences with early childhood education. This review focused on the findings of the studies that reflected on mothers and the collective experiences of parents, as this was what was represented in the literature. Therefore, the experiences of father and other caregivers, such as grandparents, were not captured and remain unknown.

Conclusion of Part 2: Primary Caregivers' Experience and Perception of Having a Child with a Disability in New Zealand

Despite the diversity of studies in the second literature review, there was consistency within the results and conclusions drawn. The studies revealed the main variables influencing the impact of a child's disability on daily life is the parents' ability to adapt and adjust their parenting style to manage the additional stressors and responsibilities that present when parenting a child with a disability (Gold, 2016; Lee, 2019; Oskram, 2020; Tucker, 2004; Zhang & Li, 2021). Parents reported an absence of support to help them with these challenges leading to increased pressure which put them at greater risk of mental health issues such as anxiety, depression, and stress (Gold, 2016; Hitchcock et al., 2020; Williams, Alzahrer, et al., 2021; Zhang & Li, 2021). Of concern, during the 20 years that this research has been conducted, there appears to be no significant change in the parents' experiences reported.

Summary of Parts 1 and 2

Together, parts 1 and 2 of the literature review clearly evidence that parents (and more often mothers) experience a significant burden of care and are required to make substantial lifestyle changes to accommodate their child's needs. The same conclusions are repeatedly drawn; that is, the systems around the family and child have a significant role to play. There is consistent evidence that the stress and impact of raising a child with any type of disability is largely because of socially constructed barriers and inadequate health, education, and social systems. Together, these fail to provide the needed support for parents and rehabilitation therapy for children as opposed to the cause being the child themselves. This, in turn, puts significant responsibility (and therefore stress) on parents.

As my research is focused on the experiences of primary caregivers of children with CP in NZ, and one aim is to explore the influence of disability services on this experience, a review of the literature was undertaken (in August 2021) to discover how support services

for children with CP are structured and delivered in NZ. This third review includes an analysis of the government legislation and strategies relating to the structure and provision of the disability services currently available in NZ.

Part 3. The Impact of Policies and Legislation on the Structure and Delivery of Support Services for Children with Cerebral Palsy and their Families in New Zealand³

In NZ, children who are diagnosed with CP and their families are provided disability services through two distinct pathways. This is either through the application of the Accident Compensation Corporation (ACC) legislation (the ACC pathway) or through the Disability Support Services (the DSS pathway), where care is delivered by Te Whatu Ora Health NZ districts (Whaikaha Ministry of Disabled People, 2022b). These pathways dictate how treatment and interventions are structured and delivered to children living with CP and subsequently result in significant variation in service delivery based on post code and pathway allocation (MoH, 2017; Whaikaha Ministry of Disabled People, 2022a). Māori and Pacific families face additional challenges and barriers to comprehensive care based on limited culturally specific services within these two pathways (Ratima & Ratima, 2007). Learning how to navigate these two complex systems creates additional anxiety and stress for families who are already living a complex life (Smith & Blamires, 2022). Service gaps and inequity are evident in the current model of service delivery, and it is timely to highlight these barriers, given the establishment of Te Whatu Ora Health NZ and Whaikaha - Ministry for Disabled People in July 2022. Considering there is limited literature available, this review seeks to describe how disability services are structured and delivered to children living with CP and their families in NZ through policy and legislation.

³ Note: In this section, the introduction, search strategy, conclusion, parts of the discussion and documents referenced in Appendices C and D were written by Meg Smith and are included in the following publication (Appendix B): Smith, M., Blamires, J., & Foster, M. (2022). The impact of policies and legislation on the structure and delivery of support services for children with cerebral palsy and their families in Aotearoa New Zealand: A professional perspective. *Nursing Praxis in New Zealand*, 38(3), 1-10. <https://doi.org/10.36951/001c.38925>

Search Strategy

A comprehensive search of grey literature took place in August 2021 with the intention to identify key documents and legislative acts related to disability services for children (16 years and under) and their families living with CP in NZ. Grey literature refers to literature produced on all levels of government, academics, business and industry in print and electronic formats that are protected by intellectual property rights, of sufficient quality to be collected and preserved by library holdings or institutional repositories, but not controlled by commercial publishers. (Schöpfel, 2010, p.17)

The sources searched included key governmental and service provider websites: MoH, MoE, Ministry of Justice, Office for Disability Issues, Parliamentary Counsel Offices, ACC, Office of the Auditor General, Taikura Trust, ABI Rehabilitation, Ohomairangi Trust, Starship Child Health, Southern Health, Counties Manukau Health, and Waitematā Health. Key documents and policy related to the health and education systems and disability services were reviewed, along with legislative acts. I read through the documents looking for common content and topics which I then grouped as below.

Key Documents and Legislative Acts

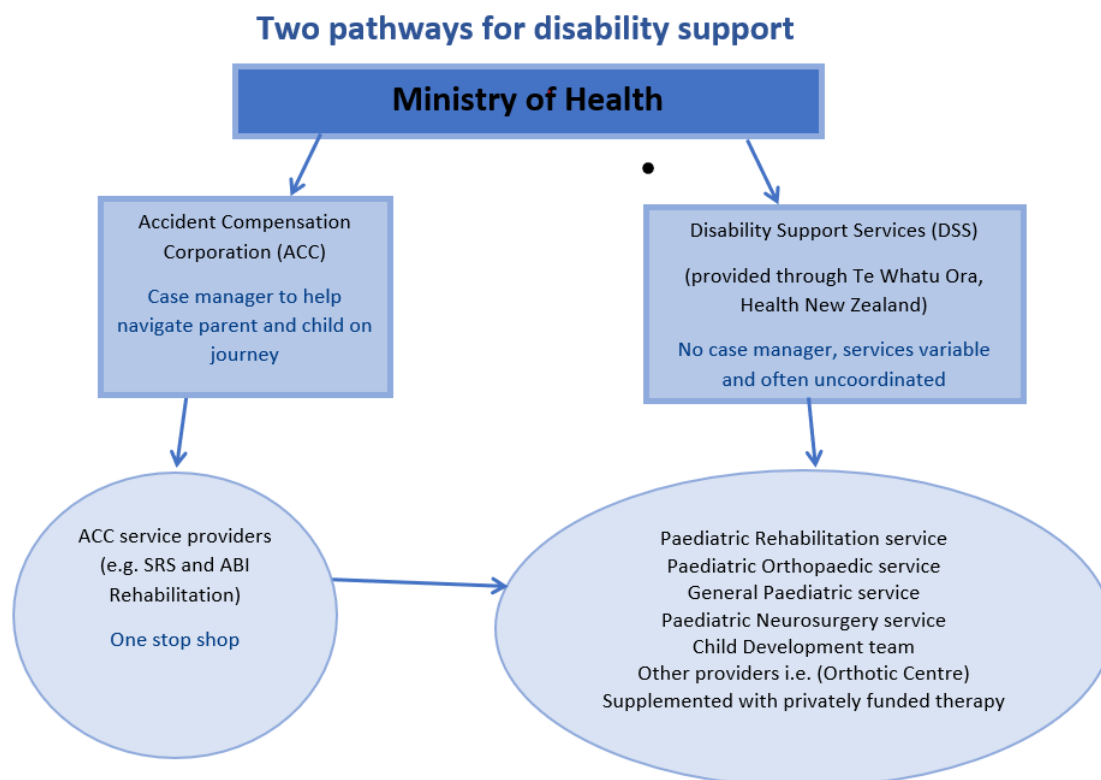
This review revealed that the system is solidly grounded on seven key documents (Appendix C) and five significant legislative acts (Appendix D). The seven key documents lay out a clear structure and framework that underpins the expectations, policy, responsibilities, strategies, and plans for how the health system should operate and deliver healthcare services. The legislative acts provide the legal framework for NZ's health and disability system and play a significant role in how children and young people with CP and their families experience health care in NZ. These acts work together to provide a framework for how the health system is organised and services delivered (New Zealand Public Health & Disability Act 2000). Legislation is enacted to ensure accountability in the public health system to promote the health and well-being of the people of NZ (New Zealand Public Health & Disability Act 2000). The acts guide the laws about preventing injuries and the rehabilitation and entitlements of injured people (Employure, 2021). They also make financial provisions by way of disability allowance payments to carers of children with CP (Social Security Act 1964, NZ).

Current Services

Services for children in NZ with CP are delivered by two MoH (2018a) funded, distinct, disability support pathways (see Fig. 2). These are the ACC pathway and the DSS pathway. Children may be eligible for a variety of support services within the primary, secondary, and tertiary healthcare settings depending on the specifics of their diagnoses, where they live, and which pathway they are allocated (MoH, 2018a). Each pathway has different inclusion criteria depending on the aetiology of the child's brain injury. These pathways are complex and have led to inequities and gaps in service delivery (Williams, Alzaher, et al., 2021).

Figure 2.

Two Pathways for Disability Support



The Accident Compensation Corporation Pathway

A child on the ACC pathway will have acquired a brain injury following a treatment injury, trauma or accident (e.g., hypoxic brain injury following a complicated labour). They will be accepted by ACC under the ACC Amendment Act 2019 (Accident Compensation Act 2019,

NZ). Of the 1,380 children included on the NZCP Register (NZCPR), Research Officer Alexandra Sorhage of the NZCPR reports that only 8% (or 110) are funded by ACC (personal communication, August 27, 2021). Dr Pauline Penney, Operations Manager at ABI Rehabilitation NZ, explained that a case manager is allocated who can provide coordinated, holistic wrap-around care based on an individual assessment. Dr Penney elaborated that there is also access to a multidisciplinary team of health professionals providing physical therapy interventions and other support (personal communication, October 20, 2021). Children can also access the Disability Support Service (DSS) pathway for disability related services such as surgery and specialist care (Whaikaha Ministry of Disabled People, n.d.). While the ACC pathway is considered the gold standard of care, children can still experience inconsistencies and variations when accessing services on the DSS pathway. Once on the ACC pathway a person can stay on it for life, receiving care, support, and therapy based on individual needs. Dr Pauline Penney, Operations Manager at ABI Rehabilitation NZ, revealed that it is estimated that one person on the ACC pathway over their lifetime may cost up to NZ\$40 million (personal communication, August 20, 2021). It is not surprising, therefore, that ACC has a rigorous process for accepting cases, especially given that the aetiology of brain trauma is not always clear and the costs involved with a lifelong condition such as CP are high. The process of applying for ACC can take many years to resolve and have a significant additional impact on the health and well-being of parents (Smith & Blamires, 2022).

The Disability Support Service Pathway

A child under this pathway will have suffered an injury to the brain (e.g., an unexplained stroke) that leads to a diagnosis of CP. Due to the unexplained nature of the cerebral event they are unlikely to meet the ACC criteria and will therefore follow the DSS pathway (Whaikaha Ministry of Disabled People, n.d.). The DSS pathway was developed by and is funded through the MoH. It is informed by the disability strategy and action plans. This pathway provides whatever support and treatment is available within a public system that is variable and complex. Children on this pathway are likely to be more impacted by their parents' ability to understand and navigate the system (Williams, Alzaher, et al., 2021). There are 1,270 children (19 years and under) registered on the NZCPR who are not funded by ACC. However, based on a prevalence estimate of 2 per 1,000 and MoH DHB population

data, Research Officer Alexandra Sorhage of the NZCPR estimates that the actual number may be up to twice as high (personal communication, August 27, 2021). Support will be provided via a district or regional hospital's child development service (Whaikaha Ministry of Disabled People, 2022a) which consists of a multidisciplinary team of health professionals who focus on teaching parents to provide physical therapy interventions to their child. Equipment and specialist input can also be accessed. Care provided on this pathway varies considerably and is often delivered in a fragmented, uncoordinated way (Whaikaha Ministry of Disabled People, n.d.). There is free access to a needs assessment and service coordination (NASC) provider, which is a not-for-profit organisation funded by the MoH (e.g., Taikura Trust). Services offered through NASC consist mainly of support for the main caregiver (respite support) or allocated capped individual funding (Taikura Trust, n.d.).

Ministry of Education Support

Families with children on either pathway (ACC or DSS) can also access MoE support when their child is under 5-years-old through the Early Intervention Service. This means that families on the DSS pathway get preschool support from both MoH and MoE. Specialist support includes early intervention teachers, Māori cultural advisors, education support workers, psychologists, and speech-language therapists. The early intervention team can work with families and early childhood centres to provide support with developmental delay, behaviour, and communication issues (MoE, 2020). Once a child on the DSS pathway starts school, care is transferred from MoH to MoE. Those on ACC can also access this support on top of their ongoing ACC support. The MoH to MoE transfer results in supports moving to a targeted focus on the child's educational needs and includes a variety of services aimed to support children who have significant learning needs to access the school curriculum (MoE, 2021). Children considered high needs and meeting a strict criteria can access the ongoing resource scheme (ORS) which includes access to a teacher aide whose role is to support the classroom teacher to support the child (MoE, 2021). The physical disability service provides a specialist therapist to make recommendations on how the school can support a child's physical needs. Children with high learning or behavioural needs may be eligible for teacher aid assistance through the in-class support service (MoE, 2021) if they do not receive ORS funding. The learning and behaviour service provides support to teachers who have children with significant learning needs in their class.

Cultural Considerations

Te Tiriti o Waitangi is a founding human rights document (New Zealand Government, n.d) that has a significant place in NZ's society. Te Tiriti o Waitangi requires acknowledgement and recognition on how legislation, policy, and service delivery are structured. However, it is clear that the foundational documents that lay out expectations for Māori (e.g., the Māori Health Strategy and Māori Disability Action Plan) are not meeting their health needs (Waitangi Tribunal, 2019). The Wai2575 Kaupapa Inquiry into Health Services and Outcomes report found numerous breaches of the principles of Te Tiriti o Waitangi (Waitangi Tribunal, 2019), and while the Māori Disability Action plan, 2018-2022 states that all organisations must have capability and capacity to provide services responsive to Māori cultural needs (MOH, 2018b), there are still a number of cultural barriers faced by Māori children and families that impact their access to disability services. These include negative attitudes and underlying unfriendliness to Māori on the part of service providers.

Another example is the rural urban divide. This is a phenomenon where children and families in major urban centres are more likely than those in rural communities to have access to a wide range of disability services including specific types of service delivery that take a Kaupapa Māori approach (Ratima & Ratima, 2007; Ratima et al., 1995). Dr Pauline Penney Operations Manager at ABI Rehabilitation commented that "occasionally clients ask for a Māori provider and we try to meet this request, but it's not easy as this segment of the workforce remains under-represented" (personal communications, October 20, 2021). The MoH (2018b, 2018c) website describes both Māori and Pacific support service pathways. These pathways indicate that there are culturally appropriate disability services available; however, it is unclear how they have been translated into practice. Paul Harvey, Portfolio Manager at the MOH, and Renata Kotua, lived experience and CP Society Member Support worker, both reveal that in reality it appears that all children, regardless of ethnicity, are required to access the disability system in the same way and particular attention to individual cultural needs is based on the service provider's capability and/or resources to do this (personal communication, August 25, 2021).

Discussion of Part 3: The Impact of Policies and Legislation on the Structure and Delivery of Support Services for Children with Cerebral Palsy and their Families in New Zealand

NZ's disability system is complex with a range of legislative, policy, and strategic documentation in place that shape the delivery of disability services (Starship, 2019a;

Whaikaha Ministry of Disabled People, 2022a). However, the way these various documents have been translated into practice has led to a wide range of inequities in care delivery to children and families living with CP. The current system allows for children with the same level of CP related disability, albeit caused by different events, a different pathway of care. A child on the ACC pathway can access one stop case managed wrap around care while a child with CP on the DSS pathway may experience difficulty in navigating a more fragmented and under-resourced system. These children are less likely to receive timely and appropriate treatment. Further, access to support is heavily dependent on parents' capacity to navigate the system, ask the right questions, and have the financial means to supplement necessary therapy privately that is not readily available through the public system (Bradley, 2022; Williams, Mackey, et al., 2021; Wynd, 2015). The Health and Disability System Review (2020) report describes a complex and unnecessarily fragmented healthcare system where significant duplication of activity and variation creates a post code lottery when it comes to accessing services. A child's access to care should not be determined by where they live, yet this remains the reality for many families (Health and Disability System Review, 2020). Neuwelt-Kearns et al. (2020) revealed that families of children living with disabilities experience considerable financial and social burden.

The ACC pathway is not without issue. While it promotes an evidence-based, consumer-informed approach, critiques have highlighted a lack of integration of feedback into operational improvements (Bradley, 2022; Provost, 2014). Furthermore, while the ACC pathway appears to have more resources available for children and families living with CP, it is often very difficult and time consuming to have applications to be accepted approved (Bradley, 2022).

Additionally, the present system fails to adequately address the need of Māori and Pacific children. One contributing factor is that it appears that both the ACC and DSS systems and pathways were established without meaningful incorporation of Te Tiriti o Waitangi and Māori cultural values. This foundational oversight has inadvertently caused more health inequity for Māori (Craig et al., 2016; Waitangi Tribunal, 2019). Māori continue to experience poorer health outcomes than non-Māori across all areas of health, including access to and quality of disability services (Bowden et al., 2015; Reid et al., 2017). Socio-economic deprivation and lower health literacy further compound these disparities, making it more difficult for Māori to access the care and support they require (Neuwelt-Kearns et

al., 2020; Waitangi Tribunal, 2019). Neuwelt-Kearns et al. (2020) described the system as privileging “those who have networks, disposable time and resources, and navigational knowledge of Pākehā systems” (p.5).

There is evidence of a need for greater government investment in financial assistance and meaningful data collection to inform resource allocation, legislative documentation, and policy development (Neuwelt-Kearns et al., 2020). Without such measures, inequities in the system are likely to persist or deepen.

Limitations of the Review of Part 3. The Impact of Policies and Legislation on the Structure and Delivery of Support Services for Children with Cerebral Palsy and their Families in New Zealand

This review was limited to grey literature available on the internet in August 2021. The intention was to identify key documents, policy, and legislative acts related to the health and education system and disability services for children (16 years and under) and their families living with CP in NZ. Therefore, information was excluded if it was not relevant to these variables.

Conclusion of Part 3. The Impact of Policies and Legislation on the Structure and Delivery of Support Services for Children with Cerebral Palsy and their Families in New Zealand

The current arrangement of the health and disability support system in NZ is complex. It has led to inequities that impact on the health, well-being, and opportunities of children with CP and their families. The DSS pathway lacks coordination and has unexplained variations affecting all children with CP across the Te Whatu Ora Health NZ districts and the country. In addition, there is a lack of literature on the child’s caregivers’ or families’ experience of living with a child with CP, access to healthcare services, or information on ethnic disparities of care delivery. For positive changes to be made, work needs to occur in a careful, coordinated, timely manner. It is only when all these variables are explored and considered, along with legislation, policy, and strategies that guide the system, that opportunities can be created for meaningful change. Only then can improvements happen, and inequities be addressed.

Conclusion of the Combined 3 Part Review

This three-part review of the literature has highlighted how raising a child with CP and/or other disabilities results in significant impact and stress on many aspects of life and requires primary caregivers to make significant lifestyle adjustments (Lee, 2019; Nyante & Carpenter, 2019). Lack of understanding from friends, family, and community (Gold, 2016; Lee, 2019; Mohamed Madi et al., 2019); the physical challenges of caring (Singogo et al., 2015; Vadivelan et al., 2020); as well as financial and environmental challenges, all contribute to struggles and stress for the primary caregiver (Vadivelan et al., 2020; Williams, Alzaher, et al., 2021; Zhang & Li, 2021). The literature highlights that for parents to feel positive and in control, and for the child to live their best life, parents need to understand and competently navigate the complex health, education, and social systems within their country (Alaee et al., 2014). For parents to do so, they must receive appropriate support and resources. There is overwhelming evidence in the literature that this does not occur in a clear, consistent, coordinated, and adequate way. There appears to be a mismatch between support and services needed and those delivered resulting in a deficiency of support across the whole system. It is evident that until this is addressed, children and their families will continue to be negatively impacted, feel unsupported, and have their opportunities compromised. The third part of the literature review highlighted how legislation, policy, and strategic planning has informed the way disability services are shaped and delivered in NZ. The way these have been implemented has led to wide variations in care resulting in inequities which have impacted children living with CP and their families, and particularly for Māori and Pacifica families (Sorhage et al., 2022).

This three-part review of the literature has highlighted significant gaps with regards to the NZ context. While some things about the local experience of raising a disabled child are known, there is a lack of understanding of the experience of raising a child living with CP. It is also not known if there is a difference in experience in relation to the type of disability services and support children living with CP and their caregivers receive. It is clear from the literature on parents' experience that this is an important phenomenon to understand and that conducting specific research would make a significant contribution to the understanding of this situation within the NZ context. International literature supports

this perspective, indicating that for improvements to happen, specific local research is needed (Afonso et al., 2020; Hayles et al., 2015).

There is untapped experience and knowledge within NZ primary caregivers of children with CP. By exploring the experiences of parents more deeply, there is an opportunity to understand the extent of the current situation and provide a more meaningful picture into what this experience looks like. This, in turn, could assist with ascertaining whether any changes are required to the way disability supports are provided in NZ. A study with this focus could inform whether there is a need to change societal attitudes on inclusion and acceptance, develop interventions to support carers, and improve strategies for rehabilitation. Findings could also be used to inform and educate health and education professionals and services about this important issue. Through understanding this experience there is also the potential to positively impact the health outcomes and quality of life of primary caregivers and children living with CP as new information could be used to inform recommendations that lead to changes in policy and legislation.

Chapter Three. Methodology and Methods

Chapter Two presented a three-part review of the literature as a way of understanding current knowledge of primary caregivers' experiences of having a child with CP and how this relates to the NZ context. The first part reviewed primary caregivers' experience of having a child with CP. The second part explored what is known about the experience of parenting a disabled child in NZ. The third part reviewed the policies and legislation that impact the structure and delivery of support services for children living with CP and their families in NZ. This thorough and multipronged review of the literature provided the first part of the theoretical scaffolding for the current study and confirmed my "initial hunch that the problem is worth studying" (Thorne, 2016, p. 60). Given the limited understanding of primary caregivers' experiences of having a child who lives with CP within NZ, and the aim of the current study to create new knowledge, a qualitative approach was considered fitting.

Qualitative research originates from the social sciences as a method to study human phenomena that cannot be otherwise quantified, specifically when interpretation and human subjectivity are involved (Thorne et al., 2016). Therefore, it is the preferred approach for explaining human experiences as it provides detailed information and gives insight into people's individual health and illness experiences which is consistent with the intent of this study (Thorne, 1997). When considering which qualitative methodological approach to take for this study, I explored phenomenology, grounded theory, and interpretive description (ID).

Adopting phenomenological methodology would have framed this research as seeking to explore how individual caregivers make meaning of experiences, delving into the essence of caregiving in this context was not aligned with my intent to understand the experiences and perspectives of caregivers in relation to personal and systemic challenges and influences (Creswell, 2013; van Manen, 1997). I wanted to explore broader contextual influences as opposed to understanding the essence of their lived experience.

Phenomenology, with its focus on individual core meaning removed from context seemed limiting and not the right approach or fit. It did not lend itself to producing findings that could be practically applied nor allow my knowledge and experience to be acknowledged. I would have had to 'bracket' my experience and preconceptions which did not fit well with my personal affinity to naturalistic enquiry and belief that researchers cannot be neutral

observers (van Manen, 1997). Further, it was not an approach that I found easy to understand. I found the methodological underpinnings heavy reading, difficult to comprehend, and the approach did not inspire or excite me. I could not imagine using this approach and do not believe that phenomenology fits my research question therefore, it made no sense to pursue this methodology.

Grounded theory draws on experience to understand how, and uses theory to explain phenomenon (Charmaz, 2006). I understand that it is interested in the social process (grounding in sociology) and is designed to develop theories that explain processes or social interactions. However, it did not seem to have value with moving beyond the theory. That is, I could not clearly see, from articles such as Hayles et al. (2015), how the findings could be used to influence and affect change in practice which was what I was wanting to achieve. I attempted to articulate my research question through a grounded theory lens; for example, “What is the main concern for families and children living with CP and how do they manage it?” It did not fit with my study intent of wanting to understand more broadly the experiences and perspectives of caregivers’ worlds. I was not aiming to develop new theories of parenting a child with CP; rather, to understand and apply insights within existing knowledge.

I then considered ID and found that the methodology was the best fit for what I wanted to study. It would allow me to both interpret and describe the experiences of primary caregivers, and it would provide me with the framework to affect change. It also would allow me to acknowledge and consider the data from my positionality. This made sense and felt like the right approach to take (Thorne, 2016).

Methodology – Interpretive Description

ID is an approach with epistemological roots within nursing science (Thorne, 2016). It was developed by Canadian nurse, Sally Thorne, in the 1980s when she and colleagues identified a lack of qualitative research methodologies that specifically suited practice orientated professions such as nursing (Thorne, 2016). While it has its roots in traditional qualitative methodologies such as grounded theory, phenomenology, and ethnography, the key difference is that ID is less concerned with generating theory and more focused on generating credible and meaningful disciplinary knowledge (Thorne, 1997) relevant to the clinical context of applied health disciplines (Hunt, 2009). It does this by seeking to

understand individual experiences and providing insight for practice improvement (Thorne, 2016).

Over the years ID has grown, developed, expanded, and been adopted by other practice orientated professions such as education and social work (Thorne, 2016). The methodology uses an analytical inductive approach which provides a way of understanding the human experience of disease and conditions and its impact on clinical context and practice. It allows for both reliable and meaningful disciplinary knowledge to be generated (Teodoro et al., 2018). Smythe (2012) described ID methodology as doing exactly what it says—it interprets, describes, and provides a philosophical and methodological way of understanding social reality. It allows the practitioner to draw on their own practice knowledge as well as relevant literature, and to combine this with the perspectives and worldviews of their participants to contribute to what is known about practice reality (Thorne, 2016).

The intention of this study is to uncover the rich and meaningful experiences of primary caregivers on a deeper level and to be able to use this new knowledge to influence practice change. When using ID, credibility is established when the research question is consistent with the epistemological positioning and study design. Thorne (2016) stated that this alignment is essential for epistemological integrity to be achieved. I carefully crafted the research question, 'What are the experiences and perspectives of primary caregivers raising a school aged child with CP in NZ? Framing the question in this way achieves what Thorne (2016) explained as reflecting the aim of ID in the applied context of health professional disciplines and intending "to uncover that which is accessible through the data sources available" (p. 57) which, in this research, is the study participants.

Theoretical Paradigms

Lincoln and Guba (2016) described three dominant theoretical paradigms within qualitative research that can be viewed as a set of basic beliefs or 'world views' that guide different lines of enquiry. These three dominant paradigms are conventional inquiry (guided by positivism), critical inquiry (guided by critical theory), and interpretive inquiry (guided by interpretivism or constructivism) (Denzin & Lincoln, 2000). Interpretive inquiry exists in the constructivist paradigm; thus, is primarily concerned with understanding people's experiences in a humanistic and interpretive way. It offers researchers the opportunity to

examine the complex human experience as people live and interact within their own social worlds (Appleton & King, 2002; Lincoln & Guba, 2016; Schwandt, 1994). Guba and Lincoln (1994) suggested that the constructivist aims to understand the different ways people experience living in the world and achieve some consensus of significance, while always being receptive to new explanations through experience and meaning (Appleton & King, 2002; Guba & Lincoln, 1994). Consistent with the purpose and objectives of this study, the interpretivist paradigm, can consider the existence of multiple realities for primary caregivers caring for a child with CP where knowledge will be co-created during the interaction between the researcher and participants.

The Philosophical Assumptions of Interpretive Description

Two main philosophical perspectives, ontology and epistemology, provide a lens through which a researcher can position their study within their chosen paradigm (Al-Ababneh, 2020; Goertz & Mahoney, 2012; Thorne, 2016). Ontology relates to the nature of reality and explores what exists in the human world that can be known or studied (Al-Sadi, 2015). Thorne (2016) referred to this as the nature of being and considered reality to be relative. The ontological perspective of ID is constructivist, where the view is that reality exists but only as known through the human mind and socially constructed meanings (Al-Sadi, 2015). Ontological positioning within ID relates to nursing as it allows nurses to recognise that not everyone they encounter will have the same experiences; rather, some are similar and others will be unique (Thorne, 2016).

Epistemology is concerned with how knowledge is created and understood (Al-Sadi, 2015). Thorne (2016) referred to this as the nature of knowledge. In ID, the epistemological positioning is interpretivism (as opposed to positivism) and the researcher is not separate from the research but is influenced by their perspectives and values (Al-Sadi, 2015). Knowledge is produced by exploring and understanding the social world of the people being studied and knowledge is seen as personal, subjective, and unique. The researcher understands the social world and human behaviour using their own, as well as the participants', perspectives (Al-Sadi, 2015).

When the ontological and epistemological perspectives are considered together, this approach leads to knowledge being produced by exploring and understanding (not discovering) the social world of the participants involved in the project and focusing on their

meaning and interpretations (Al-Sadi, 2015). Through this paradigm both created and distinct reality of health and illness experience are recognised and knowledge is developed through balancing the general and the particular (Thorne, 1997).

This study is guided by a constructivist/interpretivist paradigm as it seeks to understand the participants' (primary caregivers') experiences (raising a child with CP) and assumes that each experience is different and important to understand through an interactive (interviewing) process between the researcher and the participant. This positioning acknowledges that it is impossible for the researcher to detach themselves from the research and that the findings will be influenced by their perspectives and values (Al-Sadi, 2015). Therefore, the positioning of the researcher must be explicitly stated because it allows preconceived assumptions to be included in the study design so that they are acknowledged and managed to ensure credibility and mitigate unintentional bias (Thorne, 2016).

Framing Theoretical Forestructure

Framing a study is the important foundational work done at the outset. This is where planning for the construction of the study takes place and is the starting point from which the study is built. It is an important part of the process as the decisions made at this point will influence all aspects of the project. According to Thorne (2016), the key to success with this stage is to accurately define the "intellectual positioning" (p. 59) of the project. This includes considering the assumptions, values, and beliefs that are present; what is known about the topic; and what is the purpose and intention of the research (Thorne, 2016).

Framing consists of two key elements. The first is a review of the literature. This allows for establishing initial thoughts about the research direction, and provides the information needed to inform and validate the purpose and intentions of the study. The second element addresses the preconceived assumptions of the researcher. Essentially, it requires the researcher to reflect on what they bring to the study. It includes understanding the knowledge they bring to the topic, the assumptions they have made from knowing what they know, the bias they may have, and the multiple positions that they may hold within this knowledge. Thorne (2016) referred to this concept as theoretical forestructure and linked to it three key elements: locating theoretical allegiances, locating self within a discipline, and locating one's personal relationship to the ideas held.

Theoretical Allegiances

Locating one's theoretical allegiances is an essential component of qualitative research in ID, as it requires the researcher to be transparent about the perspectives and frameworks that inform their inquiry, while remaining open to emergent understandings (Thorne, 2016). In this study, I began by engaging in a pre-assumption interview with my doctoral supervisor to surface and critically reflect on my own assumptions about caregiver burden and the systemic challenges faced by parents of children with disabilities. This reflexive process helped me to identify the influence of my personal experience as a mother of a child with CP. It also helped me to recognise the influence of my professional background as a paediatric nurse, where I have consistently worked within a family-centred care paradigm. This framework recognises parents and caregivers as experts on their child and positions them as central to collaborative, holistic care planning (Matziou et al., 2018; Shields et al., 2006). My allegiance to this model shaped my attentiveness to the expertise and authority of the parents in my research and aligns with the philosophical commitments of ID to knowledge that is both contextually grounded and clinically relevant (Thorne et al., 1997). At the same time, I remained open to the ways in which parental experiences might challenge or extend this framework, and I viewed my theoretical positioning as a guide rather than a fixed lens.

Disciplinary Orientation

Disciplinary orientation is a key element to theoretical forestructure. Thorne (2016) discussed the importance of exploring and declaring one's position within their discipline and in relationship to the study. While there is a school of thought that researchers should be a 'blank slate' or impartial and unbiased in their view and approach to the research, Thorne explained how this is "inconsistent with the advancement of disciplinary knowledge within applied fields such as the health professions" (p. 72). It also fails to acknowledge that disciplinary knowledge development is often a motivating driving force to undertake the research (Thorne, 2016). The way a researcher is orientated within their discipline, whether or not consciously aware of this positioning, Thorne (2016) believed powerfully shapes the research thinking, design, and outcomes. Thorne (2016) said that the influence disciplinary orientation has on this work is significant and can affect the overall impact and quality of it. Therefore, it is important to thoughtfully consider this aspect and to declare and

acknowledge it from the outset to ensure transparency and recognise that without this crucial clarification, challenges to the integrity of the method and design logic may arise (Thorne, 2016).

This research study is orientated in the discipline of nursing. This is both relevant and important because nursing is concerned with the general human health and illness experience at levels ranging from the cellular to the global, while devoting the vast proportion of its emphasis upon the everyday reality of actual and particular people in their own unique circumstances (Thorne, 2016). My motivation to undertake this research is rooted in my disciplinary identity as a nurse, where the imperative to improve patient and family experiences drives both clinical and scholarly inquiry.

Nursing is a relational practice based on delivering skilled, safe, high quality, evidence-based care that focuses on supporting people and communities. It aims to enhance, maintain, and restore health, and alleviate the effects of illness or support a peaceful death (DalPezzo, 2009; Thorne et al., 1998). Nursing recognises the uniqueness of the human condition and, as an experienced nurse, I understand this perspective. This view shaped my desire to use research as a tool to inform change at both the individual and system levels. My clinical experience has provided me with an in-depth understanding of how health systems operate, as well as a deep awareness of how structural and interpersonal factors intersect in shaping patient and family experiences. My nursing practice is guided by the belief that while each person's experience of illness or disability is unique, there are often shared meanings among individuals navigating similar health-related journeys. These commonalities, however, do not erase personal variation; instead, they coexist and enrich our understanding of human experience in health contexts. Nursing has taught me to approach others with empathy, to listen attentively, and to remain sensitive to the subjective meanings people assign to their experiences. This disciplinary orientation significantly influenced my engagement with participants in this study, fostering practices of empathy, active listening, and critical observation, all of which are central to ethically grounded, person-centred research.

As a researcher, I acknowledge the nursing construct by seeking to understand primary caregivers' experience in the world of disability within a nursing context. This research is based on a constructivist/interpretivist paradigm which sits within ontological and epistemological positioning. The study design aligns with the practice of nursing

because of the use of one on one in depth interviews as the primary data source which acknowledges nursing principles and practice of human connectivity (Thorne, 2016).

Researcher Positionality and Personal Perspective

The last part of Thorne's (2016) theoretical framework clarifies the positionality and personal perspective of the researcher. As with disciplinary orientation, it is important (and expected) when using the ID framework to acknowledge each researcher's unique personal positionality (Thorne, 2016). From a personal perspective, the researcher will not come from a neutral stance; therefore, along with managing the disciplinary bias, it is necessary to acknowledge and manage any personal bias and influencing factors from their personal world (Thorne, 2016). This must be done at the outset of the study as part of designing and conducting the study. As with managing disciplinary bias it must also be done in a thoughtful and considered way that reflects on and declares both what the researcher knows about the topic, how they know it, and how their personal views may influence the research (Thorne, 2016). It is, therefore, important that I now declare my personal positionality within this research.

I come into this study as a paediatric nurse, a mother of a school age child with CP, a member of the community I am seeking to study, a member of the CP Society of NZ Board, and a novice researcher. My personal perspective within this study is underpinned by the journey that I have taken through life. During my 30 years as a nurse, I have always been drawn to working with children. My experiences working as a paediatric nurse have provided me with insights into the world of child disability and the opportunity of working with children living with disabilities alongside their parents and family. Through providing support for these children and their families during their healthcare journey, I have gained both heart-warming and confronting insights into the impact that having a disability has on families and parents. Children are positive, in the moment, and progressive with their health recovery, and they do not often understand the significance of their situation when in healthcare environments. Up until the last decade my perspective as a health professional was very much influenced by my understanding of how children see the world and by my master's degree into therapeutic supports for hospitalised children. While my child health nursing experience gave me insight into the lives of the families and parents, I now realise

that I really had no meaningful understanding of their experience as parents until I became one myself.

During the last 14 years I have had the privilege of being intimately acquainted with the world of both parenting and disability through my daughter Molly who lives with CP, and it has changed my worldview and perspective on life. The experience has been both humbling and confronting, and led me to feel both grateful and frustrated. It has provided me with a clearer understanding of inequity and discrimination and how hard it can be for some people living with disability to simply live. I have come into this research wanting to understand more about the experiences of people, like me, who are raising a child with CP in NZ.

However, the motivation to commence my doctoral journey came from a time of reflection made possible because of the first NZ COVID-19 lockdown in March 2020. During this time, I took the opportunity to think about my life, goals, and aspirations. I realised with acute clarity that after a decade of living (as a mother) in the disability world and spending time feeling frustrated and disheartened by the lack of awareness, opportunities, and supports for my daughter and other children with CP, that I could instead redirect this energy into making a difference for children and their families in NZ through conducting research. My daughter Molly lives with CP; therefore, I am living within the world that I am seeking to study. Throughout Molly's life, I have gained insight into a world where inequities exist both in general and in the way the government support systems operate. The formal support system for children with CP seems to vary widely and so much is left up to the parent to navigate, negotiate, advocate, and co-ordinate care in order to provide the opportunities and environment for their child to thrive.

Following lockdown, and within the same year, three more key influencing factors presented themselves which served to both deepen my resolve to commence a meaningful doctoral study and shape the direction of it. The first factor was when I read an article that reported on research in which I had participated. It was a study looking at the early diagnosis management of children with CP. I saw first-hand how the research results were used to highlight this issue, educate health professionals, and support parents on the need for early and timely diagnosis. The second factor was work that a group of concerned parents of children with CP (of which I was part of) took to expose unregulated and unusual work that was happening within the CP Society of NZ. This ultimately led to myself and five

others being voted onto the CP Society of NZ Board where we found ourselves in a position to be able to advocate and progress the Society in a positive and meaningful way. The third factor was that during the work that took place to bring the CP Society of NZ back on track, I discovered a whole new and amazing community of families and parents that had a child who was living with CP. This was an eye-opening experience and led me to realise that there were others experiencing the same (and often greater) struggles as me. It was a humbling and heartwarming experience to meet parents who were facing such significant challenges and doing so with extraordinary inner strength, determination, and positivity. All these experiences led me to the conclusion that, in my opinion, NZ could do better for children with CP and their families, and that a good place to start would be by understanding the experience of those living within that world.

Being an Insider

As a primary caregiver of a child living with CP, I am in the privileged position of being an inside researcher. Byrne et al. (2015) defined an inside researcher as a member of the community being studied, rather than merely a researcher with access or connections to the community. This comes with challenges and advantages, both of which require acknowledgment. Aburn et al. (2021) cited the main challenges to being an insider as power differentials in relationships (either minimised if the researcher is familiar to the participants or concerns related to the risk of coercion during recruitment), managing one's own emotions as a researcher, the risk of assumed understanding, and the risk of participants over-disclosing due to the shared experience. Reflective practice is one way that these challenges can be managed and minimised, and is discussed in more detail later (Aburn et al., 2021).

The advantages of being an insider include having expert topic knowledge, an ability to establish rapid rapport and, therefore, provide the opportunity to generate rich data and an ability to interpret the data because of contextual knowledge. It is believed that participants are more likely to be open and honest with an insider which can lead to a cathartic and therapeutic experience (Aburn et al., 2021).

However, the situation must be carefully managed (Aburn et al., 2021; Chavez, 2015). I acknowledge that by having an appreciation and understanding of both the research topic and lived experience, and by living in the world I am researching, that I must

constantly be mindful of recognising and managing any bias so as not to allow it to influence this study. At the outset of the doctoral journey, my position was acknowledged by completing a pre-conceived assumptions interview with my primary supervisor. Personal bias was managed by the adoption of a variety of recommended strategies which are discussed in more detail in the study design section.

Evaluation Criteria for Interpretive Description

ID studies generally seek to provide insights into the human experience within a qualitative framework. The nature of qualitative research means there is potential for significant variation within a researcher's approach and their study design (Thorne, 2016). This has led to a general concern for the credibility and quality of studies that use ID methodology (Thorne, 2016). In response, it is important to ensure integrity, credibility, and robustness are applied to an ID study design. Thorne (2016), recommended acknowledging and adopting four general principles when designing and conducting a study using ID—epistemological integrity, representative credibility, analytic logic, and interpretive authority. These are discussed below in relation to how they have been incorporated within this research study.

Epistemology is a way to explain what is known and how it is known. Integrity in this context is when a study has been designed in a way that allows others to have trust and confidence in both the research design and findings (Al-Ababneh, 2020; Goertz & Mahoney, 2012). Epistemological integrity is when there is transparency between the researcher and their knowledge of the topic so that assumptions and views can be managed (Thorne, 2016). It is achieved when there is alignment between the research question and epistemological positioning (Thorne, 2016). It requires the researcher to acknowledge, explain, and reveal a strong link between the assumptions they have made about their knowledge of the research topic and the decisions they have made regarding the methodological approach for the study design. The epistemological integrity of this study has been acknowledged through the declaration of both my disciplinary orientation and personal positioning underpinning this research. It has allowed me to be transparent about the knowledge and beliefs that I hold, as well as any preconceived views I had at the outset of the study. This, in turn, allowed me to put strategies in place to carefully manage these beliefs and views as recommended by Thorne (2016). I have also conducted three separate reviews of the

literature which outlined the experience of parents of children with CP in other countries, the experience of parents of children with a disability in NZ, and the support services for children in NZ with CP. These all helped inform my research.

Representative credibility is a way of measuring accuracy and truth of research findings. When using ID, credibility is established when the research question is consistent with the epistemological positioning and study design (Thorne, 2019). One way Thorne (2016) recommended achieving credibility is through the triangulation of data sources. This method, well supported by other qualitative approaches (Carter et al., 2014; Moon, 2019), is when a variety of techniques are used to collect and validate data. For example, in this research I used field notes and reflective journaling as a way of being able to reflect on the data collected in interviews, so that I could refine questions and improve interview technique. Field notes were taken while interviewing and reflective journaling was done following each interview and at other times as thoughts and reflections came to mind (Thorne, 2016). This was a good way of recording developing thinking (Sbaraini et al., 2011; Smythe, 2012). Field notes and reflective journaling (examples in Appendix E) were treated as important components of the analytic process and allowed me to capture contextual details, emerging insights, and reflexive responses during and following interviews. I reviewed them iteratively alongside the transcripts and they helped to identify patterns, refine emerging themes, and monitor the evolution of analytic thinking. For example, when participants talked about their experiences with receiving their child's diagnosis, I was able to look back through field notes and journal entries from previous interviews and review reflections and observations of the other participants I had interviewed. I was then able to bring this information into my analysis to deepen my interpretation, provide contextual nuance, and support triangulation across data sources. I noted that many mothers often became emotional, their voices changed, and many quietly (or even silently) cried. These techniques enabled me to achieve triangulation of data sources and credibility of the study (Thorne, 2016). Another way credibility was achieved was using purposeful sampling; and is discussed in more detail in the forthcoming research design section.

Analytic knowledge is the practice of ensuring that evidence of logic (e.g., audit trails and frameworks) is sufficiently visible throughout a study design so that it allows the reader to confirm or reject its credibility (Thorne, 2016). In this study an audit trail was developed through the practice of taking field notes and reflective journaling as data were collected,

interpreted, and understood (Appendix E). This practice supported the credibility of the study (Thorne, 2016). The content of the notes taken and journaling recorded was discussed and reviewed with supervisors to ensure that insider bias was managed. During data analysis, Morse's cognitive processing framework was used (Morse, 1994; Thorne et al., 2016) to support the concept of analytic logic (outlined in the data analysis section below).

Interpretative authority addresses the requirement that any personal bias is kept external (Thorne, 2016). It is important for ensuring that the interpretation of the data made by the researcher is trustworthy and credible. Thorne (2016) said that it is achieved by building systems into the study design that allow for checking interpretations against those of study participants; demonstrate that the claims made about the data within the method are grounded; and show an awareness of the social and knowledge community context (the world of caregiving and disability) into which the research findings will be directed. In this study, interpretative authority was achieved in two ways. The first was by regularly asking supervisors to review, challenge, and seek clarification of the interpretations that I was making throughout the analysis phase. The second was my commitment to continually practicing the art of reflection which encouraged a considerate and analytical shift beyond intuitive inquiry to a carefully constructed crafted inquiry. I recognise that the knowledge, experience, and background that I bring to this study will shape and influence the way I position myself into the research environment. By regularly reflecting with my supervisors, I was able to discuss and acknowledge how the interpretation I placed on the data was influenced by personal, cultural, and clinical experiences.

Research Study Design

One of the ways credibility in research can be established is to discuss one's theoretical position. "Theoretical positioning ensures that the findings will contribute to a larger theoretical project of concern for the discipline" (Thorne, 2016, p. 65). During this phase, the following four strategies were used to manage bias and ensure credibility.

1. I maintained written journals, including field notes and personal reflections (Lincoln & Guba, 1985). These were aimed to support study credibility and achieve a triangulation of data source (Thorne, 2016).

2. I had regular meetings with supervisors and asked them to review, challenge, and seek clarification of thoughts, ideas, and interpretations. These strategies ensured that claims made about the data were grounded (Thorne, 2016).
3. I developed and maintained an audit trail (Greene, 2014). This involved keeping records of the steps taken and decisions made when working raw data into themes and interpretations. It ensured that there was a record of the process and how interpretations and conclusions were reached (Thompson Burdine et al., 2021).
4. I actively engaged in reflexivity. This required a degree of both social and emotional distance (Greene, 2014). I ensured I was successfully supported to do this by consulting academic literature on the topic and seeking support from my supervisors.

Foundational Underpinnings of an Interpretive Descriptive Study

ID does not come with a prescriptive approach that requires research to be conducted in a certain way. Instead, it lays out a set of seven common assumptions, grounded in the naturalistic tradition (Lincoln & Guba, 1985), to be considered when building the foundations of an ID study (Thorne, 2016). These assumptions will be discussed in relation to how they were integrated into the design of this research.

The first of the seven common assumptions is that the research will be conducted in an ethical and respectful way, in the natural environment of the participant. In the case of this study, participants were asked where they would like the interview to take place. This led to interviews being conducted in people's homes, in a café, or on Zoom. The one interview in a café was at the participant's request and a short trip from their home. The interview was conducted in early January and the café was very quiet, so we were able to sit away from other patrons and be easily heard. The second assumption is that the research will value the knowledge that is gained from individual perspectives and experiences as a basis for practice insight. In this study all information and knowledge gained were carefully considered during the data analysis phase and reflected in the findings. The third is to make the most of both shared and diverse views within a common focus of interest. This is relevant in the study as participants were united in wanting to share their knowledge to support practice advancement which was able to be done through gaining a greater

understanding of both their common and unique views. The fourth is that the research reflects issues that acknowledge the time and context within which human expressions are played out. This relates to the study as it acknowledges the participants' whole caregiver/parenting journey and experience. The fifth common assumption is that there is a socially constructed element to human experiences which cannot be separated from the individual. Regarding this research the participant was interviewed and considered in the context of their wider family life and social support constructs as they cannot be viewed in isolation. The sixth common assumption is to recognise that there may be multiple realities that, at times, could be contradictory. In this study these could include acknowledging the many roles and responsibilities that participants (e.g., spouse, parent, caregiver, career person) could have which might lead to one person holding different perspectives depending on which role they were doing. The final assumption is that the knower and the known influence each other in the construction of the research outcomes (Lincoln et al., 2011). In this study it included me acknowledging and declaring my positionality and factoring it into the study design and methodological approach. The following section outlines the study methods using these seven assumptions as guiding principles.

Methods

Participants

Participants were selected using purposeful sampling. This type of sampling recruits specific individuals based on their unique perspectives and experiences who can provide deeper insights into the research topic (Thorne, 2008). Purposeful sampling can ensure that the chosen study participants will bring a wide range of experience to provide rich data and detail to the research (Patton, 2015). It also provides an effective approach to identify and seek out those participants who are best equipped to discuss the subject matter being explored (Patton, 2015). This approach acknowledges Thorne's (2016) fourth principle for ensuring representative credibility. The participants in this study were defined as being the primary caregivers of children living with CP. The term 'primary caregiver' in this context refers to a person that has the primary responsibility for the day-to-day care of a dependent child (Office for Early Childhood Education, n.d.). This could be a biological or non-biological parent, a grandparent, relative or other. To reflect the ethnically diverse population of NZ, participants were purposively selected to include those who would represent people from

Māori, Pacific Island, Asian, and European backgrounds consistent with national demographic patterns (Statistics New Zealand, 2024). As this research was for a doctoral degree it was deemed appropriate to aim for a sample size of up to 15 participants. This was also considered appropriate within ID methodology which, while not being directive regarding participant numbers, advocates for rich quality data over quantity (Thorne, 2016).

Inclusion Criteria

My intention was to recruit a diverse sample of primary caregivers to ensure a wide spectrum of voices. This diversity was sought by way of including primary caregivers who met the following inclusion criteria:

- Primary caregivers of children aged 5-16 years with a confirmed diagnosis of CP. This age range was chosen because prior to turning 5 years there is more equity within the system providing support services for children with CP and their families. On starting school, a large portion of care is transferred from the MoH to the MoE (MoE, 2021; MoH, 2012). Once children turn 16 years, they generally enter adult support services (Starship, 2019b). However, some paediatric disability support services might transfer children who have been under their care for most of their lives later than this, due to long standing relationships and fear that the adult services will not provide the same attention and care.
- Consent from each participant and willingness to participate.
- Receiving support through any disability support pathway (e.g., ACC, DSS, or other, such as privately funded).
- From different ethnic backgrounds (Māori, Pacific, Asian, European/Pākehā).
- From varying socio-economic backgrounds.
- Able to communicate in English.

Exclusion Criteria

Non-English-speaking primary caregivers and potential participants not meeting the inclusion criteria were excluded.

Ethical Considerations Prior to Recruitment

Ethics approval for the study was sought and granted by the AUT Ethics Committee (reference number 22/343) (Appendix F).

Recruitment Strategy

Following ethics approval, a participant recruitment post and flyer was published on the 'Cerebral Palsy Kids of NZ' Facebook page on November 30, 2022 (Appendix G). It was important that potential participants did not feel obliged or pressured to participate and this was reflected through a carefully written flyer. The flyer provided a brief overview of the study and invited interested people to contact me if they were both interested in taking part or wanted to know more. Within half an hour of the post being published 22 people had responded and over the coming days more people expressed interest. Potential participants were invited to express their interest via email; however, most people preferred to send a personal message directly via Facebook messenger. This proved to be an easy and efficient method of communication. It was used to seek further information and ascertain whether the participant met the study inclusion criteria and then arrange an interview if indicated. An email address was requested to send the participant information sheet to (Appendix H). The participant flyer was also included in the research section of the CP society of NZ webpage. Over the next week dozens more people made contact. Due to the amount of interest, the maximum number of 15 participants were easily recruited. Careful consideration went into the possibility of submitting an ethics amendment to interview more participants; however, a reminder of the scope of this doctoral work focused the process back to recruiting the maximum number of 15 participants as indicated in the research proposal. All participants were offered (and accepted) a \$40 koha (gift) in recognition of their time commitment.

Ethical Considerations Prior to Data Collection

Prior to commencing data collection, three main ethical considerations required addressing. These were ensuring the confidentiality and privacy of participants (Creswell, 2003), prioritising their safety and emotional well-being (Dempsey et al., 2016), and maintaining clarity about my professional role while adhering to good interviewing practices (Nathan et al, 2019).

Confidentiality and Privacy

The first consideration was to ensure participants' confidentiality and privacy was maintained throughout all stages of the research study by incorporating it into the study design (Creswell, 2003). Creswell (2003) stated that it includes protecting participant identity throughout recruitment, data collection, analysis, and publishing. In this study, participants were provided with an information sheet prior to their interview, explaining how their privacy and confidentiality would be protected (Appendix H). It included the following eight measures. First, participants' names (and any other personal information that could identify them) were removed from their transcript. Second, interview recordings and transcripts were limited to only the members of the research team. Third, all identifiable details were held securely and accessible only to myself as the interviewer. Fourth, no information identifying the participants would be included in any of the project reports or publications. The fifth measure was that participants were allocated a pseudonym by myself which was used throughout the research (Allen & Wiles, 2016). Six, all information was stored on a password protected computer (data security). Seven, consent forms were stored in a separate secured filing cabinet. Lastly, interview recordings were all transcribed through an application using artificial intelligence technology and were deleted immediately after transcribing was complete.

I acknowledged in the research proposal the need to be mindful that the study participants are part of a small community and I asked my supervisors to hold me to account if indicated. During the consent process all participants were reassured verbally that participation was confidential as written in the study information sheet. However, while it was explained to them that they would never be identified in the research, it was pointed out that due to the sampling coming from a reasonably small community of people, there was a risk that they might be identifiable to some people. This risk was included in the consent form and participants were made aware prior to signing the form. It was also explained that no information identifying them as a participant would be included in reports or publications. Prior to the interview commencing all participants were informed that a data management and security system was in place to protect their identity and information.

Emotional Support

The second ethical consideration, ensuring the safety and emotional well-being of participants, was acknowledged. I was aware of the possibility that participants talking about such a deeply personal topic could elicit a strong emotional response and cause distress. An agreement was reached with AUT counselling service that if a participant experienced psychological distress as a direct result of participating in the research, then AUT Student Counselling and Mental Health was able to offer three free sessions of confidential counselling support. Participants were provided with information on how to independently access this free and confidential counselling through the AUT Student Counselling and Mental Health department and did not need to inform me if they decided to proceed.

Professionalism

The third consideration was to make sure I was clear about my role and that my interactions with participants were always professional. I did this by consciously ensuring I was thinking as an interviewer. I adopted the mindset that I have when at work which is being respectful, polite, and engaged.

Participant Information

Once it was ascertained that a person was a suitable study participant, they were provided with a participant information sheet (Appendix H) via email or Facebook messenger. This 3-page information sheet provided details relating to me, my supporting supervisors, the purpose of the research, what was involved if they agreed to participate, and how the findings would be presented. It also covered any possible benefits and risks to them, as well as confidentiality and privacy, and emotional support as mentioned above. Participants were contacted via email, Facebook messenger, or text messages to arrange an interview day, time, and location.

Voluntary Participation and Consent

At the beginning of each interview the participant was asked if they had read the information sheet and if they had any questions. If requested, information was elaborated on. The opportunity was taken to reiterate the scope and purpose of the study. Participants

were invited to ask further questions during the interview or at any time following the interview. Before the interview started, the consent form was read. I stressed that participation was voluntary, and that the participant could withdraw at any time up until findings were generated. Two consent forms (Appendices I and J) were used, one for face-to-face interviews and another for interviews via Zoom. Once the consent forms were signed, they were stored in a folder in a locked cabinet, separate from the interview data.

Cultural Support

I enlisted two people, one who identified as Māori and the other as Pacific Island, to provide advice and support on behalf of their cultural groups on my recruitment strategy. These two people were recommended by the CP Society as being cultural ambassadors within the CP world and both live with CP. Advice and support was specifically sought with regards to cultural considerations with participant recruitment and interviewing. I met with each one separately for guidance and feedback. They provided suggestions such as offering a koha or a donation (Māori cultural support) and reminding participants of upcoming interviews the day before (Pacific Islands support). They both suggested offering the presence of a cultural support person during interviews. All suggestions were adopted into the recruitment strategy and interviews. While all participants were offered the opportunity to have an appropriate cultural support person attend the interview if desired, none took up this offer.

Data Collection

Thorne (2016) presented a range of data collection and analytic strategies available for use such as interviews, focus groups, and participant observation, as well as purposive and theoretical sampling and thematic analysis. Thorne (2016) advised the researcher to carefully consider all options and work through the strengths and limitations they bring. The end goal is to choose an approach (or approaches) that matches what is being studied with the data collection method that is likely to produce the most meaningful responses. In this research, interviews were chosen as the data collection method to understand how primary caregivers of children living with CP describe their experiences.

The decision to choose interviews as the method of data collection was influenced by my experiences of working as a paediatric nurse with children living with disability and their families. Much of the joy and satisfaction that these experiences brought were because

of the opportunity I had to make connections with children and their families, through being present, taking the time to understand their needs, planning care together, and working as a team to achieve the best outcome for both the child and family. Without a doubt this has influenced my theoretical position with regards to qualitative research and the desire to collect my data through individual interviews. This is a phenomena Thorne (2016) discussed as being common with nurses who she says “tend to favour individual interviewing as a primary data source, in keeping with the human connectivity that is central to enacting clinical practice” (p. 74). It is consistent with my belief that data collection for this study was best achieved through a series of individual interviews.

A semi structured interview style was used to allow for flexibility in questioning. It also allowed for capturing a deeper understanding of lived experiences within an individual primary caregiver’s context (Polit et al., 2001). Open ended questions were used. They were deemed to best fit with the interpretivist-constructivist theoretical framework because they allow participants to reflect on personal subjective experience and then develop understanding around this interpretation through constructing and reconstructing the experience (Lincoln & Guba, 1985; Thorne, 2008). Participants were allowed to talk without interruption which enabled them to respond in their own words, in their own way, and fostered deeper responses that were meaningful to each individual participant as opposed to responding to pre-determined responses (Polit & Beck, 2006). An interview guide (Appendix K) was used and included warm up questions such as ‘tell me about yourself’ and open questions such as ‘tell me about your child’?

In addition, demographic information about the participant was collected including their age, gender, ethnicity, level of education, and geographic location (ethnic data were collected prior to recruitment to ensure cultural diversity in line with the population). This additional information was collected to more deeply understand the participant group.

Interview Process

Recruitment and interviews were conducted over a 20-week period from November 30, 2022 to April 18, 2023. The process was relatively straightforward, with four interviews conducted in person and 11 via Zoom. Although the original intention was to prioritise in-person interviews, it became clear during the process that participants preferred Zoom. and there was no discernible difference in the depth or quality of data collected between the

two modes. I discovered that both approaches enabled the interviewees to feel comfortable and talk openly on a deeply personal level. This is consistent with the benefits of face to face interviews as reported by Saarijärvi and Bratt (2021), who stated that body language, facial expressions, and other non-verbal social signals help with creating a safe and comfortable atmosphere. While Zoom presented potential limitations, such as interruptions or connectivity issues (Oliffe et al., 2021), these were not significant and did not negatively impact the research. In fact, the benefits of using Zoom far outweighed these drawbacks. It enabled greater accessibility across NZ, extending the recruitment reach and enhancing inclusivity (Oliffe et al., 2021). It also reduced travel costs and time, eliminated the need for interviewer safety protocols, and allowed participants to speak from a familiar environment while maintaining privacy. Some noted that being able to participate from home meant that they could do it with their child/children at home saving on childcare costs which was particularly helpful. All participants who were interviewed on Zoom had access to a computer and internet, and none of the participants indicated that a virtual interview would not be possible. The flexibility, convenience, and privacy offered by virtual interviews contributed to rich and candid discussions. This approach was consistent with the values underpinning the research and was supported by both Māori and Pacific cultural advisors.

At the outset of each interview, I confirmed that the participant had read the information sheet that had been emailed to them and reiterated the purpose of the study. Participants then gave informed consent—verbally for Zoom interviews (Appendix J) and in writing for in-person interviews (Appendix I). It was evident from the overwhelming response during recruitment that people understood the study's intention and they were keen to share their story. Time was given to build rapport, introduce ourselves, and share backgrounds. This approach honoured the Māori concept of *whakawhanaungatanga*, which Rewi (2014) described as “the process of establishing relationships and relating well to others” (p. 244). This was critical to setting a respectful, open tone for the interview. Participants were warmly welcomed and thanked for their time (*mihi*).

Throughout the interviews, I reassured the participants that the information and stories they shared as part of the research process would be treated with respect and care. This demonstrated and acknowledged the Māori concept of *manaakitanga*—showing care, respect, and protection for participants (Jenkins, 2022); and was reflected in my tone,

behaviour, and approach. My process was supported through ongoing consultation with Māori and Pacific advisors to ensure culturally safe and responsive engagement.

During the interview process I was mindful of the importance of manaakitanga and ensuring the participants felt relaxed and safe. I started the interview with a smile and warm welcome. My approach was open and curious (Thorne, 2016), with non-verbal cues, such as nodding, to show I was interested, listening, and engaged while they were talking, and making sounds to acknowledge I was hearing what they were saying (St-Yves, 2013). I made sure my demeanour was positive and encouraging. While I spent time prior to the interview mentally preparing, I found this approach came quite naturally for me. Each interview began with warm-up questions, guided by an interview framework (Appendix K) that included open-ended prompts aimed to encourage the participant to recount their experience and perspective of raising a child with CP. These included questions about experiences with health and education systems, as well as social support services and day to day life. While this guide was particularly useful in the early interviews, it became less central over time as conversations flowed more freely. As the study progressed, participants often spoke at length without prompting, and new questions emerged in response to themes from earlier interviews. I began to add linkages asking questions such as, “Many participants have mentioned XYZ—what has your experience been?” (Agee, 2009; Dunwoodie et al., 2023). Interviews typically lasted 90 minutes, with some extending to 2-hours, reflecting participants’ enthusiasm and desire to share their stories.

Reflexivity

Berger (2015) described reflexivity in qualitative research as “continual internal dialogue and critical self-evaluation of researcher’s positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome” (p. 220). In other words, qualitative researchers practice reflexivity to acknowledge, understand, and manage how their values, views, and position shape and influence their study (Olmos-Vega et al., 2023; Thompson Burdine et al., 2021). Reflexivity is an important skill to master when using ID methodology and the practice of it helps to ensure that there is credibility to the research. Thompson Burdine et al. (2021) stated that reflexivity can be practiced several ways including journaling, engaging in open discussions with relevant people, and by reflecting internally on the research process.

In this study, I was aware of my own bias and lived experience, and was mindful of the importance of minimising the impact of this awareness on the interview process. I discovered that spending time prior to each interview mentally preparing and ensuring my mindset was placed in the researcher zone was helpful. I found it easier than anticipated as I knew of only two of the mothers and many of the participants relayed experiences that were quite different to mine. The two mothers that I knew were through the network of mothers of children living with CP that I discovered during COVID-19 and we were not well acquainted. I declared this connection to my supervisors and from our discussions I consciously decided not to interview them until I had completed at least half the interviews and had become more comfortable with my interviewing skills. This allowed me to minimise the impact of knowing them and conduct the interviews in a similar manner to the others. One difference to note is that because these two mothers may have felt more comfortable with me, they invited me to conduct the interviews in their homes. I expected that I would know more of the participants due to the nature of the small community. However, because I did not, I found it easy to put my mother/lived experience and nurse perspective to one side and just wear my researcher hat. After I had conducted the first two interviews, I found slipping into the researcher role easier and easier, especially when it was apparent that the participants were warming up easily and did not require much prompting. Participants appeared happy to talk for long periods without prompting. It felt as though they had a sense of relief that they could not only talk without interruption but in a space where they felt safe to be honest and real without judgement. These are important aspects of good interviewing (Adams, 2010). This process was supported by on-going self-reflection, journaling, and regular discussions with my supervisors.

At the completion of each interview, I made sure that I allowed extra time to write down my reflections on the interview itself, the participant, and key words and themes that I had picked up. I wrote down anything that was similar or different to the experience of other interviews and reflections on my approach and interactions. For example, I noticed that many of the mothers who had experienced unexpected premature labour still felt associated trauma; however, there were some differences in perception of their experience with disability services. After only a few interviews, themes became apparent around concepts such as impact on family life (everything centred around the child's needs), the lack of support early on, the trauma of those who had difficult labours, and time in the

neonatal intensive care unit (NICU). I captured my thoughts on what they said and any judgements or assumptions; for example, noting down my thoughts around why a mother had not applied for ACC for their child when they clearly qualified.

I critiqued my interviewing technique and thought about ways I, as a novice researcher, could improve (Adams, 2010; Thorne, 2016). I found this helpful and, as a result, made ongoing improvements to my interviewing technique throughout the process which included responding less, and making sure the participant was truly able to talk without interruption and say everything they wanted. I found the more I did this, the longer the participant spoke. I also started saying 'tell me about that' when they brought something up. I found the more interviewing I did, the more emotions were shown by the participants, with many spanning a spectrum of sad and crying to happy and laughing and everything in between. I did a lot of reflecting on how the participants presented, their demeanour and the tone of their voice. These field notes and personal reflections (Appendix E), as recommended by Lincoln and Guba (1985), provided a triangulation of the data which supported the credibility of the study (Thorne, 2016).

By maintaining an audit trail (Greene, 2014) of my evolving thinking, emerging themes developed. It allowed a way for me to record the process and be able to demonstrate how interpretations and conclusions were reached (Thompson Burdine et al., 2021). Alongside the audit trail, I had regular meetings with my supervisors and asked them to review, challenge, and seek clarification of thoughts, ideas, and interpretations. This provided a way of ensuring that claims made about the data were grounded (Thorne, 2016). During this process I learnt a lot about engaging in reflexivity and how it requires a degree of both social and emotional distance (Greene, 2014). I also discovered that this practice allowed me to think both considerately and critically, and supported my reflecting to move beyond intuitive inquiry to a carefully constructed crafted inquiry (Thorne, 2016). During supervision meetings I was able to talk freely about this process and appreciated the insights and guidance provided by my supervisors which ensured I was actively utilising the required strategies to make sure the study was credible and personal biases were managed.

Data Management

The interviews were recorded digitally and transcribed into text through the 'Transcribe' application/website (<https://transcribe.com/>) using artificial intelligence technology. Once

each interview was transcribed and saved, it was immediately deleted from the 'Transcribe' application. The first interview was manually transcribed. Although it took many hours, it was a worthwhile exercise as it allowed for complete immersion in the data and enabled a reflective practice on how and what questions were asked. This is an approach recommended by Thorne (2016). Following transcription, several hours were spent per interview, going through each transcript while listening to the recording to ensure accuracy and familiarise myself with the data.

A copy of the digital recordings and the transcribed interviews was stored on a password protected computer and backed up on a hard drive. During this process each participant was randomly allocated a pseudonym that was attached to their data. The interview data were shared with supervisors who provided feedback via email and during supervision sessions on refining my approach. For example, I initially found it hard to say 'tell me about your child with CP' because it seemed so broad and general, but my primary supervisor reinforced to me that this was the right approach and that it allowed space for the participants to talk about what was important to them with regards to their child. This was a useful and informative process and helped support a strong interview technique and uncover emerging themes.

Data Analysis

Data analysis using an ID methodology is not a step-by-step approach; rather, a creative and flexible process that allows the researcher to make informed choices (Thompson et al., 2021). There is usually an element of looking for patterns and similarities, deficits and gaps, across a topic. There should be careful reading between the lines not just reading the lines. This enables the researcher to ask questions, listen to the responses, and then make sense of the answers through looking for patterns (Morse, 1994; Thorne et al., 2016). There are a variety of approaches from other methodologies that the ID framework can utilise such as constant comparative analysis from grounded theory (Eaves, 2001). However, the main objective should be to stay true to the epistemological positioning so that epistemological integrity within the ID framework can be achieved. My data analysis was guided by Morse's (1994) cognitive processing framework, the process of which is explained in detail below and summarised in Table 3.

In this study the transcribed interview data were subjected to an iterative, interpretive approach (Thorne, 2009) which allowed knowledge to be inductively generated from within the data and considered in the context of the data (Corbin & Strauss, 2015; Thorne, 2016). Thorne (2008) described the course of analysis as an interactive and iterative process between the researcher and the study participant. It presents an intimate engagement with the data, which affirms rigour and adds validity to the findings. An iterative reasoning process can then be used to make sense of and understand data. Data are concurrently collected and analysed. There will be infinite possibilities in terms of groupings, relationships, and associations which will allow for data to be sorted into a manageable set by using a type of coding (Thorne, 2016). The use of a data software programme for storing data and assisting with storing developing themes was considered; however, it was decided to adopt a more ‘manual’ approach to analysing the data. For example, reading and taking notes in a Microsoft Word document, printing transcripts, and highlighting key themes and quotes, as well as using large pieces of paper to organise and sort themes. A manual approach was chosen deliberately to maintain a close connection with the data. Engaging physically with printed transcripts, handwritten notes, and the large A3 sheets used for thematic mapping enabled me to fully embrace the analytic process and allowed me to intuitively explore patterns and relationships across the data.

Table 3.

Summary of the Data Analysis Process

Step	Description of Activity	Data Sources Used
1. Data collection and initial reflection	Immediately after each interview, field notes were written and reflective journal entries completed to capture first impressions, emotional responses, and contextual details.	Interview recordings, field notes, reflective journal
2. Transcription and accuracy checks	Interviews were transcribed, then reviewed alongside audio recordings to ensure accuracy and make minor edits.	Audio recordings, typed transcripts
3. Immersion and comprehending	Transcripts were read and re-read multiple times; notes	Transcripts, reflective journal

Step	Description of Activity	Data Sources Used
	were made in Word documents and by hand. The reflections in my journal helped deepen my understanding of the mothers' experiences.	
4. Coding and synthesising	Key ideas, quotes, and shared experiences were highlighted and grouped using printed transcripts, colour coding, and large sheets of paper. Themes began to emerge through comparison across transcripts.	Transcripts, notes, visual thematic maps
5. Theorising	Patterns and relationships among themes were interpreted in the context of literature and theory. New questions were asked of the data to test developing ideas.	Emerging themes, research literature, journal reflections
6. Re-contextualising	Findings were considered in terms of their application to clinical practice and implications for supporting parents of children with CP.	Final themes, full data set, research context and intent.

Morse's (1994) cognitive processing framework guided data analysis. This framework consists of four elements—comprehending, synthesising, theorising, and re-contextualising. Comprehending is when the researcher learns everything about the experiences of the study participants through listening, reading, and re-reading the data transcripts. Morse said this process starts at data collection. It was an experience I really enjoyed and was made more satisfying by the opportunity it provided to reflect and improve. As the interviews progressed, and it became common place for the participants to talk uninterrupted for long periods, I found myself able to focus solely on listening and hearing what they had to say. I became more comfortable with watching the range of emotions the participants went through and noticed that as they opened up more, they became more willing to share experiences that upset them. At the completion of each interview and transcription, I spent several hours going through the recording while studying the transcribed data to ensure it had been correctly translated and to make any edits or amendments as required. This

allowed me to both listen to the interview and read the transcript which provided the opportunity to get fully immersed in the data. I then printed out each transcript and put them into a folder for easy viewing. In addition to interview transcripts, I maintained a reflective journal and field notes (examples in Appendix E) throughout data collection and analysis. These provided the opportunity to triangulate my data. They served as another source of insight which helped me to document initial impressions after each interview, decisions made during the process, contextual observations and emotional reactions to participant relaying their experiences. I regularly returned to these reflections and integrated them into the analysis process, particularly during the comprehending and synthesising stages of Morse's framework. For example, they helped me to keep track of my thinking and any assumptions I was making, as well as to refine emerging themes.

The second element, synthesising, is the process of studying the data to extract common features or themes (Thorne, 2016). Once all the interviews were transcribed, reviewed, printed, and placed in folders, I spent hours and hours slowly and carefully reading each one while taking notes on what I was seeing, highlighting sections I thought were important and capturing quotes that felt significant. I took a lot of notes and looked for both shared experiences as well as significant unique experiences. I laid out large pieces of paper and started looking at how I could group the shared experiences (Appendix L). I created summary sheets for each participant, outlining key themes, emotional tones, and contextual factors. These were then used in the synthesising phase, where I began clustering similar ideas across transcripts using colour coding and notes. At this stage, reflective journal entries often helped clarify ambiguous statements or provided context to deepen interpretation.

Morse's third element in the framework is theorising. This is developing 'best guesses' to explain the data findings. At this stage further questions can be asked of the data and in the context of other data and theory (Thorne, 2016). The fourth element, re-contextualising, is the final step where the researcher articulates how the findings could be applied in practice as well as the implications of the newly generated knowledge.

Chapter Summary

This chapter has explored what ID methodology is, why it was chosen for this study, and how it has been applied and incorporated into the study design. Within the explanation of the

methodological approach, I have included information on the theoretical paradigms and philosophical assumptions of ID and how these have been considered, acknowledged, and integrated into the study design. I have discussed the framing of the theoretical forestructure, including information regarding the disciplinary orientation of the study (within the discipline of nursing), my positionality as a researcher, and the evaluation criteria. The evaluation criteria provide a framework to ensure there is integrity, credibility, and robustness applied throughout the study design. This chapter has also detailed how Thorne's (2016) seven assumptions of ID have been considered and applied during the development of this study, and included an explanation of how bias was managed and credibility ensured which is critical to the integrity of the study due to my positionality as a member of the community I am studying. Detailed information on study participants and recruitment, the interview process, data management, and data analysis has been provided. The following chapter presents an introduction to the research findings.

Chapter Four. Presentation of Findings

This chapter provides a description of the demographics and geographical spread of the 15 participants who were involved in the research interviews. This will be followed by an introduction of the findings. The subsequent three chapters will describe the findings in detail.

The Participants

Fifteen interviews were conducted between November 2022 and April 2023. A summary of participant characteristics can be found in Table 4. The participants were all mothers between the ages of 37 and 51 years. Of the 15 mothers interviewed, 14 were the biological mother and one was a stepmother of a child with a confirmed diagnosis of CP. The stepmother had known the child for most of the child's 10 years of life. The participant group culturally identified as: Pākehā ($n=7$), Māori ($n=3$), Māori Pākehā ($n=2$), Pacific peoples ($n=1$), Samoan Māori ($n=1$), Pākehā and other ($n=1$). A Pākehā is a New Zealander of European descent (Moorfield, n.d-b), a Māori is an Indigenous New Zealander of Pacific descent (Moorfield, n.d-a), and Pacific people migrated from the Pacific Islands such as Samoa, Cook Islands, Tonga, Niue, and Fiji (Foliaki et al., 2006, p. 180). Geographically, the majority of participants were from Auckland ($n=8$), then Christchurch ($n=3$), with one each from Wellington, Napier, Nelson, and Whangarei (see Fig. 3).

Fourteen participants were recruited through the CP Kids of NZ Facebook page. The last participant was recruited through personal contacts to ensure the study had adequate cultural representation. This participant was of Pacific Island descent, and the approach was recommended by the study's Pacific Island cultural advisor. More potential participants than the study allowed for indicated that they would like to be interviewed; consequently, the approach was to focus on selecting participants that would ensure a fair representation of the population.

The 15 children of the participants interviewed were all between the ages of 5 and 13 years. Eight were female and seven males. Four were supported by the ACC; 11 were not. The types of CP varied with the most common spastic diplegia ($n=5$) followed by hemiplegia ($n=4$) and spastic quadriplegia ($n=4$). The remaining two were, dyskinetic and triplegic CP. The level of physical disability covered the full range from GMFCS 1 to 5. All children

presented with other issues such as vision impairment, cognitive impairment, sensory challenges, and epilepsy; and were either living with the person interviewed full time ($n=12$) or most of the time ($n=3$). None of the children were present during the interviews.

Table 4.

Participant Characteristics

	Pseudonym	Gender	Age (years)	Ethnicity	Child's gender	Child's age (years)
1	Rebecca	Female	38	Māori/Pākehā	Female	10
2	Kelly	Female	39	Pākehā	Female	11
3	Lisa	Female	45	Pākehā/Other	Male	10
4	Louise	Female	43	Māori/Pākehā	Female	9
5	Michelle	Female	42	Pākehā	Male	12
6	Jennifer	Female	51	Pākehā	Male	13
7	Anne	Female	40	Pākehā	Female	9
8	Julia	Female	39	Pākehā	Female	9
9	Claire	Female	46	Pākehā	Male	8
10	Joanne	Female	45	Pākehā	Female	10
11	Heather	Female	37	Māori/Samoan	Male	6
12	Amanda	Female	40	Māori	Female	5
13	Wendy	Female	46	Māori	Female	7
14	Fiona	Female	51	Māori	Male	10
15	Stephanie	Female	46	Pacific Island	Male	11

Figure 3.

Geographical Distribution of Participants



Introduction to the Findings

During the interviews there was an overwhelming sense from participants that the birth of their child marked the start of a parenting journey that was very different to what they had expected and they were forced to make a significant adjustment to a different way of parenting. From the first interview question, 'tell me about your child', mothers recounted how, like many other parents to be, they had spent years planning for a family and were excited about the prospect of having a child. They recalled having happy joyful pictures in their mind's eye envisioning what this experience would be like. They remembered feeling excited and had clear ideas of all the positive ways having a child would enhance their lives. However, for all of the mothers the story turned out quite differently, and it was evident that this dream had not been realised. Instead, their experiences of becoming a parent had been difficult and required them to adjust, adapt, and find a different way of parenting. This

concept of adjusting to a different way of parenting became the overarching framework that was underpinned by the study findings which fall into three major themes, the difficult start, rowing upstream, and winning but not as expected. These are depicted in the Figure 4 schematic

Figure 4.

Schematic Depicting Themes

Adjustment to a different way of parenting		
The difficult start	Rowing upstream	Winning but not as expected
<ul style="list-style-type: none"> • A complicated labour • The emotional roller coaster of NICU • Receiving the diagnosis • Affected marriages 	<ul style="list-style-type: none"> • Keeping the boat afloat-finding parenting hard • Paddling through the ACC rapids • Navigating the school currents • Lost in the funding stream 	<ul style="list-style-type: none"> • Growth through gratitude • A warm blanket of community support

When I immersed myself in the data, I found myself thinking of the participants' experiences as a journey. I imagined a pregnant mother travelling along a river in a boat with everything they needed for their trip. The water was smooth and the river straight. This depicted a straightforward pregnancy, until it was not (unexpected and early labour). Then there was a sharp turn in the river with rapids appearing out of nowhere, leading to the emotional roller coaster world of the neonatal intensive care unit (NICU). Following this shift, many mothers felt like their boat had capsized and all their carefully packed belongings disappeared overboard. When they found themselves sent home from NICU, alone, they felt like they were left clinging onto the side of the capsized boat. Eventually they were able to right the boat and get back in but they felt confused and disorientated (receiving the CP diagnosis) and did not know where they were or where the river was taking them. This confusion was due to the way many mothers had received the news of the diagnosis which was unclear and upsetting. They found they were no longer on a straight river in calm water but instead on a river with twists and turns and unpredictable rapids and currents. This represents the loss of friendships and disruption (sometimes permanent) to their marriages and marked the first major theme from the study's findings, the difficult start. This theme presents the impacts, trauma, and challenges mothers faced while adjusting to being a parent. During the interviews, when asked to talk about their experience of raising a child with CP, many of the

mothers started from when they went into labour, which was often premature and unexpected requiring an emergency caesarean section. Mothers talked about all the unexpected twists and turns their life had taken when their child was born which included experiencing a complicated labour, the emotional roller coaster in the NICU, receiving their child's diagnosis, and the cumulative trauma of these experiences which, for some, negatively impacted their marriages. These experiences often left mothers feeling unsupported and lost. Many openly talked about the impact on their own mental health and well-being, and described the struggle and trauma that resulted. This information, while not directly answering the research question, provided important contextual information that helped explain some of their later experiences and had significant influence over the parent they had become.

Continuing along the river, mothers were trying to frantically bail water out of their boat while plugging holes (caused when the boat capsized), steering away from rapids and currents, and navigating the unpredictable river. This marked the start of feeling as though they were rowing upstream. Rowing upstream reflected how I saw the parents being. They were navigating life and trying to fill many roles (e.g., parent, caregiver, spouse, colleague) and finding their parenting role hard. This was because suddenly they had to understand and navigate the complicated role of parenting a child with CP which included understanding their child's condition, needs, and how to access support for them from the complex system of disability services. The fixing of holes in the boat to keep it afloat symbolises the managing of appointments, equipment, therapy, and attending to their child's physical and emotional needs. The river was full of rapids which represents battles with ACC. Navigating the school current depicts mothers' struggles at school to be heard and the advocating they were required to do. Lost in the funding stream is where the boat ended up when it came through the rapids and currents. It symbolises the inconsistent and inadequate financial information, support and funding. This was a very difficult time in parents' life with constant work and worry while often living with unresolved trauma from the difficult start. Many were exhausted and felt like their whole life was centred around their child's life and needs. I felt that the analogy of rowing upstream most accurately reflected the struggles, stresses, and burden the mothers felt. They described working against a resistance (current) which came from the health and education systems and led to them to advocating and sometimes fighting to get their child's needs met. They found this

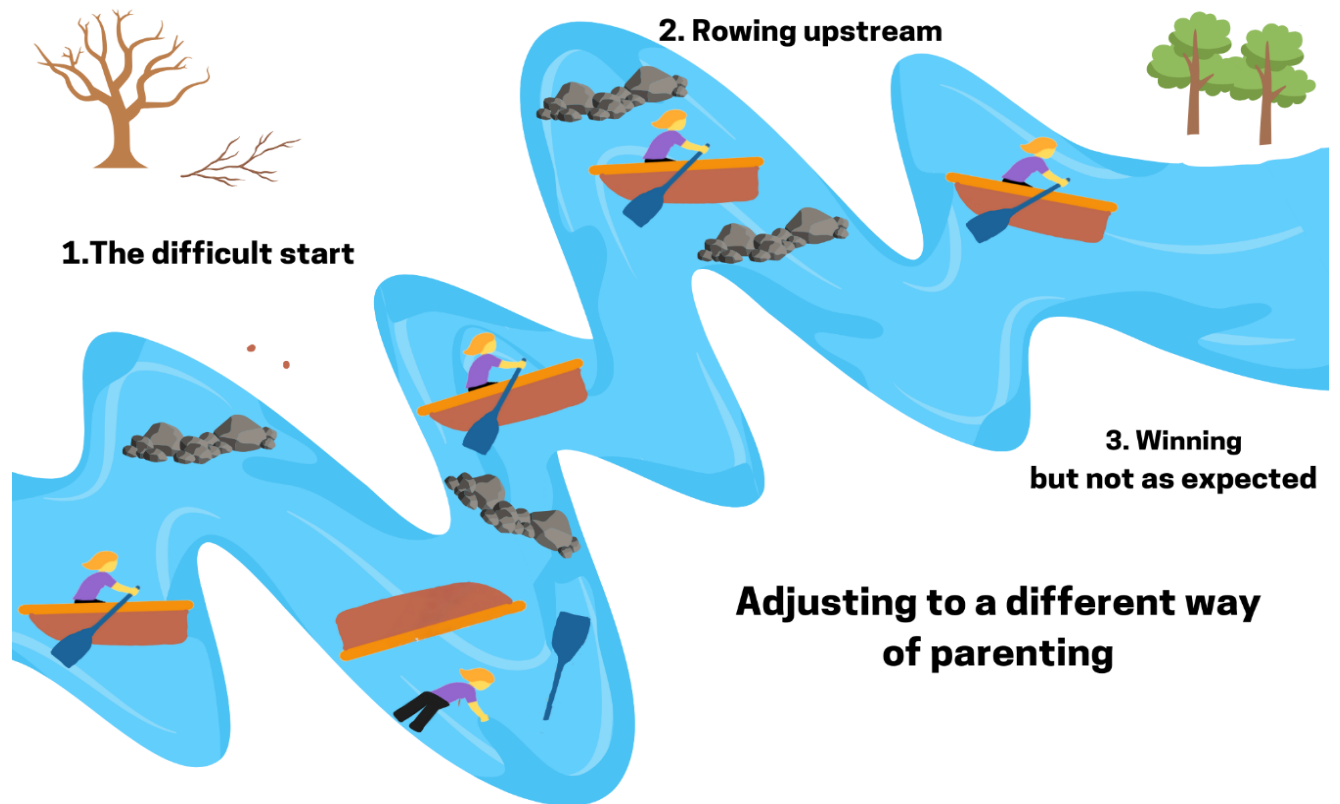
exhausting and often felt lost and let down by the systems that they thought were there to support them. This all required them to adjust to a different way of parenting than expected.

The last major theme of winning but not as expected sees mothers accepting their situation and focusing on the positives. Mothers were becoming more proficient with fixing the holes, and bailing water and had learnt the skills of navigating a boat on an unpredictable river. They were more at peace with not knowing (going with the flow) where they were heading or what the future would hold. They often felt gratitude and pride in both their child for their strength, resilience, and positivity, and also in themselves for the parent they had become and the way they had adjusted to this different way of parenting. This change allowed mothers to experience personal growth and gain new perspectives and worldviews. The change led to smoother water on a straighter river that was easier to traverse. Additionally, many had discovered a warm blanket of community support.

These three themes are depicted as a pictogram in Figure 5. The findings are presented in the following three chapters (one theme per chapter). They reflect mothers' experiences of raising a school aged child who is living with CP in NZ and describe how they adjusted to a different way of parenting.

Figure 5.

Pictogram Depicting Themes



Chapter Five. The Difficult Start

The first theme, the difficult start, provides important contextual information outlining a backdrop of trauma that originated from the moment of birth, where mothers described a challenging start in their journey of becoming a parent of a child with CP. This challenging start spanned from a complicated labour, the emotional rollercoaster in the Neonatal Intensive Care Unit (NICU), to learning of the diagnosis and the subsequent impact on their marriages (depicted in Fig. 6). Although the intention of this study was to focus on the experiences of parents of 'school aged' children with CP, these early experiences provide important background information that represent the starting point of a challenging journey of raising a school aged child with CP.

Figure 6.

Schematic Depicting the Difficult Start Subthemes



A Complicated Labour

The first subtheme, 'a complicated labour', highlights how mothers had assumed their pregnancy would go to full term and the experience of labour would be a 'normal' one. However, for many, the course of events surrounding their labour turned out differently than they had expected and resulted in ongoing trauma as they struggled to process how they had ended up having such a complicated labour experience. Mothers were quick to identify key points in time where things should not have happened in a particular way or where they felt things should have happened differently during their pregnancy. They felt this mismanagement subsequently contributed to complicating their labour. For example, Anne thought she should have been identified as high risk during her pregnancy, an omission she believes led to delays with a timely response to her critically ill baby on delivery.

When I look back at the pregnancy and how many people had seen me because of being sick or were involved in some way, shape or form, that outcome could have been quite different if they had only ticked the box to say that I was high risk and

peds [paediatrics] had been on standby, then it wouldn't have taken the 4-minutes or whatever it was to resuscitate her. (Anne)

Many of the mothers talked about their experiences of unexpectedly going into labour alone at home, usually early (at 24-32 weeks gestation), and then being rushed to hospital in an ambulance where often their baby needed resuscitating, sometimes multiple times. Joanne woke up in the middle of the night at 29 weeks pregnant and discovered she was haemorrhaging. She recalled being rushed to the hospital in an ambulance thinking she had lost her baby.

Everything went pear shaped and I started like twitching. They woke up the clinical director in the middle of the night and they said, you need to deliver the baby. So she came early and they were super worried because on the scan they thought she would only be 900 grams, but she was 1,080 and the kilo was apparently a golden milestone for survival. So, the brain bleed was just unlucky. She only made it because she was in the hospital and they could resuscitate and ventilate her. (Joanne)

These emergency situations during labour had a profound and ongoing impact on the mothers as evidenced by their responses when recounting the stories. Many became emotional and cried as they described these birthing experiences and how unprepared they were for the unexpected events of labour. Some were still living with associated trauma at the time of the interview; yet, they were willing to relive their experience as a way of making sense of it. Jennifer, who had also unexpectedly gone into labour at home, described it as "horrendous." The locum midwife (who she later discovered was very junior) had just visited and told Jennifer that she had a couple more days to go. Shortly after the midwife left Jennifer felt "something wasn't right" and, on investigating, she recalled feeling the gravity of the situation when she thought the umbilical cord was emerging. When the midwife arrived back Jennifer felt more shocked when she saw the colour drain from the midwife's face and "the look of horror when she said it's a foot." Jennifer referred to finding herself in an ambulance with sirens blaring as "pretty hideous." This experience had a long-lasting negative impact on Jennifer, physically and emotionally, so much so that she still experiences feelings of dread and anxiety when hearing the sounds of an ambulance, even in the distance. "Like an ambulance drove up behind me one day when I was driving, I had to pull

over. I just burst into tears. I was shaking. It took me 5-minutes to recompose myself to keep driving” (Jennifer).

The complexity of labour experienced by many of the participants represented the difficult start to parenting and the memories and recollections of this time were still quite raw. There was a strong sense of resentment, anger, and sadness as mothers described feeling vulnerable and lost at a time when they should have been happy. Many did not have an explanation for the premature and/or emergency nature of their labour which added to their unresolved trauma and started them off on the backfoot. For half of the mothers the situation was further exacerbated by the shocking news that their baby was critically ill and required an admission to the NICU for intervention and care, further contributing to their sense of a difficult start to their parenting journey.

The Emotional Rollercoaster of the Neonatal Intensive Care Unit

The second subtheme underpinning a difficult start revolves around the mothers’ rich descriptions of their time in the NICU. Amanda, Jennifer, Julia, Joanne, and Wendy, who had spent time in a NICU, had an additional layer of trauma. Their healthcare experiences at this time became the benchmark by which they measured their subsequent encounters. Soon after their traumatic labour, Jennifer, Julia, Joanne, and Wendy, recounted the experience of their babies being admitted to the NICU. Mothers were not prepared for this unplanned and unexpected stay, which lasted between 1 and 6 months and added to the trauma they had already experienced. Once again, they found themselves caught off guard as they had not imagined this would happen following the birth of their child.

Mothers were shocked and struggled to process the fast-changing and unfamiliar NICU environment in which they found themselves. They were overwhelmed by a range of strong, upsetting, and stressful emotions including loneliness, confusion, worry, hope, loss, and feeling out of control. They found themselves having to trust people (health professionals) they did not know with their baby’s life. Wendy described this time as “like being on an emotional rollercoaster.” NICU was a foreign environment, it was clinical and filled with confusing medical language, strange noises, other stressed parents, and very sick babies. During this time, they witnessed the regular occurrence of neonatal death. This strange environment, and seeing other parents experiencing similar or greater trauma,

compounded feelings of stress and required a considerable adjustment to what they had envisioned for themselves as new parents.

Their baby was born with the same issues as ours, their baby died. During our high dependency time, there were about 22 babies that came in and only four of them including [Wendy's baby] went out. (Wendy)

Mothers often did not know what was happening or whether their baby was going to live or die. This experience was all-consuming, and it left mothers with no capacity to think or focus on anything other than their baby. They lived from day to day in the hope that their baby would survive. For many, there was an absence of adequate emotional and psychological support from either the hospital system or their own support network to help them process the array of emotions they experienced. Years later, at the time of the interview, many were still living with unresolved trauma.

Mothers' perceptions of lack of support came from feeling left alone by staff in NICU who were too busy focusing on and caring for their baby to be able to attend to and address mothers' emotional and psychological needs. Jennifer, Heather, Wendy, and Amanda said this manifested as post-traumatic stress disorder (PTSD) of which the traumatic surroundings, uncertainty, and exposure to a range of distressing experiences all contributed. Jennifer and Amanda both felt their PTSD was increased by the confusing and negative messages communicated by the medical team. For Jennifer it was being told that her son would not survive. For Amanda it was seeing her daughter being resuscitated on delivery and being asked daily by doctors to "pull the plug" on her baby.

That was the real asshole thing about it. So, they bring her back to life and then they basically told me to pull the plug on her. Every person afterwards just pulled me into a room and kept telling me, you need to pull the plug on her. And that's the blunt word, you know, of course they buttered it up with a bit of prettiness, but they basically were saying, pull the plug. Well, life is going to be hard for her. And they didn't just do this once, they almost did this daily to me while I was in NICU.
(Amanda)

Mixed messages from the medical team created anger and conflict for Amanda. On the one hand, the doctors were doing everything they could to save her small baby; on the

other hand, they were telling her to let her baby die. With no one to talk to, Amanda felt distressed, alone, and unsupported in her struggle to understand the situation. Feeling alone in NICU was a shared experience by many of the mothers who felt the focus of care needed to be on saving their babies' lives. However, they would have also liked to be more emotionally supported. Mothers said they appreciated the nurses who kept them updated and spent time explaining what was happening with their baby, but did not feel the nurses had the capacity to attend to their emotional needs. Some mothers were upset with the way the doctors would rush in each morning, throw new terms at them, and then be gone.

The doctor comes in for 2-minutes and they throw some daggers at you to try and catch and then you got to figure it all out. And it's the nurses that kind of coach you through understanding what's just been said. The nurses will give you like first-hand experience; the nurses have always been really amazing. (Amanda)

Mothers' need to navigate and process their rollercoaster of complex emotions, while coming to understand this different mothering role, went unfulfilled, with seemingly no one within NICU able to provide emotional support. When asked if she had been provided social work support (knowing from my own experience as a nurse that this should be offered) Amanda replied that the social workers only seemed to be able to provide meals to take home. While this practical support was appreciated by some, it did not cater for the desperately needed emotional support. Mothers, mourning the loss of the keenly anticipated parental role they had hoped to take on, were left alone to make sense of their new parenting situation. Consistently, the time in NICU represented a sharp departure from what mothers had envisioned as the starting point to their parenting journey. It was where the smooth river water they were on met unexpected rapids, and they found themselves in a scary situation that was out of their control. Several mothers shared that one of the most difficult aspects of being in the NICU was not knowing what to do, especially because they could not easily touch or hold their baby. Wendy described this as an incredibly difficult part of the NICU experience: "You can't hold your baby for what in essence ended up being 27 days (crying). When you do have your first hug, you're so scared, she doesn't even look like a normal baby."

Mothers who lived locally to the NICU, such as Joanne and Wendy, still felt the pain of not being allowed to stay overnight. They had to leave their baby and go home each evening not knowing if their baby was going to make it through the night.

It's like when you come in in the morning and the nurses are like, she had a lot of episodes last night, we had to resuscitate her three times and that was most days.

So, it was difficult going home from the hospital without your baby. (Wendy)

Coming into the NICU in the morning and hearing this kind of news was heart wrenching and further exacerbated the emotional rollercoaster they were on during this time. Wendy found herself in a constant daily state of worry and hope. Hope that her baby would survive and worry that her baby would die; something she witnessed happening to other babies daily.

While the time in NICU was without a doubt an emotional rollercoaster and contributed to the difficult start, mothers were able to retrospectively reflect on positive aspects of their time in NICU. It was remembered as being the best possible place for their babies and they were grateful for the high standard of clinical care received. Mothers took comfort from staff expertise, many citing the nurses as being skilled and attentive to their baby's needs. Julia described the clinical skill and expertise to save tiny lives as "amazing" and credited her daughter's existence to the NICU healthcare team. While Joanne reflected, "We had this whole amazing secret world that I never want to go back to again, it was probably the best healthcare we've had in the entire experience."

Joanne's reference to NICU as probably the best healthcare that she had experienced is significant in the context of the frequent hospital appointments and admissions that she has attended throughout her 10 years of mothering her disabled child. Never wanting to go back reflects the traumatic nature of having a critically ill baby in a foreign environment where there is limited ability to influence events.

This section has highlighted how difficult the experience of being in NICU was for mothers. While they felt their babies received the best care and credited staff with their baby's survival, they were left feeling traumatised in the absence of any meaningful support to help navigate and process complex emotions and adjust to a different way of parenting than expected. At some point during this rollercoaster ride another challenge presented itself when mothers discovered that their child had CP. This discovery consistently occurred

in a casual and delayed way that resulted in additional stress for mothers. Receiving the diagnosis is presented as the third subtheme contributing to the difficult start.

Receiving the Diagnosis – ‘What is Wrong with my Child?’

Mothers’ experience of receiving the diagnosis of CP for their child was emotionally taxing due to the significant variation in timing, manner of delivery, and absence of support from those who delivered the news. Some, like Julia and Michelle, who had spent time in NICU, had received the diagnosis within the first few weeks of their child’s life. For others, the diagnosis came at different stages within the first 4 years, often through interactions with doctors, therapists, or other specialists, either in person or over the phone. Many mothers expressed dissatisfaction with the casual and offhand way in which the diagnosis was delivered, which often lacked empathy, came with minimal information, and was devoid of support. Heather received a phone call while with her son at another medical appointment which she found very upsetting.

To be honest, at that time, I didn’t know what CP was. Then as soon as I heard, I was completely shocked. I was like, please, Lord no... and to hear the results of the MRI [magnetic resonance imaging] over the phone when I was in another appointment, it was just quite surreal. I didn’t appreciate being told over the phone. (Heather)

Mothers described their frustration about having to directly ask doctors or therapists for clarification when they noticed unexplained variations with their child’s developmental milestones. They articulated how they had to be the initiator, how they had to keep asking the questions such as ‘what’s wrong with him?’; and for some, who had proactively researched, ‘does my child have CP?’. Claire recalled receiving her son’s diagnosis at a paediatrician appointment that she had requested. She arrived with her 10-month-old son unaware that other health professionals (e.g., occupational therapists and physiotherapists) had also been invited. She had not taken her husband as she was not expecting to receive such significant and upsetting news.

And then they said, “oh we don’t want you to panic, but we think, no we know that (son) has got CP.” And I mean, I didn’t know anything, I drove home thinking, I don’t know if I should laugh or cry, I was numb. I didn’t know how to feel and because I was on my own, a lot of it went in one ear and out the other. (Claire)

Hearing the news about her son in this way was overwhelming and profoundly affected Claire. She was blindsided by the situation of spending an hour with unfamiliar health professionals and felt unsure of what to do afterwards, especially since the paediatrician advised against using Google, citing the highly variable nature of CP.

However, the language used by health professionals often left mothers confused and searching for answers, with some turning to Google for information. Those that searched Google were left feeling shocked, worried, and filled with questions with no one to ask for clarification and support. Many described being given the diagnosis and then left on their own to work out what it meant and what to do.

So, the lady (specialist) there just had a look, she was just observing, asking questions, and then straight away she just said, I think your son has CP, and we looked at each other and thought, I've heard this word before, but I don't know what it is... then she tried to explain it to us, but when she did, I didn't really understand. She was using big words and stuff and so I had to go home and Google it. And then that's when I knew, I was like, oh no, this is what it is. And I was worried, you know... we didn't get any support. (Stephanie)

Several mothers were initially told their child's disability would be more severe than it turned out to be, leading to significant distress. Jennifer, for instance, was initially informed in the NICU that her son would be in a "vegetative state" requiring suctioning every 15 minutes, to then be told the best-case scenario would see him in a wheelchair. Her son now walks unaided and attends a mainstream school.

These narratives illustrate the variation in experiences that mothers had with learning of their child's diagnosis and a consistency with the lack of support to understand what the diagnosis meant. These factors added to the list of challenges mothers encountered and contributed to the difficult start they experienced of being their child's mother. Many said they were left in the dark about their child's prognosis and future which tested their trust in the health system. They were quick to offer up suggestions for how the delivery of the diagnosis could have been better. They would have appreciated a more empathic, caring, and considerate approach, along with written information on CP and details of how to access ongoing support.

I got a generic pamphlet. But honestly you get this diagnosis and you have no idea what to do about it. I always thought, man, if the doctors worked alongside the Cerebral Palsy Foundation and the Brain Injured Children's Trust or places like that. And if the doctor said, "look, your daughter has suffered a serious injury which is leading to CP. I know it seems scary but there's a few different societies out here and Facebook groups that will actually help you and this is the kind of funding that you might need." It's like they need a little intro pack, as opposed to, you know, a pamphlet of what CP is. (Amanda)

For many mothers, the news of the diagnosis, coupled with earlier challenges, had a significant negative impact on their marriages with a substantial number breaking down. Affected marriages is the fourth and final subtheme, contributing to the difficult start.

Affected Marriages

The early years of having a child with CP were layered with disruption, stress, and the burden of unresolved trauma from difficult labours, time in the NICU, and delivery of the diagnosis. Some had additional layers of stress with struggles to get pregnant, miscarriages, and one mother losing a baby at full term. These situations left mothers feeling vulnerable, fragile, alone, and marked a period of their life that was very difficult. Many attributed these difficult experiences as impacting their ability to adjust to a different way of parenting than envisaged and causing the breakdown of their marriages. Mothers talked about discovering that they were "quite broken inside" (Wendy) from all the preceding experiences. While in NICU they had found themselves in a state of survival with all their energy focused on their often critically ill baby at the expense of their marriage. "You become this crazy mum warrior where you think you've got to take on the world to help your child and dad just gets pushed to the side" (Amanda). For mothers in NICU, like Amanda, not being able to actively care for and mother their babies as expected led them to become a laser focused "crazy warrior mum" who spent all their energy intently focusing on what they could do for their baby. The NICU environment highlighted just how little fathers could do and the limited capacity mothers had to support and acknowledge fathers. This tense situation contributed to major disruption in many marriages.

I didn't have room for empathy over what he couldn't do because I was having issues about what I couldn't do (crying), you know, I couldn't touch my child without getting told off. So, my focus was not on my marriage at all, and then it just ends up being a very cold place for him. (Wendy)

Several mothers who experienced depression and/or PTSD revealed that the birth of their child negatively impacted their husband's mental health. This was either due to the child's difficult start and disability or because of the mother's response to the situation which often left husbands feeling unsure of their parenting role and/or ignored by their wife who had no capacity or energy to attend to their marriage. This resulted in marital disharmony and breakdown.

With the amount of support that I gave her (child with CP) and what she needed, I couldn't give that to him (husband) anymore. And he has suffered from depression for years. And just that lack of support from me because I was putting it into (her child) kind of destabilised our relationship quite a lot. It's tough because I think a huge part of it impacted my marriage. I'm divorced now. (Julia)

This situation led some husbands to revert to unhealthy coping mechanisms such as drug and alcohol abuse. There was added complexity for couples who had already been dealing with other unresolved trauma previously mentioned, such as struggles to get pregnant, losing a baby, and the death of close family members. All these factors compounded, negatively impacting their relationships and ultimately contributing to the demise of marriages, as surmised by several of the mothers. In many of these cases, the birth of their child with CP was the tipping point between coping and not coping for both parents. Mothers whose marriages permanently ended all found themselves having to make another difficult adjustment into the world of carrying the majority of the parenting responsibilities and in a separate abode to the other parent. This led to further work, adjustments, and emotional turmoil for mothers who felt resentful and let down by their child's father. These narratives illustrate mothers' struggles with navigating the challenging start of their child's life and how these variables impacted and contributed to tension and breakdowns in their marriages.

It (the birth of their child with CP) definitely pushed him (Dad) to another level, it was a trigger, and then I think he just got progressively worse, it's a thing. I know lots of mothers who are now single mums. And honestly the stress in the system as well, the stress of the hospital care, the Ministry, all of that, the funding that gets intense and you just become this ball of anger, you're just constantly frustrated and in a trauma state. Then seeing all the things that are so unfair and the differences between ACC and MoH, what a huge difference that is. And the struggle that people have just to get ACC. Like it's constant fighting. Then you bring that home and you start fighting with your partner and they kind of leave you to it. (Amanda)

In a few cases there were positive relationship outcomes with marriages that had experienced significant disruption but were later able to repair and strengthen. Some mothers whose marriages came back together described their relationships as being reestablished on more solid and reinforced foundations. In these cases, the husbands had been absent from the family home for over a year, with the mothers identifying the stress of raising a child with CP as a key factor contributing to the breakdown of the relationship. They also identified additional factors, such as the use of drugs and alcohol as a coping mechanism, and past unresolved trauma, as underlying issues that led to the relationship breakdown. Mothers described marriage reconciliation as occurring through hard work with help of external supports such as the Family Court counselling and unique circumstances like the COVID-19 lockdowns. For example, Joanne credited the structured guidance and support from the Family Court as pivotal in creating the conditions necessary for healing and reunification, "We got really good support from the family court who put us with a psychologist. We had 12 sessions and it was really good." Wendy's marriage, which broke down following the traumatic premature birth and prolonged NICU stay, came back together during the COVID-19 lockdown. This period provided the space and time needed for reflection and reconnection, allowing the couple to repair their relationship and ultimately emerge stronger than ever.

Our marriage is in the best place that we've ever been. And probably 2021, funnily enough during COVID (laugh), is probably when we ended up working through a lot of that. Because you're kind of stuck. So, I think COVID did a lot of positive things for

our family (laugh). It helped us grow in that sense and become more emotionally aware and care a little more. (Wendy)

One mother described how moving from a big city to a more rural location offered their newly reunited relationship a much-needed fresh start, which helped them to leave behind some of the pressures and negative influences of the past.

Summary

This chapter explored the theme of a difficult start, a critical period that shaped mothers' perceptions and experiences of raising a school-aged child with CP in NZ. The interviews revealed a shared experience of having to adjust to a different way of parenting with four key subthemes emerging: a complicated labour, the emotional roller coaster of NICU, receiving the diagnosis, and affected marriages.

Many mothers faced an unexpected and challenging start, with premature labour, emergency caesareans, and the overwhelming experience of having a fragile baby in the NICU. While they felt their babies received good care, most mothers felt emotionally unsupported and were left to navigate a rollercoaster of feelings on their own. Nurses provided some assistance but the emotional toll of these early experiences was often left unaddressed, leaving lasting effects on their mental health. The diagnosis of their child's condition was frequently delivered in an unsupportive manner, deepening the sense of isolation and trauma. For some, these layers of distress contributed to the breakdown of their marriages, adding to the complexity of their parenting journey. This scary and uncertain beginning into the world of mothering was a traumatic, difficult, and exhausting start to their parenting journey. For many, this time in their lives had a profound effect both on the mothers' physical health and their mental health and well-being. Overwhelmingly, the difficult start required them to adjust to a different way of parenting.

The next chapter presents the theme of rowing upstream. It explores both the work and worry mothers experience when parenting their child with CP along with the fighting and advocating they do to get support for their child and themselves.

Chapter Six. Rowing Upstream

The second theme, rowing upstream, represents the mothers' ongoing struggle while parenting their child with CP. This theme deepens the concept of adjusting to a different way of parenting, highlighting the complex, emotionally demanding, and often overwhelming journey these mothers undertook.

The metaphor of rowing upstream effectively captures the challenges and resistance mothers encountered as they attempted to understand and meet their child's needs within a complex and often inadequate system of disability services. Mothers described feeling overwhelmed by a parenting role that had become increasingly complicated, likening their efforts to pushing against an invisible force or struggling against a strong current. This continual resistance compelled them to advocate, and sometimes fight, for their child's needs, leaving them feeling exhausted, disillusioned, and let down by systems they had expected to provide support. Four subthemes illustrate different aspects of this struggle: keeping the boat afloat, paddling through the ACC rapids, navigating the school currents, and lost in the funding stream (Figure 7).

Figure 7.

Schematic Depicting Rowing Upstream Subthemes



Keeping the boat afloat encapsulates the stress, exhaustion, and burden mothers carried, as well as the persistence and strength required to keep going. Mothers revealed that they found parenting their child hard due to increased and ongoing dependency to meet their needs. Managing therapy appointments, specialist care, emotional support, and day-to-day logistics was likened to plugging holes in a boat to keep it from sinking. The second subtheme of paddling through the ACC rapids reveals the challenges and struggles of eligible families to get their ACC applications for funding approved. The third subtheme, navigating the school currents, highlights the struggles and advocating required by mothers in the school environment due to the change and reduction in government support that

occurred when their child started school. The final subtheme is represented by mothers working hard to plug holes and steer their boat through rapids and currents only to find themselves lost in a stream which symbolises the confusion and challenges they faced with understanding inconsistent and inadequate financial support and funding. Mothers revealed that there is no single source of truth when it comes to financial support and government funding. Together, these subthemes illustrate the continual work, worry, and burden of responsibility mothers felt, and the constant battle and advocacy required in caring for and supporting their child's needs. Many were exhausted, still living with unresolved trauma from the difficult start and felt like their whole life was centred around their child's needs. This situation required them to adjust to a different way of parenting than expected.

As background to this chapter, it is important to understand that the mothers interviewed were experiencing two types of upstream currents. One upstream current represents those supported by ACC. This current was not as strong and had people alongside to support progress and ensure an easier journey. The second current represents those under the government disability support services or DSS pathway who felt less supported and had to work harder to make less progress.

Keeping the Boat Afloat

Within the context of the difficult start to their child's life, and subsequent challenges, many mothers became aware that parenting their child was much harder than parenting non-disabled children and required considerable adjustment.

It's hugely different, it is a lot more time consuming. It is a lot more isolating than a normal parent. It is a lot more complicated to know what's going work for your child and you spend a lot of time advocating for your own child or having to pay for things. You are very much dependent on finding a lot of the answers yourself. (Anne)

Mothers noted that parenting their child with CP required more from them and they felt the weight of having to constantly understand their child's often changing needs to identify and provide appropriate timely support.

Mothers, primarily those not supported by ACC, described spending time researching their child's condition and needs with little or no help, and having to go into battle to obtain the support they believed their child needed. This was exhausting, hard work, not always

successful; and left them feeling resentful, alone, lost, and let down. I likened this situation to trying to keep the boat afloat while bailing water, fixing holes, and rowing upstream. The only way they felt they could be heard and access support for their child was by being a squeaky wheel or going into battle. “Because I believe that you’re responsible to make sure that they get the best support that is out there for them. And that’s not forthcoming unless you’re a squeaky wheel, and it shouldn’t be like that” (Jennifer).

All of these challenges contributed to mothers feeling their parenting role was harder. They talked about the constant challenge of finding a balance between being their child’s carer, mother, and also being their own individual person with needs and desires. They became emotional when relaying how vastly different and harder their parenting experience was to what they had expected. There was a sadness in their voice when they talked about feeling as though they were missing out on being the type of parent they had imagined; for instance, missing out on parenting experiences such as family bike rides, bush walks, career opportunities, and/or being able to re-enter the workforce. Mothers felt isolated both physically and emotionally because of their child’s disability. For many, a large part of their life involved juggling their time between multiple responsibilities such as the usual family and parenting responsibilities, work, and the additional demands their child with CP required as caregiver, therapist, and case manager. These latter roles involved doing things such as personal care, home goal-based therapy, and administrative tasks related to their child’s disability. They found these additional responsibilities hard. Family life was often carefully planned around managing the multitude of therapy, specialist, and hospital appointments; researching their child’s disability and needs; applying for funding; and managing paid carers.

Mothers attended to the daily, often complex, physical needs of their child and were constantly adjusting their schedules depending on their child’s needs on the day. This impacted the rest of the family who had to accommodate and fit in, and required additional time and energy from mothers which they felt took them away from other family commitments: “Our entire life, our whole family life revolves around (child) and I just can’t seem to figure out a way to get balanced, her needs dictate everything” (Joanne).

Many described how finding time to relax was impossible. If they were not actively helping or supporting their child, they were thinking about and planning what they needed to do next. Joanne described it as always needing to be “on” and “ready” to accommodate

and support her child as required. She referred to managing this additional cognitive and physical load as being equivalent to more than a full-time job. “It’s more than a full-time job... and that’s not even with her, just the advocacy, sorting out equipment. The visits for equipment are just mental because she's always growing out of things” (Joanne).

Some mothers of children with more significant physical disabilities felt another aspect of parenting that was particularly hard was thinking about the future. Their worry was threefold. Firstly, they had come to a sobering understanding that they were always going to have a dependent child that would need a lifetime of care; “We’ve suddenly come to the realisation that we are never going to be free of each other. There’s no 24-hour support for people with disabilities” (Joanne). Secondly, they were concerned about how they would support their child’s increasing physical needs (i.e., showering, toileting, feeding, and mobilisation) as they got older, bigger, and heavier. Lastly, they felt uncomfortable with the uncertainty of who would care for their adult child in the future if they were no longer able or not around to do so. These three concerns and worry about the future elicited an emotional response with many crying as they realised how much harder parenting might get for them.

Mothers coped with the hardness of parenting in a variety of ways. For some this was using alcohol and cigarettes; others found relief with anti-depressants, counselling, and talking to friends and family. Several mothers, after using some of these coping mechanisms, turned to exercise which they found gave them a new sense of purpose and helped alleviate some of the pressure they felt.

My walking has really helped my mental health. When I started walking it was just to get out of the house. And then I started doing hiking. And then I started setting goals, that has really helped my mental health and to also physically release any kind of tension and aggression that I have. (Amanda)

This subtheme has highlighted how mothers felt parenting their child with a disability was much harder than parenting a child without a disability. They experienced it as exhausting and like having to row upstream while bailing water and fixing holes in the boat. The main reason cited for feeling like this was the child’s complex needs and dependency on them. Mothers whose child met the criteria for ACC funding experienced another layer of difficulty with having to spend significant time and energy to get their application

approved—this is presented in the following subtheme of paddling or battling through the ACC rapids.

Paddling Through the Accident Compensation Corporation Rapids

The second subtheme, paddling through the ACC rapids, continues to reflect the worry and work mothers experienced, and the significant fighting and advocating that was required regarding ACC. Mothers with children on the ACC pathway felt considerably more supported once approved for funding; however, while awaiting approval they experienced significant stress, worry, work, and fighting due to the prolonged and arduous ACC application process. The energy expended was likened to that required for rowing a boat upstream and through rapids. Amanda, Jennifer, Anne, and Kelly, whose children had received their head injury and subsequent disability from an accident or treatment injury, were eligible for ongoing care and support through ACC. While their children all met the strict ACC criteria, the process of being accepted took significant time and resources. Many of the mothers interviewed were informed that it was common knowledge for ACC applications to be declined at least once, if not twice, in the hope that applications would not be resubmitted. This was frustrating for mothers whose claims were initially rejected despite their medical teams admitting fault at birth. “We did an application, it got declined. I did this random therapy class and they said oh ACC always declines in the first instance in the hope that you can’t be bothered to fight” (Amanda).

Amanda and Jennifer spent years fighting ACC, which caused stress and anxiety and had a negative impact on their mental health and well-being. Both mothers revealed either they or their husbands worked extra hours or jobs to fund the battle to get their ACC claim approved. Jennifer eventually found energy and inner strength from another mother who had gone before her, and who helped Jennifer navigate the process. She connected Jennifer with lawyers who worked pro-bono and eventually won the case for her through the High Court. These experiences were overwhelming, disempowering, all-consuming, and made mothers feel as if they were constantly battling and rowing upstream. However, they persevered because they were acutely aware of the substantial positive difference that being supported by ACC would have on both their child’s quality of life as well as their own. Mothers gained this knowledge through hearing about and talking to other parents whose children were supported by ACC. Unfortunately, battling ACC often occurred at the expense of ensuring their child had adequate support and therapy while they were waiting for

approval. However, when they finally received ACC approval, mothers felt relieved and considered the battle worthwhile despite the high personal cost, “he’s on ACC for life, which is why I didn’t give up” (Jennifer).

Mothers with children supported by ACC were satisfied with the resources, equipment, and therapy their child received, as well as the support from their ACC case manager with navigating the system and coordinating care. They felt supported to understand available services, identify their child’s needs, and access appropriate assistance for their child. They attributed this support to providing their child with more opportunities to thrive. Those mothers who had spent time without ACC support unanimously felt the relief of no longer having to worry and fight. All these variables significantly improved daily life for these families. Amanda commented on the differences between the two systems and the advantages of being supported by ACC.

It was a huge difference, this is what was ridiculous, the MoH (DSS pathway) compared to ACC, we would see our physio maybe once every 8 weeks if we were lucky, and then once we were on ACC we see them weekly if not twice weekly and we’ve got them at our beck and call. It’s such a huge difference between ACC and MoH. And you know what? I feel really sad about that because I think of all the premmy [premature] kids or the kids who’ve got CP who aren’t on ACC, they’re always going to be on the back foot. (Amanda)

Mothers such as Joanne, Julia, Wendy, and Michelle, whose children were not supported by ACC, were envious of families that were and noted the stark difference between the support pathways and subsequent inequities. They observed children from families funded through ACC with similar levels of disability who were better supported both emotionally and physically. These mothers saw families who, unlike them, did not have to struggle with variables such as navigating the complex system alone, getting support when needed, and accessing therapy and equipment according to their child’s needs, as opposed to what was available. These mothers noted ACC supported families were able to get things such as two sets of certain equipment; for example, a standing frame so one frame could stay at school making day to day life easier. Joanne, Julia, and others longed to not have to fight for equipment or be left to work out what was the best support for their child. While they understood the health professionals providing support in the public system were doing

their best in a strained and under resourced environment, they perceived the gap between them and their ACC funded counterparts as significant, inequitable, and unfair, with their child missing out on care, opportunities, and better outcomes because of the way their CP had occurred. Mothers struggled to understand why the system was set up in such a way.

The big problem for me is the inequity between the two systems (pathways). So our equipment is really good. My daughter has good equipment, but she only has one set of it. So that means we have to transport everything between school and home. Now she's 10, her standing frame and her walker, they're massive. You can't transport them. If we're under ACC, you get two sets of equipment because it's not safe to transport it. But under MoH (DSS pathway) you don't, you get one set of equipment, like that's a big inequity that leads to bad health outcomes. (Joanne)

Several mothers were battling guilt in the knowledge that while they thought their children would qualify for ACC, they did not think they had the energy or capacity required for the fight to obtain it. However, some were beginning to realise they may no longer have the choice as their child grew bigger, their needs increased, and they found it more challenging to provide the required care.

This section has highlighted the significant battles that mothers experienced with getting their child's ACC application approved and how it made them feel as though they were paddling upstream and trying to get away from rapids against a strong current. Once ACC funding was gained, the rapids dissipated and the upstream current waned, resulting in relief for mothers. Having ACC approval led to mothers feeling that themselves, their family, and child, were better supported and had better access to care and equipment. Mothers of children not supported by ACC noted significant inequities in the system and continued to face strong upstream currents. All the battling, stress, and energy used to paddle upstream required mothers to adjust to a different way of parenting than expected. The following subtheme presents the experiences mothers had when their child started school.

Navigating the School Currents

The third subtheme, navigating the school currents, was generated when it became clear during data analysis that the relationships, connections, and challenges surrounding school experiences marked a profound period of change, adjustment, and disharmony. Mothers

whose children were not supported by ACC talked the most about the transition to school in relation to the change in disability related government support. They described how the application of government support within the mainstream school environment occurred in a variable and inconsistent way and felt mainstream schools were not set up, nor staff adequately trained, to accommodate children with CP.

From the time I've had her and realised the complexities of the health system and then the complexities of the disability and trying to understand things, has made me realise how little our teachers actually have the knowledge, skills, and experience of disability. (Anne)

The start of school was a challenging transitional period for mothers who had spent the first 5 years of their child's life being their therapist, caregiver, and case manager, navigating the system, accessing support, and managing appointments. The transition to school marked mothers' realisation that disability support would be different. Funding and therapy previously provided by the MoH would now be managed by the MoE, which resulted in a noticeable shift to a different and often reduced level and type of assistance than they were accustomed to. MoH support received during the pre-school years had been holistic and empowered parents to enhance the overall well-being and quality of life for their child. Through the MoH, mothers had received support for their child in the form of regular therapy sessions and access to a variety of health professionals (i.e., physiotherapists and occupational therapists) who focused on enabling their child to achieve key milestones and independence. In contrast, MoE support was narrow with a focus on enabling children to access the school educational curriculum. Many mothers were caught off guard by this change and did not immediately grasp its significance. They felt confused, stressed, and worried as they struggled to understand and adapt to this new approach and the different type of parenting required. All these emotions led to them feeling like they were in a constant state of pushing against an invisible force or rowing upstream.

Once my daughter turned five, she was just abandoned by therapists. And I am pragmatic. I know that the health system cannot meet every need, it has to be rationed, that's just life, but to get no therapy from five and to be told like this is it. (Joanne)

Mothers such as Joanne, Julia, Fiona, and Lisa described how the focus on accessing the curriculum did not acknowledge the importance of providing support for other critical needs such as physical (including equipment, toileting, eating); emotional; and social support (forming friendships and playing at break times). An example was articulated by Lisa who described how her son really needed support connecting with peers and developing friendships. He found it challenging in his wheelchair; “it’s just too hard to keep up” (Lisa) with other children. However, this issue was not considered a priority or within the scope of provision for support at school.

Mothers also admitted to being unclear and even confused about what MoE support was available and often what support their child was receiving. They described the rules and criteria for MoE services as ambiguous or lacking. This situation reflected the underlying confusing messaging and often unclear communication from both schools and MoE workers. Several mothers believed that their children would qualify for a higher-level of MoE support; however, their applications were declined citing that their child was “not bad enough” or that there were “no staff available” or that “their child simply didn’t qualify.”

We can’t get any physio through the hospital because apparently, he doesn’t qualify. According to the MoH we don’t meet guidelines because he is also ORS [ongoing resourcing scheme] funded. But the ORS funding doesn’t cover regular physio because the ORS funding is to help him with his education at school not physio. So it is that catch 22 and that’s for a high needs child. (Anne)

This situation left mothers feeling frustrated as they had to fight and advocate (row upstream) for academic support and equipment they believed should be available at school, such as assistive technology, mobility equipment, and teacher aids. Often there were significant unexplained delays; for example, Anne was still waiting for a headset she had requested 3 years previously to support her child at school. There was a strong sense that firm advocacy was required to ensure their child was adequately supported and set up to have a positive school experience. Such advocacy was constant and unrelenting.

Joanne struggled for months with school staff who were not trained to use a hoist to enable her daughter to spend time out of her wheelchair. She had to actively seek out a hoist trainer to teach staff when the school was not forthcoming. Delays with this situation led to her daughter not being moved from her wheelchair for long periods and subsequently

sustaining a skin infection. Joanne, Julia, Wendy, and Michelle were disheartened knowing that more dedicated support could greatly alleviate their child's challenges. Julia and Joanne were further frustrated that their children were only supported to be in the classroom as opposed to being supported to learn and progress academically.

I think at the moment the 15 hours support that she gets means that she can participate. If she was on high/very high funding and had more hours (of support) she'd be able to have an education. (Joanne)

Mothers felt disempowered, ignored, and not acknowledged for their expertise. Mothers, like Michelle, Joanne, Julia, and Fiona, wanted to remain actively involved in their child's education as they were during the pre-school years, including being treated as an essential member of their child's team and recognised for their expertise. However, once their child started school, mothers discovered a clear mismatch between the school's expectation and their own. They found themselves excluded from important conversations and meetings at school including goal setting and educational planning for their child. This resulted in plans and goals that mothers did not consider entirely relevant or a priority.

Prior to school everything is about teaching me, so I become an expert. Then you start school and you're like nothing. Like all that knowledge is just left with me. There's this whole new team, new learning assistants, new teachers, new physio, new occupational therapist and they're like, oh we've got this. We will do it our way, and they don't even acknowledge that you have that knowledge. So, the health system teaches me to be my daughter's main therapist and then you start school and you don't even have a voice at the table. Everything just kind of happens to you and it's really disempowering. (Joanne)

Mothers believed their only recourse for adequate school support was to be a squeaky wheel or find another school. Mothers admitted to feeling upset and deeply exhausted by the constant need to row upstream against a strong current. For some it meant they had to consciously select which "battles to fight" (Wendy) in order to ensure they had the energy required to advocate for their child's most important needs. Some mothers chose to move their child to a different school, spending significant time, work, and energy finding the right school for their child. Julia, Joanne, Heather, and others had gone through this process, sometimes several times, in a quest to find the best school for their

child. This included ensuring factors such as good communication, inclusivity, collaboration, adequate teacher aide hours, ability to provide assistance with activities such as toileting and socialising, as well as a wheelchair and hoist friendly environment were available. Julia moved her daughter through several schools before she found one that was acceptable; she reflects on her experience:

My heart feels heavy when I say it but we've got this incredible health system where we intervene and we've got this crap community system where we just don't help them anymore. We don't pick it up at school, like all the stuff they've done in NICU to save her life is phenomenal. Like mind-blowing that they saved this kid with the amount of crap that she had going on. But they can't top her hours up at school so she can learn you know and like we have to fight for basic access to toilets. Like this is the split that I just don't understand. (Julia)

Overall, the mothers of children with ACC funding did not report the same degree of rowing upstream or having to be a squeaky wheel. In general, they were much happier with their school experience. However, several mothers disclosed incidences where communication had broken down which led to upsetting situations. A powerful example was given by Kelly whose daughter had gone to school camp without her needs being accounted for or accommodated. This event had a significant impact on her daughter creating "huge anxiety," trauma, and subsequent fear of school trips.

Two years ago when she went to camp, they didn't take [her disability] into account, you know, that she needs the extra help. So when it came to shower time, they just left her to it and she nearly fell over. And then when it came to helping her get dressed and needing the extra hand they didn't help. They wouldn't let her do activities because they didn't want to push her up in her wheelchair because it was quite a way away and they said it'd be too hard to do it. So they left her out of the activity. (Kelly)

Louise and Amanda, whose children attended schools exclusively for those with special needs, expressed contentment with their relationship with the school and support provided. While such schools appeared better suited to meet their children's needs, many mothers, such as Joanne, Julia, Joanne, and Heather, believed in their children's right to attend mainstream schools. This came from a strong belief that their child had just as much

rights as the next child to be included and treated as a valued member of both the school community and society. However, they found the lack of communication, support, and funding to be both frustrating and distressing.

I was adamant she needs to go to a school within her community. She's smart. I really thought about special schools, but cognitively she's fine. Her friends at school are friends she's had from daycare when she was two. I think you belong in your community. That's not a disservice to other people. Everyone's situation is different, I just think kids should go to the local school. (Joanne)

These narratives reflect how government support through the MoE in mainstream schools for those not supported by ACC is inappropriate or inadequate; and how collaboration, partnership, and clear communication is missing. As a result, mothers felt disempowered, upset, and lost, with the only options of advocating, fighting, or moving schools. While mothers of children supported by ACC were at an advantage, their experience still identified room for improvement with school communication. Mothers of children at special needs schools were happy with their school interactions and experiences. The fourth and final subtheme presents the wider issues around financial support and government funding.

Lost in the Funding Stream

The fourth and final subtheme of rowing upstream, lost in the funding stream, describes how the funding information and financial support for children with CP was complex and variable, with mixed messaging and poor information. This situation contributed to mothers having to adjust to a different way of parenting as they had not anticipated having to manage disability related costs or rely on government funding. While all mothers received some sort of financial support from the government, those with children not on ACC commonly considered it as tokenistic and inadequate to cover disability related expenses. Many mothers also commented on the additional administrative work required to manage factors such as paying for carers and claiming for carer support.

So you've got to manage that (carers). You've got to be the employer and manage and do the HR. It sucks. Every second Sunday I sit there for 2 hours and do the

payroll and I just get mad that I'm working for free. I think it's really unfair. Because if there was an agency, someone would get paid to do that job. (Joanne)

Mothers were also frustrated and disheartened by receiving fragmented information regarding funding and financial support which led to gaps in knowledge about available support for their children. Mothers described how they often felt uncertain about whom to ask or what questions to pose. They stated the implications of not knowing or finding out little pieces of information over the years had a direct negative impact on their child's outcome and quality of life. This also increased their worry and the workload required to keep on top of their child's needs. Many reported that they gained the most useful pieces of information from other parents, usually mothers they had connected with through a Facebook community support group. Others received information by chance during encounters with health professionals. Overall, this disorganisation resulted in stress, feelings of guilt for not knowing, and disappointment with having to live with the consequences of their child missing out on opportunities for which they were eligible.

Up until the other day I didn't realise there was additional funding we could get, that's what I mean by you don't necessarily know what is available. Because if I'd known that this thing was available 4 years ago, I probably would've applied for it back then and actually we would've probably had more physio and had more occupational therapy because it does make a difference to her especially her fine motor skills, it makes a huge difference. (Wendy)

These diverse experiences led to significant variations in the amount and type of assistance received, as well as differing levels of understanding of what was available. In the absence of a single reliable source of truth, mothers also received conflicting information from different sources. The financial support received was based on their child's needs and factors such as information provided by parents and the expertise of the worker allocating financial support. In some cases, this meant children were eligible for much more than they were receiving. At the time of the interview, some mothers were still unsure about eligibility criteria or how to access various financial support. Others were frustrated at not receiving important information in a timely and consistent manner. "You've really got to stumble across it by word of mouth. Like when someone's diagnosed, they should just give you like a handbook" (Wendy).

When her daughter was 8-years-old, Wendy learnt “by chance” of substantial financial support that she could have been receiving since her child’s birth.

So, I was at horse riding last month and we were talking with one of the other mums and her boy has CP as well. She was talking about something called individualised funding and I said, what is that? She said, ‘oh, you know, you get it through the hospital’. She said, ‘just write away to this guy and he’ll get back to you’. Which I did. They did get back to me, but this has only just happened like last week where before this I didn’t even know that this was a thing and now we are just waiting to hear back from the person who will work with us on what we might be entitled to receive. And I’m thinking, okay, so she’s nearly eight. (Wendy)

Mothers who inadvertently discovered their child was eligible for more financial support than they were allocated, were frustrated their child had missed out on sometimes years of support, and often spent a significant amount of time and energy on arduous applications. Some mothers discovered financial support was available to modify homes; for example, to accommodate wheelchairs and make bathrooms accessible. However, delays, prolonged processes, disruptions, and bureaucracy led families (like Michelle’s) to use their own savings to get this work done. Mothers also revealed funding was limited to one home modification with a cap of NZ\$15,000 which was inadequate and unrealistic.

Funding for access to the home under the MoH system is capped at \$15,000. And the advice is if you can’t get access to your home within that to pay for it yourself or move. So for us, we can’t do either of those things. (Joanne)

Many mothers felt the strain of inadequate financial support which, coupled with not being able to work or working less to support their child, left them having to adjust to living with a reduced family income and making sacrifices. With this also came the responsibility of making important decisions, including whether they could afford the often-high cost of private therapy services because “what the public system offered isn’t enough” (Joanne), live with their child missing out, or muster up the energy to advocate for their child. The burden of this decision weighed heavily on the minds of mothers who felt worn down by the responsibility of constantly having to make big decisions as to what support their child would or would not get, how much they could fight and advocate for, and then spend time worrying about whether they had made the right decision. This stressful situation left mothers having to adjust to a different way of parenting than expected.

I do feel that there's not a lot of support and I do feel that everything's underfunded and understaffed and you've got to kind of make things happen for yourself and make your own way a lot of the time. And you probably only get anywhere by pushing. (Anne)

In contrast, mothers supported by ACC felt well assisted by their assigned case manager who provided information, guided them to understand their eligibility for financial support, and ensured they received it. Having a case manager was considered a big advantage, reducing the need to fight and advocate and, therefore, lowering the stress and worry.

Jennifer, who had experienced years without ACC, found that once her child was accepted by ACC, they provided a "decent" support package which included weekly payments and vastly improved access to equipment, medical care, and therapy. She also received additional support including a mobility vehicle, home modifications, and, for her son, a new tricycle and wheelchair, a second pair of glasses, various home equipment, regular occupational and physical therapy input, and funded full day teacher aides for class excursions. All these variables significantly improved both their lives.

This section has highlighted the absence of a single source of reliable truth for information regarding government funding and financial support. It has also revealed that funding (excluding ACC) was considered inadequate, inconsistent, and inequitable by mothers. In response, mothers found themselves in a state of advocating and fighting for their child which required them to parent differently. Their experience has been presented through the analogy of rowing a boat upstream. Those mothers with children supported by ACC were in general satisfied with what they received; and while their experience was also likened to rowing a boat upstream, they were supported by a current of ACC funds which enabled a less turbulent journey.

Summary

This chapter has presented the theme of rowing upstream which is about both the work and worry mothers experience when parenting their child with CP, and the fighting and advocating they do to get support for their child and themselves. Together, work and worry, with fighting and advocating, underpin the experience and perception of mothers rowing

upstream against an invisible current. Rowing upstream has been represented through four subthemes reflecting how much harder mothers felt parenting their child with CP was (keeping the boat afloat); the exhausting battle to get support through ACC (paddling through the ACC rapids); experiences at school and the impact of a change and reduction in government support (navigating the school currents); and, lastly, how the absence of a single source of truth with regards to government funding led mothers to receive variable and inconsistent information, funding, and support (lost in the funding stream). The last two subthemes primarily relate more to mothers with children not supported by ACC and reflect the inadequate and inequitable support received through mainstream schools and government funding. Mothers with children under ACC were relatively satisfied with assistance provided but suffered significant negative impacts from the battle required to secure ACC support. All these variables required mothers to adjust to a different way of parenting than expected.

The next chapter presents the third and final theme—winning but not as expected. It is explained through two subthemes: growth through gratitude and the discovery of a warm blanket of community support.

Chapter Seven. Winning, But Not as Expected

Winning, but not as expected, is the third and final theme that supports the overarching concept of a different way of parenting and represents the place that many mothers arrived at emotionally and intellectually. As mothers developed greater confidence and competence in their parenting role, and began to accept their circumstances, this stage was likened to the river straightening, the water calming, and the boat steadying; all of which offered a sense of relief, as if land was finally visible in the distance.

This theme has two subthemes depicted in Figure 8. The first is growth through gratitude. This subtheme appeared as the mothers relayed stories of emotional battles, stress, and trauma; yet, through these experiences, developed a strong sense of gratitude and pride towards their child as well as pride in themselves. They also experienced personal growth and gained new perspectives of what was important to them in life. The second subtheme represents the warm blanket of community support mothers felt safely wrapped in. This was a place where they felt understood and heard by others going through similar experiences. Together these subthemes represent winning in life, just not in a way any of the mothers had anticipated or expected.

Figure 8.

Schematic Depicting Winning But Not as Expected Subthemes



Growth Though Gratitude

The first subtheme that contributes to winning, but not as expected, appeared during the interviews when mothers beamed with joy and admiration as they talked about their children. When asked the simple question 'tell me about your child,' I could see gratitude and pride in their faces as they spoke using a range of positive adjectives such as funny, positive, determined, strong, and resilient. The mothers articulated how although their journey as a parent had been a different and perhaps more challenging one, their love and respect for their child was paramount. There was a strong sense from the mothers that they

saw their children with CP as embattled along with themselves. Amanda described her daughter as a “true warrior” because she was “someone who pushes through all these physical pains and can still bust out the biggest smile.” Despite the underlying sadness from the daily challenges their children lived, mothers felt privileged, humbled, and grateful to be their child’s parent.

My son is the best (laugh) thing, he is the best human that I’ve ever come across. I think he’s just amazing and I feel incredibly grateful. I feel so much gratitude just to be his mother, although I would not have chosen this for him, but I can see my life is so much richer because of him. (Heather)

All the mothers talked about how much they admired their children for the unique and special ability they possessed to positively influence those around them. There was a strong sense from many that they were proud of the determined way their children had succeeded with key milestones despite the physical challenges they faced. These experiences provided mothers with insight into the extra effort and focus it took their children to achieve what non disabled people might consider as small or insignificant tasks (such as dressing or putting on their shoes) and they felt deeply proud of the perseverance their child demonstrated. “Those small achievements are huge” (Anne) and were a cause for celebration.

For Amanda, Heather, Fiona, and Wendy, these experiences extended into a pride they felt in themselves for the parent they had become. They had emerged from dark times and risen to the challenge of learning how to support their child’s unique needs and make adjustments in their own parenting expectations. Over the years, mothers had become increasingly aware of the challenges, limitations, and struggles associated with the realities of living with a disability, and had been shocked at the discovery that they were living in a world that was not built for people with disabilities, “because life unfortunately is not made for people in wheelchairs and especially not for children in wheelchairs” (Michelle). Through this experience mothers saw a different world through their child’s eyes. They experienced the injustice of how much harder it was to live with a disability, both on a daily basis (to achieve basic life tasks) and within a society not set up to cater for disability. However, they were buoyed by their child’s positive and determined approach to life. This positive approach became a gift which provided mothers with the opportunity to grow and develop

as a person and gain a new perspective on life. This was winning, but just not as expected. It was a space where they had made peace with their situation and had been able to make the adjustment to a different way of parenting than they had envisaged.

Joanne, Amanda, Anne, and Stephanie said it helped them to be more empathetic and they appreciated the way it prompted them to refocus and reflect on life priorities. Joanne, Michelle, Julia, Louise, and Stephanie, in an endeavour to understand how to best support their child, discovered the benefits of slowing down the pace of their family life. Slowing down was noted as being an important aspect for fostering success and independence.

So you know the positives are that he's helped open our eyes to how life can be and how sometimes it's better to focus on the little things. You know a lot of times in life you get stuck focusing on the big things. Whereas with (my son) it's the little things that matter the most. And so it helps us slow down as well in our own stuff and say well actually let's focus on the little things. Big things don't always matter. (Michelle)

Slowing down was achieved by allowing more space in the family schedule to accommodate for the extra time the child needed to learn and do a variety of daily tasks (i.e., dressing and washing) as well as therapy. Slowing down required mothers to refine their ability to be patient (which many felt they had succeeded to do) and rewarded them with a more empowered child who, through having enough time to practice and learn key tasks, was able to achieve milestones and become more independent. All these positive impacts for the mothers were wins, just not the type of winning any of them had imagined before having their child.

This new worldview led to a significant change in life values for Heather, Julia, Fiona, and Wendy who articulated how they no longer measured success by career, financial gains, or material items but by the amount of joy and satisfaction they obtained by having more time and greater connections with their child and other key people in their lives. They enjoyed acknowledging and celebrating their child's unique successes and experiencing the positive influence their children had on other people in their world. This was a significant positive adjustment to a different way of parenting as they had reached a place where they had more control over their life as a mother of a child with CP. For Claire, this was the

pleasure of seeing her extended family's eyes "open up" to the world of disability after previously being "very ignorant." While Amanda elaborated:

I've seen her change people. I've seen her turn hard men into soft emotional wrecks, because she touches people's wairua (soul) and makes them question their own morals and their own kind of reality, you know? She makes you stop and go, what's really important here? You start to really open your eyes up. I've seen changes in my family, a lot of my friends, just how they look at life differently. (Amanda)

There was no denying that while the journey had been tough, most of the mothers had come a long way from where they started with regards to their personal growth and evolved worldview.

I get frustrated and I have these horrible moments where I'm just like fuck I hate my life. But then I have the complete opposite of that at the same time. I think far out, who was I back then? You know, before I had her, I do not even know that person. I'm a completely different person. I'm stronger, there's so many positives about her that actually do help strengthen our family as a whole. (Amanda)

Navigating this bumpy journey, while challenging and hard at times, led mothers to live a more meaningful and satisfying life where they refocused their priorities and worldview, enabling them grow as a person and value what they had. This emotional journey and subsequent adjustment into a different way of parenting was a win, but just not as any of the mothers had expected. Another influential insight was the discovery of a community of parents of children with CP who understood the challenges and journey. This is presented as the second and final subtheme of winning, but not as expected.

A Warm Blanket of Community Support

The second subtheme contributing to winning, but not as expected, describes the friendships, networks, and community of support that positively impacted the mothers' adjustment to a different way of parenting. Many mothers felt that long-standing friendships had not survived following the birth of their child as they were no longer able to maintain them in the way they had previously. This inability to attend to friendships was directly attributed to having to spend much of their energy focusing on their child's complex care requirements; a situation which left mothers with limited energy to socialise and keep

connected. Mothers felt that their longstanding friends did not understand their new life or the enormity of the adjustment they were required to make.

While some friendships had ended because of the stress, strain, and isolation of having a child with CP, mothers discovered an invaluable community of people that understood what they were going through and offered an abundance of support and advice. Many mothers said that their parenting journey had been made easier due to the discovery of this supportive community of people having similar experiences. In a different way to longstanding friendships, this community provided them with support through a group of people in the disability world that did not hold the same friendship expectations and understood their situation and limited capacity. For Kelly, Wendy, Amanda, and Julia, some connections and friendships had started in the NICU, through other hospital experiences, or activities such as therapy centres and conductive education in the pre-school years. These situations provided a prime opportunity to connect and talk with other parents, share stories, knowledge, and advice.

We went to conductive education when she was little and that was really good support because you can be around the people that you have things in common with, so yes, it was nice to have groups that you can sort of get to know other people in that same situation. (Kelly)

Others had initially connected into this community via Facebook support groups, with some developing into personal friendships. This community of support was described as having a transformative influence, a place where mothers felt an instant and meaningful connection and could be heard, seen, and understood. It was like they were welcomed and wrapped in a warm blanket of community support and care, where they could find both practical advice and emotional support to navigate and understand the health and education system, as well as assistance with understanding what their child's disability meant and what supports were available.

It has introduced me to a whole new world of people. I'm now in a community with other disability people around versus in isolation. I have discovered things; like for example, when the nappies were no longer in stock for the girls' dry nights, and I couldn't get any, someone else (from the disabled community) was just like, I've got

a supply, I'll drop it off on your doorstep. That's one of the positive things behind disability is when you actually start to find that community. (Anne)

The online aspect to this community offered the benefit of mothers being able to choose when and how often to connect, and could be managed around their child's needs and schedule. This community was both unexpected and a big win for mothers who had started from such a difficult place with their parenting journey. They were back in their boat travelling down a smooth river with clarity on where they were heading. Mothers, such as Anne, Lisa, and Jennifer, noted this community as being more helpful and supportive than any health professional they had encountered. Joanne, Julia, and Lisa had found out about various treatments, rehabilitation, therapy, and even surgery in this space. Within this community mothers felt able to share their struggles and challenges freely and openly without judgement. They also enjoyed being able to provide support and information to others. "I really like the people that I've met through the disability world, it's just a different kind of level of engagement. It's like an instant deeper level of understanding. It's cool" (Louise).

Many mothers received support with long lasting positive benefits, such as help with applying for more resources, therapy, and assistance for their child. For example, Jennifer was supported by a mother whom she had never met yet volunteered significant time to help her fight, and ultimately win, a 9-year battle with ACC. This had a significant positive impact on her son and the whole family's quality of life and well-being leading to considerably more government support and resources. In addition, Louise was supported by a mother to make a formal complaint to the Health and Disability Commission which also resulted in more support. This type of support was highly valued by mothers, many of whom were grappling with navigating the complex disability systems. For mothers, such as Joanne and Amanda, this connection enabled planning for the future, as they were able watch online conversations with people whose children were older so they could build a picture of what was ahead.

I think every mother of a CP kid is always trying to somehow make it easier for the next parent who joins this journey, these people that have come before us become our support network. (Amanda)

Overwhelmingly, mothers consistently gained lifelong friendships through this unexpected community which enabled deep meaningful connections. For many, it was also a source of easy online interactions that removed the pressure of having to maintain friendships in person or meet a set of preconceived friendship expectations which they felt necessary with their prior long-standing friendships. Within this network mothers felt safely wrapped in a warm blanket of community support, this was winning—just not as expected.

Summary

This chapter has presented the theme of winning, but not as expected; and the two subthemes—growth through gratitude and a warm blanket of community support. The first, growth through gratitude represented the gratitude and pride mothers felt for their children, the pride they felt in themselves, the personal growth, and new perspectives that they gained. Mothers were proud and grateful for the positive, determined, and resilient way their child approached life with a disability. They were also proud of the parent they had become. It was evident that children acted as a kind of role model, providing mothers with the opportunity for personal growth and new perspectives. This opportunity led mothers to reevaluate and refocus their life priorities. As such, many were subsequently living a different sort of life at a slower pace where the small things were valued and celebrated. Many indicated they had come a long way from when they first had their child, and this reflection enabled a feeling of satisfaction and peace with their life that they had not expected.

The second subtheme was the discovery of a new community of support. This unique community of other parents offered a warm blanket of support for mothers and a place where they felt understood and cared for. Equally it was a community where they could reciprocate and provide support and care to others. For many this was a game changer, and for some it led to considerably more government support and resources for their child and family. All these experiences led to mothers feeling positive about their parenting journey and that they were winning in life, just in a different way to what they had imagined and expected.

Chapter Eight. Discussion

CP is a neurodevelopmental disorder and the leading cause of neurological impairment and physical disability in children globally (Sadowska et al., 2020; van Eyk et al., 2023). Raising a child with CP is fraught with challenges due to their long term and complex care requirements which often exceed the usual needs of typical children. Children with CP are dependent on caregivers/parents, most frequently mothers, for daily assistance (Elangkovan & Shorey, 2020). The weight of this situation has a significant impact on both the physical and psychological health of a caregiver (Dambi & Jelsma, 2014).

This study aimed to gain a deeper understanding of the experiences and perspectives of primary caregivers raising a school aged child with CP in NZ, as well as explore and identify how disability services influence primary caregiver's experiences. The previous three chapters presented the results of the data analysis, or the findings. The current chapter concludes the thesis and provides an interpretation and discussion about the key findings in relation to the research questions. Practice implications will also be presented. The final part of this chapter offers a consideration of limitations of the study, direction for future research, and final reflections.

Summary of Findings

Strong messages evident throughout this study were the impact on the way mothers of children with CP received their child's diagnosis, the support they received from a community of parents of children with CP, and challenges with disability support through the education and health care system. The latter messages answer the second research question on how disability services influenced primary caregivers' experiences.

The findings have been presented through the overarching concept of adjusting to a different way of parenting, underpinned by three major themes—the difficult start, rowing upstream, and winning, but not as expected. The difficult start is likened to the analogy of a pregnant mother travelling along a river in a boat packed with everything needed for the trip. The water is smooth and the river straight (uneventful pregnancy) until it is not and the boat makes a sharp turn with rapids appearing out of nowhere (unexpected and early labour). They find the boat heading straight for the rapids and feel out of control. This process symbolised the emotional roller coaster of NICU. The boat capsizes and all their

belongings disappear overboard (NICU environment). They find themselves all alone and clinging to the side of the boat (discharged from NICU). They then find themselves able to right the boat and get back in but they feel confused and disorientated (receiving the CP diagnosis). They find they are no longer on a straight river in calm water but instead a river with twists and turns and unpredictable rapids and currents (marriage disruptions). This theme represented the trauma and challenges mothers faced while adjusting to being a parent. Many talked openly about the impact this experience had on their own mental health and well-being.

The second theme of rowing upstream sees a mother in the boat continuing along the river; however, the boat has been damaged from the capsize, there are holes in it. She finds herself having to frantically bail water out of the boat while plugging holes and steering away from rapids and currents on the unpredictable river. Rowing upstream represents the challenges mothers have with parenting their child who lives with a disability. The fixing of holes in the boat to keep it afloat symbolises the managing of appointments, equipment, therapy, and attending to their child's physical and emotional needs. Mothers were navigating life and trying to fill many roles (e.g., parent, caregiver, spouse, colleague), finding their parenting role hard. The river is full of currents and rapids which represent battles with ACC, struggles at school, and inconsistent and inadequate financial support and funding. It is a very difficult time in parents' life with constant work and worry while often living with unresolved trauma from the difficult start. Many were exhausted and described working against a resistance (current) which came from the health and education system and led to them advocating and sometimes fighting to get their child's needs met. This all required them to adjust to a different way of parenting than expected.

The last theme of winning, but not as expected, saw mothers becoming more proficient with plugging the holes, bailing water, and navigating a boat on the unpredictable river. They were more at peace with not knowing (going with the flow) where they were heading or what the future held. The mothers became more accepting of their situation and focussed on the positives. They discovered growth through gratitude. The water is smoother and the river straighter. The sun comes out (community support) and mothers know that they can embrace and handle the challenges of adjusting to a different way of parenting than expected.

Delivery of the Diagnosis

Receiving a diagnosis of CP for a child is a significant event that can have a long-term negative impact on the lives of parents if not delivered with care and consideration (Novak et al., 2019; Williams, Alzahr, et al., 2021). This event often marks the start of a long relationship with a variety of healthcare professionals and the health system, and can set the scene for future interactions (Novak et al., 2019). In this study, mothers described how the way and manner in which they received their child's diagnosis was insensitive, casual, and offhand, leaving them feeling unsupported and lost. In turn, it affected their trust in health professionals, their ability to adjust and adapt to their child's disability, and the different parenting role they now had to assume. This finding is supported by a wide range of studies dating as far back as 1990 (Cottrell & Summers, 1990; McKay & Hensey, 1990) which confirm that insensitive delivery of this type of life altering news has the potential to cause significant long-lasting trauma, and negatively impact parental mental health and the parent-child relationship (Baird et al., 2000; Dagenais et al., 2006; Novak et al., 2019; Williams, Alzahr, et al., 2021). This is significant as parents are the 'essential drivers' of their child's healthcare and their ability to understand and process their child's diagnosis is pivotal to accessing timely and relevant support for their child (Dagenais et al., 2006; Shevell & Shevell, 2013).

Mothers in this study described how their negative experience of receiving the diagnosis was further exacerbated when news was delivered in a way that implied they should have already known their child had CP. This finding is consistent with literature which reports how parents found out about their child's diagnosis of CP by chance, accidentally, or through indirect communication (Baird et al., 2000; Dagenais et al., 2006; Mohanty et al., 2021; Williams, Alzahr, et al., 2021). Poor communication in delivery of diagnosis, along with high expectations that healthcare professionals placed on parents already knowing about their child's diagnosis, was upsetting for parents and compromised their trust in the diagnostic process and healthcare team (Shevell & Shevell, 2013; Williams, Alzahr, et al., 2021).

Diagnosis and Post-diagnosis Information and Support

Mothers in this study reported a lack of accompanying information and post-diagnosis support, with the diagnosis often being delivered in a single conversation. There is much

written about the process of breaking bad news in general (Berkey et al., 2018; Camargo et al., 2019; Gao, 2011; Monden et al., 2016), and studies that address the experience of parents receiving a diagnosis from other conditions such as attention deficit hyperactive disorder (Legg & Tickle, 2019) and autism (Sainsbury et al., 2023). Legg and Tickle (2019) reported parents had three types of needs when receiving a diagnosis—emotional, informational, and relational; while Sainsbury et al. (2023) highlighted the battle parents experienced to get a diagnosis and support for their child. However, the process of receiving the diagnosis of CP from the parents' perspective is much less studied.

Mothers often struggled with understanding what the CP diagnosis meant for their child and did not know where to turn for reliable and relevant information. This finding is evident in other studies, where parents reported feeling unhappy with the way the diagnosis of CP was delivered including a lack of information, post-diagnosis support (practical and emotional), and clear communication (Williams, Alzaher, et al., 2021). Williams, Alzaher, et al. (2021) reported parents felt poor delivery created a barrier to accessing timely critical therapy and support for their child. Of interest, Dagenais et al. (2006) found that although parent satisfaction with the disclosure process of CP was high, there was a strong message that providing support for parents post-diagnosis was of utmost importance. Parents stated that a follow up meeting days after diagnosis, once they had recovered from the initial shock, would improve the overall experience of receiving this news (Dagenais et al., 2006). Recent research echoes this finding and cites both professional and informal support as critical to enabling parents to make sense of and understand the diagnosis, and to ensure their child receives the right interventions and care (Mohanty et al., 2021; Santos et al., 2023; Williams, Alzaher, et al., 2021).

Delay in Diagnosis

Mothers in this study revealed they had to be proactive with seeking a diagnosis for their child and had to directly ask if their child had CP. This resulted in mothers feeling unheard and misunderstood with regards to concerns about their child's development. Similarly, other studies reported how parents felt they were not listened to when voicing concerns about their child's development and were unhappy with delays when receiving the diagnosis (Baird et al., 2000; Dagenais et al., 2006; Mohanty et al., 2021; Shevell & Shevell, 2013; Williams, Alzaher, et al., 2021). Baird et al. (2000) revealed that the later a parent receives a

diagnosis the higher the degree of dissatisfaction in care. Parents want to know as early as possible, even if the diagnosis is not definitive, and they want to be informed in an honest and sensitive way (Dickinson et al., 2023; Williams, Alzaher, et al., 2021).

The diagnostic process for CP is often delayed due to the evolving nature of the condition, with early signs not always apparent in young babies (Baird et al., 2000). Clinicians frequently adopt a 'wait and see' approach, which is further complicated by the highly variable and individualised presentation of CP (Baird et al., 2000; Shevell & Shevell, 2013; te Velde et al., 2019). This diagnostic uncertainty can lead to inadvertent disclosures by other clinicians before a formal diagnosis is made (Baird et al., 2000). Additionally, many health professionals lack confidence in delivering a CP diagnosis in a manner that is supportive to families, further complicating the communication process (Novak et al., 2019).

While doctors recognise the importance of providing parents with information and support at the time of diagnosis to help them cope with their child's disability (Fernandez-Alcantara et al., 2015; Huang et al., 2010), many feel they lack adequate training to diagnose CP early (Novak et al., 2019) and deliver the news appropriately (Monden et al., 2016). There is some indication that doctors are reluctant to deliver a diagnosis because they are worried they may be blamed for the diagnosis or they are afraid of eliciting an emotional reaction in either the parents or themselves during this conversation (Berkey et al., 2018; Fallowfield & Jenkins, 2004). Others (Novak et al., 2019; Williams, Alzaher, et al., 2021) cite a lack of pathways to inform clinicians' practice and support them with diagnosis delivery. However, many doctors admit they would welcome such an approach. Evidence suggests that some doctors are either unaware of available clinical pathways and guidelines or, if aware, do not consistently use them (Fallowfield & Jenkins, 2004).

Provision of evidence-based approaches for doctors, such as the use of a protocol, guideline, checklist, or framework can be supportive and helpful with the process of delivering a diagnosis (Baird et al., 2000; Dagenais et al., 2006; McKay & Hensey, 1990; Novak et al., 2019; Shevell & Shevell, 2013; Williams, Alzaher, et al., 2021). An example is the 'best practice for delivery of bad news' SPIKES protocol (Berkey et al., 2018; Gao, 2011; Novak et al., 2019). Novak et al. (2019) adapted this protocol to use with parents of children with disabilities. The SPIKE protocol follows a logical approach that supports parents during the time of receiving the diagnosis. The SPIKE acronym is defined as; the setting (S) for the discussion to take place is appropriate; parents' perception (P) and current understanding is

assessed; parents are invited (I) to ask questions; knowledge (K) is shared; responding to emotions (E) with empathy; a summary (S) is provided and collaborative plan formulated (Novak et al, 2019). Adopting this type of approach, along with consideration of what parents want, has potential to significantly improve the diagnosis experience (Williams et al., 2021). Despite these guidelines and protocols being available, many doctors do not utilise them, citing lack of support, time, personal fears, lack of confidence, and absence of post diagnosis discussion debriefs (Fallowfield & Jenkins,2004). Unfortunately, as indicated in the current study and others, not using such guidelines results in parents continuing to receive their diagnosis in a haphazard way leaving them feeling shocked, distraught, and their mental health negatively impacted (Fallowfield & Jenkins, 2004; Greiner & Conklin, 2015).

Over 2 decades ago, the United Kingdom organisation, SCOPE (that campaigns for equality for people with CP), responded to research revealing parents' distress when receiving their child's diagnosis by establishing a multi organisational working party (Fallowfield & Jenkins 2004). They published a report on how a diagnosis should be delivered along with a 'Right from the Start' resource pack for healthcare professionals which included local policy templates, background reading materials, and videos, all aimed at promoting good communication (Fallowfield & Jenkins, 2004). However, when they audited use and uptake, they discovered that while hospitals had the local guideline template, many staff were not aware of the guidelines or of training opportunities. They concluded that new initiatives were difficult to implement and that monitoring adherence and providing evidence-based training were important for success (Fallowfield & Jenkins, 2004).

What Parents Want

While the mothers in this study did not specifically state how they would have liked the news of their child's diagnosis delivered, they were clear that improvements were needed. The literature consistently concludes that parents want easy to understand information; doctors to listen to their concerns, take them seriously, and be open, honest, and compassionate; while also providing ongoing information and practical support (Baird et al., 2000; Dickinson et al., 2023; Shevell & Shevell, 2013; Williams, Alzaher, et al., 2021). These behaviours are aligned with the various recommended guidelines and protocols for delivering bad news (Baird et al., 2000; Novak et al., 2019). Novak et al.'s (2019) review of

the literature highlights that, upon receiving their child's diagnosis, parents require comprehensive information across multiple domains. This includes an understanding of the diagnosis, available treatment options, sources of support, healthcare planning, daily caregiving responsibilities, required equipment, anticipated future outcomes, strategies for communicating the diagnosis to others, and the broader impact on family dynamics. Parents wanted hope, encouragement, reassurance, and empowerment (Shevell & Shevell, 2013). Overall, parents of children with CP expressed a desire to be recognised as partners in care, viewing the diagnostic conversation as the starting point of a high trust relationship centred on the shared goals of supporting their child to live their best possible life (Shevell & Shevell, 2013). This desire is in keeping with the findings from the mothers in this study.

Advances in medical technology and established international clinical guidelines now make early diagnosis of CP more possible (Allermo Fletcher et al., 2024; Morgan et al., 2021; Sandle et al., 2020); however, evidence indicates there is still work to be done with embedding early diagnosis into practice (Allermo Fletcher et al., 2024; Novak et al., 2019; Sandle et al., 2020; te Velde et al., 2019; Williams, Alzaher, et al., 2021). Delays in diagnosis, the challenges of diagnosing CP (due to its complexities), and the need for early diagnosis are explored in detail in the literature which cites considerable benefits of timely and early diagnosis enabling timely access to therapy and support (Dagenais et al., 2006; Guttmann et al., 2018; Novak et al., 2019; Sandle et al., 2020; Shevell & Shevell, 2013; Williams, Alzaher, et al., 2021).

The findings from the current study are important because, combined with existing research, there is clear evidence that the way a child's diagnosis is delivered matters and the way this commonly occurs is distressing for parents (Dagenais et al., 2006; Novak et al., 2019; Williams, Alzaher, et al., 2021). As evidenced in the current study and others, receiving a diagnosis is an upsetting experience for many parents and, if it is not communicated well it can result in long lasting negative impacts on mothers who are already in a vulnerable and compromised state (Baird et al., 2000; Dagenais et al., 2006; Novak et al., 2019; Williams, Alzaher, et al., 2021). A negative experience can significantly compromise their ability to adapt, adjust, and accept their life as the mother of a child with a disability. This, in turn, can negatively impact the child (Novak et al., 2019; Williams, Alzaher, et al., 2021). Conversely, if it is done well, it can pave the way to reducing stress, improved coping, and better long-term adjustment and acceptance, all of which would positively influence a child's outcomes

(Dagenais et al., 2006; Fallowfield & Jenkins, 2004; Mohanty et al., 2021; Novak et al., 2019). My study suggests that diagnosis delivery should be conducted in a sensitive, thoughtful, and empathetic manner, including careful consideration of word choice, language, timing, and context, as well as providing follow-up appointments and take-home information. This is consistent with research findings spanning decades (Cottrell & Summers, 1990; Shevell & Shevell, 2013; Williams, Alzaher, et al., 2021).

The findings of this study, together with the international and local research, indicate there is a significant disconnect between theory and practice. On one hand there is literature indicating how to deliver a diagnosis which includes recommendations of proven successful approaches such as frameworks, guidelines, and checklists (Dagenais et al., 2006; Fallowfield & Jenkins, 2004; Novak et al., 2019). On the other hand, the same authors reveal that despite these resources, there continues to be evidence that recommended approaches are not being adopted by clinicians and parents are still upset with how diagnoses are delivered (Novak et al., 2019; Williams, Alzaher, et al., 2021; Williams, Mackey, et al., 2021). There is no doubt that this is a challenging situation with healthcare professionals required to navigate the complexities of being honest about often unknown outcomes, while also providing hope and support (Fallowfield & Jenkins, 2004). Williams, Alzaher, et al. (2021) concluded that while there may not be a perfect formula for delivering a diagnosis, understanding families' needs and recognising the impact of how a diagnosis is delivered can offer valuable insights. This understanding can inform efforts to prevent trauma and enhance the experience for future parents. It seems that what is needed is a sustainable and effective way of influencing clinical practice amongst healthcare professionals to enable adoption of recommended approaches for best practice. Considering CP is the leading cause of childhood disability globally, highlighting this issue so it can be addressed can make a considerable impact.

A Community of Support

Informal community support systems with other parents of children with CP provided the most significant practical and emotional support for mothers. In this study, mothers talked freely about the extra work and burden of care they felt had come with their child's CP. The weight was heavy as they struggled to understand their parenting role and what was required of them. They talked with sadness about how they had lost support through the

ending of long-standing friendships which they attributed to a variety of reasons including the stress and strain of having a child with a disability, not feeling the gravity of their situation was understood by friends, and not being able to put the required time in to maintaining friendships. This finding aligns with research where long standing, well intended friends often do not understand the challenges associated with caring for a child with a disability and mothers find the burden of care responsibilities limits their ability to connect socially (Davis et al., 2010; Nimbalkar et al., 2014; Skok et al., 2006). Often it is easier just to withdraw, stay home, and limit contact to close family members and other mothers of children with CP with whom they could feel safe and supported (Davis et al., 2010; Dezoti et al., 2015; Mokhtari & Abootorabi, 2019; Nimbalkar et al., 2014; Singogo et al., 2015). There is also evidence that mothers felt socially rejected, discriminated against, isolated, and experienced difficulties in maintaining their own interests and social connections (Davis et al., 2009; Dezoti et al., 2015; Mokhtari & Abootorabi, 2019; Nimbalkar et al., 2014; Nyante & Carpenter, 2019; Singogo et al., 2015; Vadivelan et al., 2020).

While mothers in my study experienced the loss of long-standing friendships, it was evident their parenting journey had been made easier because of the supportive community of parents having similar experiences. Mothers described the discovery of a community or network of support with other parents impacted by CP as a game changer. It was a place where their burden was eased or alleviated by forming invaluable connections with a community of people who truly understood their experiences and offered practical and emotional support, which they could also reciprocate. Practical support included assistance with navigating and understanding the health and education system and how to access support, treatments, and funding for their child. Emotional support came through being in an environment where mothers felt their daily challenges and struggles were understood, heard, and acknowledged.

These findings are supported by evidence highlighting that strong support networks play a crucial role for mothers, positively impacting their mental health, well-being, ability to adjust, accept, adapt, and cope with the unique and often challenging aspects of mothering a child with CP (Aburn et al., 2021; Alibakhshi et al., 2021; Milbrath et al., 2008; Skok et al., 2006). Support networks provide valuable lived experience information, problem solving, and guidance (often beyond the capability of health care professionals), and serve as a buffer against threatening events (Hayles et al., 2015; A. Reid et al., 2011; Rentinck et al.,

2007; Shevell & Shevell, 2013). This finding is also supported by research revealing parents turn to digital platforms, such as Facebook groups, for social and emotional support as a low-cost assessable support option (Gruebner et al., 2022; Johnston et al., 2013; Kelly et al., 2022). Online support groups were also reported to act as a buffer against the negative health impacts of caregiving (Daynes-Kearney & Gallagher, 2023).

My study suggests that informal networks were a vital and powerful source of support for mothers, transforming their sense of feeling lost and alone into one of being truly listened to and understood in a safe space. It was in this environment that many mothers found out important information regarding their child's condition and received practical advice on how to support their child's unique needs. A significant amount of support was in relation to assisting struggling mothers to understand and navigate the often disjointed and haphazard complex formal supports for children living with disability through the health and education system. The community of support made this easier by providing experience-based advice and guidance. This is consistent with other research where parents did not know where to look or who to turn to for information and advice with regards to their child's often unique set of challenges (Nyante & Carpenter, 2019; Vadivelan et al., 2020), and they found the healthcare system confusing to navigate (Elangkovan & Shorey, 2020; Williams, Alzahr, et al., 2021). In this situation they often discovered support from other parents in similar situations (Alibakhshi et al., 2021).

The concerning aspects of this finding is despite the positive impact and importance of social networks, mothers in this study reported only finding out about them by chance when, for example, they stumbled across a Facebook support group online. It is unclear how mothers should or could have found out about support groups sooner. One opinion is that it should happen early during interactions with health professionals; however, Daynes-Kearney and Gallagher (2023) cautioned that while studies encourage professionals to provide information about online support groups to parents, they may not suit everyone and it is important to be clear about the purpose and intention of them from the outset. Discovering ways to inform mothers and parents of the existence of online support groups is particularly relevant considering there is literature highlighting the importance of social support as a moderator between, child outcome, maternal depression, stress and well-being of mothers and the indirect benefits on family functioning through psychological and physical health (Alibakhshi et al., 2021; Manuel et al., 2003; Pousada et al., 2013; Raina et al., 2005; Skok et

al., 2006). Given the important role these groups played for the mothers in this study, it is evident that something needs to be done to highlight the existence of support groups so they are not accidental discoveries.

Other Supports

Mothers in the current study talked to a lesser extent about other supports such as assistance from their husbands (or ex-husbands), mothers, and their other children. Mothers reported mixed experiences, with husbands' input seen both in a positive and negative light. This is consistent with the literature which reveals while some mothers felt supported and as though they were parenting as a team and sharing the challenging journey (Pfeifer et al., 2014), others felt as though they had been abandoned and were carrying the full weight of the parenting responsibility (Elangkovan & Shorey, 2020). Several mothers in the current study described specific incidents where they received memorable practical support from a healthcare professional that they continued to be grateful for some years later. Gomes et al. (2019) further highlighted the important role strong relationships with healthcare professionals can have on positive coping and support.

Disability Support Through Health and Education Systems – An Inequitable System

The second aim of this research was to explore and identify how disability services influence primary caregivers' experiences. A strong theme that came through was the substantial variations and inequities in support experienced through either being supported or not supported by ACC. Mothers in this study whose children were supported by ACC were considerably more satisfied with many aspects of support, funding, and care that their child received. They felt supported to be able to understand, attend to, and provide for their child's needs in a satisfactory manner. Conversely, mothers of children not supported by ACC were consistently stressed, stretched, and compromised with accessing disability related supports across both the health and education system through the DSS pathway. This is particularly concerning in light of recent NZ research by Low et al. (2021) citing maternal mental health in general as possibly the biggest factor in determining long term child health and well-being.

Through the interviews it was evident the current DSS pathway is failing children living with CP in NZ and their families—too many are missing out on vital support. The DSS pathway is complex and hard to navigate, and the inequities created by ACC result in enormous and unacceptable variations in the level of support and care received. NZ is a developed country with a publicly funded healthcare system; however, the introduction of the ACC in 1974 has contributed to systemic inequities. While ACC is widely regarded as providing a superior level of service by those who access it, its existence has created a dual pathway for disability support. The two pathways of disability support provide different levels of care depending on the aetiology of the child's CP (Bradley, 2022; Duncan, 2019; Stephens, 2004). Whether this situation has developed because of unintentional consequences of ACC (Duncan, 2019; McNaughton & McPherson, 2000; Palmer, 1994) or other reasons, such disparities warrant urgent review to ensure equitable access to support for all children with CP. This finding is significant, and while aspects are unique to NZ (ACC is an internationally unique institution) (Duncan, 2019), the two separate pathways—ACC and DSS—with different funding mechanisms have led to widespread inequities. Despite this unique aspect of the NZ system much of the experiences mothers in this study have reported are consistent with findings of international research (Hayles et al., 2015; A. Reid et al., 2011).

There is an absence of international literature regarding similar dual systems and resulting inequities in other countries. There is also a lack of local research on the inequities of the DSS pathway for children within NZ. However, previous local research has revealed that parents of children with CP and other disabilities are dissatisfied with the DSS pathway which they cite as overwhelming, unsupportive, and difficult to navigate due to factors such as long diagnostic process, inadequate resources and interventions, and a lack of service integration and coordination (Gold, 2016; Hitchcock et al., 2020; Lee, 2019; Williams, Alzahr, et al., 2021; Zhang & Li, 2021). International research reports similar dissatisfaction with insufficient and inadequate government disability supports (Alaee et al., 2014; Huang et al., 2012; Mokhtari & Abootorabi, 2019; Nimbalkar et al., 2014; Vadivelan et al., 2020).

It is clear from the findings of this study that the current system is fragmented, inequitable, and inadequately funded. This has a significant impact on individuals, as children may face unfair disadvantages leading to poorer health outcomes and reduced opportunities throughout their lives. The NZ Disability Strategy (2016-2026) has an

overarching goal to ensure NZ is a non-disabling society, “a place where disabled people have an equal opportunity to achieve their goals and aspirations, and all of New Zealand works together to make this happen” (Office for Disability Issues, 2016, p. 6), as well as action plans for implementation. However, the effects of the “current dual system of benefit provision and service delivery for disabled people has led to substantial horizontal inequities” (Stephens, 2004, p. 783) between those on the ACC pathway and those not. As it stands, mothers in this study who were supported by ACC were in a more privileged position in terms of access to disability services and relevant support for their children. This is consistent with Goodyear-Smith and Ashton (2019) who agreed issues with access to care continue and the “system is not delivering the promise of equitable health outcomes for all” (p. 432).

Urgent attention and action is required from the NZ Government to plan and deliver an equitable and transparent system of disability support services across the health and education sectors so all children (along with their parents, families, and caregivers) who are diagnosed with CP in NZ (regardless of aetiology of CP or where they live), have access to the care and support they need in order to live their best lives and be a fully included member of society. While the ACC system continues to operate as is and the disability strategy continues to fail to achieve its aims, those children and their families not supported by ACC (the majority) will continue to be disadvantaged, have poorer health outcomes, and a compromised quality of life. NZ appears to have a system of disability support services that is failing already vulnerable and disadvantaged children and creating further inequities for many. Most children with CP in NZ are forced to take the lesser resourced, more disjointed, complex DSS pathway (Smith et al., 2022). The current disparity in care based on the aetiology of a child’s CP raises important questions about equity in the health and education systems. It prompts reflection on whether all children are truly afforded the same opportunities for optimal outcomes, or whether the current structure of systems inadvertently privilege some over others. The current system is letting children, mothers, parents, families, and whole communities down. One obvious solution would be to invest in the future and provide ACC level care for all. A good example of this is Australia’s National Disability Insurance Scheme (NDIS) which is reported to be serving people with disabilities better than any previous system through the provision of an individual care approach and better more timely access to healthcare (Olney & Dickinson, 2019).

Challenges During School Transition

Change in Focus and Funding

In this study it was evident that the inequities caused by the dual support system (ACC vs DSS or non-ACC pathways) in NZ exist in the education environment as well as the health sector. In my study, mothers with children supported by ACC reported a much higher level of satisfaction with both the transition and the schooling experience. While mothers with children not supported by ACC faced significant challenges during the school transition and beyond due to unanticipated changes (and often reductions) in disability support through the DSS pathway, including a shift from a holistic, independence-focused approach to a narrow emphasis on access to schools' education curriculum.

After spending the first 5 years of their child's life being their therapist, caregiver, and case manager; navigating the system; accessing support; and managing appointments, mothers found themselves in a profound period of change, adjustment, and disharmony when their child started school. It is particularly concerning that mothers in this study consistently reported being unprepared for these changes. They found the system challenging to understand and navigate and felt excluded from their child's education by schools. Overall, they were unprepared for the change that occurred when funding mechanisms with services on the DSS pathway transferred from the MoH to the MoE. This finding has drawn attention to the stress mothers face and the complex nature of disability funding and services for children with CP in NZ. Mothers were confused as to why their children received reduced support upon entering school. With the responsibility shifting to MoE therapists, mothers noted that focus changed to guidance being provided to often under-resourced teachers, rather than the therapist delivering direct assistance to the child. Mothers also highlighted the complexity and lack of clarity in the DSS pathway related to schooling as a significant challenge. No clear rationale was identified for how changes to funding, services, and focus of care had occurred or why it persists. This is concerning when the system is evidently failing to meet the needs of the child. While the reasons behind these changes remain unclear, it is evident, from the perspective of mothers, that this approach is neither effective nor logical as it adversely affects both them and their child. In this environment, some mothers in this study were disheartened to discover during the transition that their child was not deemed 'bad enough' to be eligible for MoE support or adequate MoE support. Several mothers also felt their child missed out because MoE

therapists were in short supply. This is consistent with Hood and Hume (2024) who stated MoE disability supports within schools in general are chronically underfunded with therapists often facing unmanageable workloads.

The overall negative experiences reported in this study, mainly by mothers not supported by ACC, are consistent with findings from a 2019 NZ clinical research survey which revealed parents' impression of their disabled child's school experience was significantly more negative than parents of non-disabled children (Hood & Hume, 2024). While changes and reductions to funding have a significant impact on parents during their child's school transition and beyond, there is an absence of literature reporting on it. An Education Review Office (2008) report revealed some parents had difficulty getting information about funding and support for their child. The report noted how in some schools there was a lack of transparency about funding and articulated how this created a barrier to parents positive engagement (Education Review Office, 2008). Alsem et al. (2016) reported parents from the Netherlands perceived a change and reduction in disability support services after their child started school and felt less included and involved, which left them feeling confused and upset. Janus et al. (2008) reported that parents of children starting school in Canada felt their children received less support than initially promised, experienced delays in receiving that support, and noted a decline in the quality of services compared to what was provided during the preschool years. A more recent study by Siddiqua and Janus (2017) reported that parents of children living with CP were uncertain about what support their child received or could receive on starting school and what information was being shared. The researchers concluded that this situation led to inefficiencies and barriers for the child and parent (Siddiqua & Janus, 2017). Like the mothers in my study, Hood and Hume (2024) stated that the criteria required to access government support in schools is an arduous and drawn out difficult to navigate process, with limited criteria and inadequate funding. They concluded that this has resulted in many students missing out and that the MoE's supporting document 'Learning Support Action Plan 2019' had scope for improvement.

A Disconnect During School Transition

Some mothers in the study were unhappy with how their child's transition to school had occurred. This finding is important because the transition to school is a critical period in a

child's educational experience; and a positive, supported, and inclusive transition to school is crucial for setting the scene for strong relationships between students, families, and communities, and setting a child up to succeed (Bourke-Taylor, Cotter, Lalor, et al., 2018). This is particularly the case for children with CP who are already vulnerable and disadvantaged (Elangkovan & Shorey, 2020; Flanagan et al., 2021). However, it was evident from the findings of my study that a positive, supportive, and inclusive school transition and experience does not always happen.

A compromised school transition can further exacerbate the challenges these vulnerable children face and further widen the inequity gap. There is evidence of parental dissatisfaction in NZ school transitions dating back to 2008 (Education Review Office, 2008); and despite the situation being reported over the intervening years, it remains unchanged. International literature highlights the complexity and challenges associated with transitions to school for children with special needs. Many parents express dissatisfaction with these transitions citing issues such as poor communication from schools, a lack of coordination between preschool and school stakeholders, and insufficient training for teachers (Bourke-Taylor, Cotter, Johnson, et al., 2018; Janus et al., 2008; Siddiqua & Janus, 2017).

A report by Mhuru (2020) stated NZ school learning support systems could be difficult to navigate and did not meet what all disabled students needed to ensure an inclusive and quality education. It revealed many parents of disabled children felt their child needed more help at school than they were receiving (Mhuru, 2020).

Mothers in the current study revealed that the transfer of information during school transitions between the health and education systems occurred in an inconsistent and disjointed way. These mothers reported a significant disconnect between key stakeholders during their child's school transition which, alongside their exclusion from the process, hindered the transfer of crucial knowledge. To be more specific, this disconnect happened between the MoH therapists, school, and MoE therapists. The MoE (2024) website provides clear guidance on the school transition process, emphasising the importance of strong relationships and communication between preschool and school support services for a successful start. This study, along with the report by Hood and Hume (2024), highlights an unacceptable disconnect. It is evident that significant efforts are required to better integrate health and education within the school environment, fostering a more cohesive and coordinated approach. However, there is an absence of detail as to how this should be done

(Hood & Hume, 2024). Research from Australia and Canada further reveals a similar lack of coordination and collaborative work between health and education sectors and the negative impact on children (Bourke-Taylor, Cotter, Johnson, et al., 2018; Siddiqua & Janus, 2017). While other research indicates that the elements of a successful school transition for children with disabilities includes collaboration and continuity of key staff, along with respectful, reciprocal relationships among all parties involved (Bourne, 2007; Peters, 2010; Schischka et al., 2012).

Lack of Inclusion for Child and Parent

While it is evident that NZ has invested significant money in parental resources, reports and policy development in relation to inclusion in schools (Ministry of Education, 2024, n.d.; Ministry of Justice, 2020), both this study and others have uncovered a significant disconnect between legislation, policy, and practice (Hood & Hume, 2024; Mhuru, 2020). Mothers in this and other studies continue to be unhappy with school experiences citing influencing factors as exclusion, system complexity and disconnect, and inadequate supports for their child (Hood & Hume, 2024; Mhuru, 2020). However, these reports and resources lack details of practical application and implementation (including the MoE inclusive education guides and toolkits). A burning question is how much of this information is understood by key stakeholders (e.g. schools, education providers, MoE)? The data from this current study suggest that the answer is very little.

A significant finding regarding school transitions was that mothers in my study felt excluded from important school discussions and planning in relation to their child's education and no longer felt acknowledged as an expert, as they had during their child's preschool years. This led to mothers missing out on being able to share important information and knowledge about their child and a failure to recognise the importance of learning across the home school continuum. This finding is important because excluding parents fails to acknowledge the important role that parents play in their child's education (Abed, 2014). There is resounding evidence that strong parental partnerships with schools leads to better engagement, success, and educational outcomes for the child, and higher satisfaction for the parent who is then enabled to feel better equipped to care for and support their child's educational needs (Abed, 2014; Al-Alwan, 2014; Azizah et al., 2023;

Barlow & Humphrey, 2012; Bourke-Taylor, Cotter, Johnson, et al., 2018; Ministry of Education, 2024).

Evidence from the current and past studies indicate that mothers and parents feel excluded from their child's educational experience. The NZ Government (2024) has an education website (<https://inclusive.tki.org.nz/guides>) which promotes inclusive partnerships with parents in schools and a more general website which indicates parents should be treated as their child's experts (NZ Govt, 2024). Unfortunately, the sense of exclusion and marginalisation experienced by mothers in relation to their child's educational experience is a recurring theme in both international and local research. These studies consistently demonstrate that schools fail to recognise parents' expertise and lack a clear understanding of what constitutes effective collaborative and inclusive practice (Denman, 2014; Falkmer et al., 2015; Siddiqua & Janus, 2017). A NZ schools Education Review Office (2008) report stated parents felt unwelcome and that schools were not open to working with them. They reported struggling with entrenched attitudes by some school staff about their child with special needs (Education Review Office, 2008). Hume and Hood's (2024) report of the NZ education system revealed that while good partnership relationships between school, families, and support services directly corresponded with more positive outcomes for students, they were not universally occurring. The MoE (n.d.) has an inclusive practice tool which suggests "school staff work in a collaborative and culturally-responsive way with parents, whānau (families), and students in order to identify, support, and value the individual learning and social needs of each student." There is a clear disconnect between policy and practice, with a significant lack of detailed implementation strategies to ensure effective outcomes. This gap must be addressed urgently, as its persistence will continue to result in unacceptable and inadequate support for children and their families.

Parents and caregivers (or in the case of this study, mothers) are continuing to report exclusion and discrimination in an underfunded, inadequate, disjointed school system with a fundamental disconnect between the health and education system. If no action is taken, this situation may contribute to poorer outcomes for children and increased burden for parents. Parents may come to believe that their child's success depends entirely on their own ability to competently navigate the complex education system, advocate for their child's needs, and secure appropriate support. Consequently, they may perceive paying privately for service (that they believe should be offered through the public system)

as the only viable option. This will continue to negatively impact parents' well-being and the cycle will continue if urgent action is not taken.

Considering the concerning conclusions of the 2024 Hume and Hood report describing the NZ education system as broken and inadequately funded for neurodivergent children, urgent action is needed. NZ has an obligation to provide adequate disability support to all that need it. While this seems to happen for the first 5 years of a child's life in NZ under the MoH, the system becomes divided and inequitable once children start school. There is significant work to be done.

Implications for Practice

Diagnosis

These findings highlight that having guidelines and protocols, as well as understanding parents' experiences, is insufficient on its own. Effective implementation and meaningful engagement with parents are essential to address the gaps between policy and practice. It is concerning that there is literature dating back 20 years (Fallowfield & Jenkins, 2004) consistent with my findings indicating that, despite work being done and guidelines developed, parents are continuing to report negative experiences. This means that recommended changes to the way diagnosis should be delivered have not been successfully implemented into practice in a sustained and meaningful way. The findings from my study should be shared with all health professionals involved with providing diagnoses to parents, so that they can consider what changes are required. The current research indicates that the following suggestions should be seriously considered to address this important issue.

1. Existing guidelines/protocols/frameworks/checklists on delivering a diagnosis to families should be reviewed by experts to ascertain if any are relevant and appropriate for application to the NZ context. They should include provision of follow up appointments to further discuss diagnosis as standard practice and development of a CP toolkit for parents containing information on CP that can be relevant to individual diagnoses. They should also include where to access support, funding, and treatment options.
2. An approach on training and educating health professionals responsible for delivering diagnoses should be developed and implemented. Fallowfield and Jenkins (2004) suggested that successful training should be based on "sound

educational principles, informed by evidence, and assessed and monitored adequately” (p. 318). Experiential training in actual behavioural skills may provide more successful opportunity for them to be embedded into clinical practice.

3. There should be an easy way for health professionals to identify in a patient’s clinical records a timeline of important conversations with parents and families so there can be consistency and coordination with understanding what discussions have taken place and what support parents and families require.

Community Support Groups

Considering how important social networks are to the well-being and livelihood of mothers who have a child with CP, it is concerning that the mothers in the current study reported that they stumbled across them by chance. If, as the literature indicates, informal support groups are a significant means of physical and psychosocial support for parents (Elangkovan & Shorey, 2020), then this situation deserves considerable attention and effort to ensure that mothers are not left to discover them incidentally. Clinicians would be required to play a more active role in promoting and highlighting support groups to parents as part of the diagnosis process and include information on them as a creditable form of ongoing support. Elangkovan and Shorey (2020) suggested that clinicians adopt a family-centric approach in their care of children with CP. This approach recognises the importance of caring for the family as a whole, in the context of parental issues and the child’s environment, so that child and family well-being is enhanced and best care is provided. Specific organisations, such as the CP Society of NZ, Disability Connect, and CCS Disability Action, could also play an important role with promoting and connecting parents and families with communities of support.

Disability Supports

Navigating the health and education systems is hard and complex. Parents of children with CP are constantly working to understand what is available and to get their child the support they need. One solution in the short term could be providing case managers or health navigators for families not supported by ACC to immediately help them navigate and understand the system so they have the opportunity to maximise their child’s supports and

opportunities within the current constrained system. However, a bigger long-term change is required to support parents and reduce inequities for children with CP, all of which requires careful research, thought, and consideration and will, therefore, be discussed in the research section.

School

Considering how important a fully inclusive education is for both child and family, the findings of this research are concerning. While legislation and policy appear to be intact, the application to practice has considerable work ahead. One solution could be to include a universal school orientation handbook for parents of children with special needs starting at a mainstream school along with options for electronic and video versions. This could be given to parents 12-18 months out from their child starting school and include important information such as changes to funding and potential impact. Guidance to a regularly updated website with contact details of key health professionals and health navigators to contact for support is also recommended.

Another strategy could be a health navigator (such as described by Stretton et al. 2022) allocated to each family of a child with CP not under ACC for a 12-18-month period to help with school transitions. They could engage with families 6-9 months prior to the child starting school and continue for the same period of time following the start of school. The health navigator would act as a case manager to smooth the way and guide families to ensure they receive the right support and information tailored to their individual needs. This would include providing a connecting point between MoH and MoE to make sure parents are adequately prepared for changes to disability supports when their child starts school and provide important information to prepare the family and child during all stages of the transition. They could advocate for the families and set expectations with schools to ensure that parents are acknowledged as their child's expert and fully included in their child's school support team. Alsem et al. (2016) indicated that improving guidance for both parents and therapists with the transition to primary school can have a significant positive impact.

Kearney (2016) highlighted the critical role that school principals and teachers play in providing an inclusive environment, and revealed considerable shortfalls in this area. Resources to support teachers with understanding disabilities and how to cater for children with CP or any disability should be actively utilised by all teachers and school leadership.

Information could include what inclusion at school means and support with changing the culture of individual schools if indicated. For example, the NZ website, The Education Hub (n.d.), provides courses for teachers with the aim to help them understand neurodivergence in the school setting. The MoE (n.d.) has published an 'Inclusive Practices Toolkit' which acknowledges the crucial role that teachers and principals play, and provides a framework to review a teacher's knowledge, skills, beliefs, and values. Engagement with such a tool could lead to progress with improving inclusion of disabled children within schools (Kearney, 2016). The Inclusive Practices Toolkit is designed so that teachers and schools can evaluate their own inclusive education development and understand what support and development is required to make progress (Selvaraj, 2014).

Implications for Research

Diagnosis

Further research should be conducted into how parents want to receive the diagnosis and the best way to do this. This could lead to the development of novel frameworks, guidelines and protocols for use in practice. Research exploring the best way to influence and support embedding practice change into health professionals' approach when delivering diagnosis would be valuable. Alternatively, an intervention (health professionals must follow) could be developed and audited. An understanding of why health professionals are not using the existing pathways/guidelines (what are the barriers) could assist with informing this process.

Community Support

Further research could be undertaken to explore how networks of community support can be acknowledged, strengthened, and included in the information parents might receive at time of diagnosis. There is also an opportunity to build on the evidence that supportive friendships between parents of children with disabilities originate within a therapeutic or clinical environment (Davis et al., 2010; Milbrath et al., 2008). Research could explore how to support parents to connect in this environment; for example, the best way to provide opportunities for parents to meet and connect.

Disability Support

The NZ Government should be held to account to ensure all children with CP, regardless of the aetiology of their condition, have an equitable and fair opportunity for support and therapy so they can live their best life. For this to happen research could be helpful to inform changes. For example, a comprehensive study into the impact of ACC versus non-ACC for children with CP in NZ could include developing achievable implementable and impactful recommendations that focus on ensuring all children with CP have equitable access to disability support services across the health and education sector. Additionally, the NZ Government could benefit from researching whether an initiative, such as the Australian National Disability Insurance Scheme which aligns with the Enabling Good Lives (2021) programme that is available in some parts of NZ, should be considered for adoption. Such a scheme would provide the same high level of support to all, not just some, and could reduce the burden on families with the potential to improve health equity. Consideration of potential research projects that could emerge from work currently occurring between NZ and Australian providers of CP support such as Australian and New Zealand Cerebral Palsy Strategy Collaboration (2020), the NZ CP Clinical Network, and the NZCPR, can contribute to providing a start for understanding inequities and inform the work needed to improve the lives of people living with CP.

School

Hood and Hume (2024) recommended an update to the Education and Training Act to ensure that all children with special educational needs have access to education along with access to the supports, services, and resources that they need to fully participate in and benefit from education. This requires adequate funding and resources, alongside an integrated system in which health and education sectors collaborate throughout the childhood years (or ideally the lifespan) to maximise the opportunities and potential for all children living with disabilities in NZ. Research could explore how best to do this. Findings could inform recommended approaches to practical implementation and sustained change.

In the above section, a school transition health navigator/case manager has been suggested. Ideally a more substantial change would be made to implement current policy and guidelines into practice. One solution would be to conduct research into the possibility of adopting a model currently used in Australia such as the CP Education Centre in

Melbourne. This is a not-for-profit speciality organisation that provides statewide oversight of educational support for children with CP including specific supports for children, teachers, and parents to promote successful school experiences for children with CP (Bourke-Taylor, Cotter, Lalor, et al., 2018). It is clear that NZ has invested significant money in reports and policy development in relation to inclusion in schools. However, research is consistently reporting high stress and dissatisfaction of parents in relation to inclusive school practices. The question becomes what is needed to close the gap between what the research is revealing, what policies are asking, and what is actually happening in practice? It is evident that many families and their disabled children could be potentially positively impacted by a review into the way disability support services are delivered. Meaningful research could explore what is needed in order to close this gap. It would also be beneficial to have research exploring how to deliver a more integrated approach across the health and education sector along with consideration of a more holistic framework throughout the entire childhood.

More targeted research with a much larger sample of parents/caregivers of children with CP (and possibly other disabilities) could provide specific direction on how to improve the schooling experience for parents and children. Further research could be done to understand more deeply the child's experience of starting school, and a comparison with families supported by ACC and those whose children attend special needs schools. My study has uncovered significant inadequacies with resourcing and funding; therefore, research exploring the ideal amount of resourcing and funding required in order to deliver a fully inclusive and holistic education experience for children and their families could go a long way.

Lastly, close attention and response to the findings of Hood and Humes' (2024) report would be a good place to start. A suggestion would be to form various working groups to focus on the report's recommendations and develop responsive implementation and action plans.

Further Cerebral Palsy Research

Some final thoughts regarding implications for research are as follows. It would be valuable to explore the experiences and perceptions of other key people who are involved in the life of a child with CP. For example, further research could focus on the experience of the child

living with CP. Other research could explore the fathers, siblings, grandparents, health professionals, teachers etc experience. A greater understanding of the impact of a child living with CP on those key people could provide more information to inform the best way to provide support for those responsible for caring for a child with CP and enabling them (and the child) to live their best lives.

Further research might also explore the experiences and perceptions of caregivers of children living with other disabilities in NZ. This is an area that is under-researched. Many of the issues highlighted in this study will no doubt be relevant to parents and caregivers of children with other disabilities.

Lastly, further research to more deeply understand the experiences and perceptions of caregivers of children with CP (or any disability) within Māori and Pacifica populations within NZ, as well as those living in poverty, could make an enormous difference. Such research is important given that Māori and Pacifica children and whānau often experience increased exposure to health inequities due to the ongoing impacts of colonisation, systematic racism, and structural barriers. The available research indicates that these groups already face inequities on multiple levels yet there is an absence of specific and relevant literature to inform improvements. Further research could highlight the issues and inform policy and practice so that these groups have a chance to receive equitable access to support and care.

Dissemination Strategy

There are many ways I intend to share these research findings to advocate for and influence change. As part of my dissemination strategy, I will publish peer-reviewed journal articles and present at relevant conferences and symposiums, such as the Paediatric Society and CP Conferences, Child Health Symposiums, and other relevant forums where I can engage with clinical, academic, and lived experience audiences. I also intend to share my findings with the Office of the Children's Commissioner to support advocacy efforts and inform policy development, and with the NZ CP Clinical Network to inform quality improvements and clinical guidelines for children and families. There are several opportunities to share my findings through my connections with the CP Society. I plan to integrate these findings into the recently released CP Society CP Toolkit by developing user-friendly materials and resources such as infographics, videos, or brochures to ensure insights and key messages

are presented in relevant, relatable and practical ways to families and professionals. I will present to the network of disability support organisations that the CP Society is connected with to reach a wider disability-focused audience to ensure accessibility and impact beyond academic and professional circles. I am involved in a research project led by the CP Society exploring the impact of ACC versus DSS.

Through the CP Society I am also contributing to the development of a national statement for inclusion in an international submission, coordinated by the International Alliance of Academics of Cerebral Palsy and Childhood-Onset Disabilities in collaboration with the World Health Organization. This will help inform a collective statement to the United Nations Convention on the Rights of Persons with Disabilities highlighting the experience of those living with disabilities worldwide.

Limitations of this Research

Generalisability and Sample Size

This research has provided insights into the experiences of 15 mothers raising a child with CP in NZ. The findings are specific to these 15 mothers and cannot be generalised to the entire population of mothers raising children with CP in NZ. However, it was possible to identify common experiences amongst the participants which was supported by other research.

Diversity of Population

Although every effort was made to recruit participants that reflected NZ's varied and diverse culture and population, the purposeful sampling that occurred was in general limited to those participants that responded to the recruitment flyer. Only one mother was actively recruited, this was to ensure there was adequate Pacifica Peoples representation. This sampling situation resulted in the participants consisting entirely of mothers. Therefore, this research cannot comment on and does not reflect the experiences of fathers or other caregivers of children with CP.

Cultural Nuances

While the data included a mix of ethnicities, including Māori and Pacifica Peoples, I acknowledge that due to my European-Pākehā origin (and that of my supervisors), some of the cultural nuances within it may have been unseen or overlooked.

Geographical and Technical Limitations

While participants from all over NZ were recruited, in order for those outside of Auckland to be included, participants were required to have access to the technology (computer and internet connection) so they could be interviewed virtually. This was also the case for the recruitment of participants which predominantly occurred online through Facebook and the CP Society website, therefore limiting the opportunity to those with access to these platforms.

Researcher's Positionality

It is important to acknowledge that the collection of data, analysis, and interpretation would have been influenced by my positionality as a mother of a child with CP, a nurse, and novice researcher. During the interviews I discovered that many of the participants were raising children with significantly different clinical presentations to my daughter, and that it was easier than I expected to remove myself emotionally and to be objective. Throughout the data analysis and interpretation process I ensured that I talked about my own thoughts and experiences alongside my observations from the data in order to declare them, and enlisted support with keeping them separate. I regularly checked my thinking with my supervisors and remained open to feedback. At no point did they indicate that I was not doing justice to the data or keeping a professional researcher's lens.

Conclusions

This is the first study in NZ that I know of that provides insight into the lives of mothers raising a child with CP. Considering CP is the most common disability in NZ, this study is significant, revealing important insights, shared experiences, and perceptions of 15 mothers raising a child with CP in NZ. They all went through a process of adapting to a different way of parenting. Their mothering journey led to upset, challenges, connections, and joy.

The findings revealed a difficult start to becoming a parent, which led to trauma and interruptions. It is important for all key stakeholders from Government level (i.e., policy developers) to those working on the frontline (e.g., health professionals) to be aware of this situation and to work towards ensuring systems are in place to provide wraparound support for mothers during this time of significant change. This stage was followed by the finding that mothers had to fight and advocate to get the care and support they felt their child

required, and was represented by the concept of rowing upstream against a current. This theme is significant and indicated that there is work to be done with providing a more consistent integrated disability support system across the health and education sector and a high level of equitable care for all children living with CP in NZ. The last finding revealed that despite all the challenges mothers faced, they realised that they were actually winning, but just not as expected. Mothers were grateful and proud of what they and their child had achieved, and they highlighted the importance of communities. It is important for people involved with the care of children with CP that they are aware of this finding and that they play their part in supporting mothers to connect with these unique and powerful communities.

This study has shown the resilience and strength of NZ mothers and their children who face adversity through disability. It has highlighted the inequities in the NZ health and education systems responsible for providing disability related support and care, and uncovered the trauma mothers have experienced. These are important findings that both health and education professionals and policy makers should be made aware of. I intend to share these findings to highlight these important issues with a view to being able to influence change.

Reflections

The motivation for doing this research came about during the COVID-19 lockdown when I discovered a wonderful group of parents (mainly mothers) who were all raising a child with CP. These parents seemed to be part of a hidden world. They were all amazing people doing incredible work to raise their child in often challenging and unsupportive environments. I felt relief that there were others who understood; I felt sad about how hard their lives sounded; I felt disappointed at the struggles and barriers they were living through their children. I wanted to know more, better understand their experiences, give them a voice. When I set out to do this research, I did not anticipate being inundated by mothers wanting to be interviewed—but I was. I was very tempted to increase my participant numbers in an attempt to include them all but my primary supervisor rightly reminded me that I was doing doctoral research and that the study would become too big. When I met the mothers who participated in this study, I had already experienced over a decade of mothering my daughter Molly who lives with CP, and was well aware of the challenges she (and I as her

mother) faced daily—some days felt very hard, others brought great joy. Many of the participants, who I had not previously met, talked at length about their lives and shared rich and deeply personal experiences with me.

This study is possibly the first one to ever explore parents' experience of raising a child with CP in NZ as well as their experience of disability services and support. It has highlighted the importance of creating a society and systems that provide inclusion and support for all, not just some. It has also raised the importance of providing wraparound support at the start of (and throughout) the parenting journey, having health and education systems connected and focused on providing inclusive equitable support and care for children with CP, as well as supporting connections within disability communities. At the heart of these systems there is a child and their parent/s who are challenged and often disadvantaged because of the way the disability services and supports have been arranged and due to a general lack of knowledge and understanding from others across many parts of society. This research has given a voice to this situation and intends to be the start of ongoing conversations and work to inform a more parent/family experience-based integrated and comprehensive single pathway disability support system. A society where we meet the needs of these families in their entirety should be the focus. A country where children living with CP can have the same opportunities as non-disabled children and where parents do not need to fight and advocate would be a country where equity is achieved. This should be the vision and goal.

References

- Abeasi, D. A., Nkosi, N. G., Badoe, E., & Adjeman, J. (2024). Caring by default: experiences of caregivers of children with developmental disabilities in Ghana mirrored in the context of the stress process model. *BMC Nursing*, 23(1), 482.
<https://doi.org/10.1186/s12912-024-02142-1>
- Abed, M. (2014). Challenges to the concept “partnership with parents” in special needs education. *Journal on Educational Psychology*, 7(4), 1-11.
<https://files.eric.ed.gov/fulltext/EJ1098637.pdf>
- Aburn, E. G., Gott, M., & Hoare, K. (2021). Experiences of an insider researcher - interviewing your own colleagues. *Nurse Researcher*, 29(3), 22-28.
<https://doi.org/10.7748/nr.2021.e1794>
- Accident Compensation Act 2019 (NZ).
- Adams, E. (2010). The joys and challenges of semi-structured interviewing. *Community Practitioner*, 83(7), 18-21.
- A dugna, M. B., Nabbouh, F., Shehata, S., & Ghahari, S. (2020). Barriers and facilitators to healthcare access for children with disabilities in low and middle income sub-Saharan African countries: A scoping review. *BMC Health Services Research*, 20, 1-11.
<https://doi.org/10.1186/s12913-019-4822-6>
- Afonso, T., da Costa Silva, S. S., & Pontes, F. A. R. (2020). Perceptions of mothers of children with cerebral palsy: A look at the past and the future/Percepções de mães de crianças com paralisia cerebral: Um olhar sobre o passado e o futuro. *Revista de Pesquisa: Cuidado é Fundamental Online*, 12, 138-145.
<https://doi.org/10.9789/2175-5361.rpcfo.v12.7146>
- Agarwal, A., & Verma, I. (2012). Cerebral palsy in children: An overview. *Journal of Clinical Orthopaedics and Trauma*, 3(2), 77-81. <https://doi.org/10.1016/j.icot.2012.09.001>
- Ahmadzadeh, Z., Rassafiani, M., Amozadeh Khalili, M., & Mirmohammadkhani, M. (2015). Factors associated with quality of life in mothers of children with cerebral palsy in Iran. *Hong Kong Journal of Occupational Therapy*, 25(C), 15-22.
<https://doi.org/10.1016/j.hkjot.2015.02.002>
- Al-Ababneh, M. (2020). Linking ontology, epistemology and research methodology. *Science & Philosophy*, 8(1), 75-91. <https://doi.org/10.23756/sp.v8i1.500>

- Al-Alwan, A. (2014). Modeling the relations among parental involvement, school engagement and academic performance of high school students. *International Education Studies*, 7(4), 47-56. <https://doi.org/10.5539/ies.v7n4p47>
- Al-Dababneh, K., & Al-Zboon, E. (2018). Parents' attitudes towards their children with cerebral palsy. *Early Child Development and Care*, 188(6), 731-747. <https://doi.org/10.1080/03004430.2016.1230737>
- Al-Sadi, H. (2015). *Learner autonomy and voice in a tertiary ELT institution in Oman* [Doctoral thesis, University of Sheffield]. White Rose eTheses Online. <https://etheses.whiterose.ac.uk/id/eprint/9294/>
- Alaee, N., Shahboulaghi, F., Khankeh, H., Mohammadi, K., & Mohammad Khan Kermanshahi, S. (2014). Psychosocial challenges for parents of children with cerebral palsy: A qualitative study. *Journal of Child and Family Studies*, 24(7), 2147-2154. <https://doi.org/10.1007/s10826-014-0016-3>
- Alibakhshi, H., Azkhosh, M., Bahmani, B., Khanjani, M., & Shahboulaghi, F. (2021). Hope facilitators in parents with children suffering from cerebral palsy: A qualitative study. *Iranian Journal of Psychiatry and Behavioral Sciences*, 15(2). <https://doi.org/10.5812/ijpbs.107430>
- Allen, R. E. S., & Wiles, J. L. (2016). A rose by any other name: Participants choosing research pseudonyms. *Qualitative Research in Psychology*, 13(2), 149-165. <https://doi.org/10.1080/14780887.2015.1133746>
- Allermo Fletcher, A., Kilgour, G., Sandle, M., Kidd, S., Sheppard, A., Swallow, S., Stott, N. S., Battin, M., Korent, W., & Williams, S. A. (2024). Partnering early to provide for infants at risk of cerebral palsy (pēpi arc): Protocol for a feasibility study of a regional hub for early detection of cerebral palsy in Aotearoa New Zealand. *Frontiers in Pediatrics*, 12, 1344579. <https://doi.org/10.3389/fped.2024.1344579>
- Alsem, M., Verhoef, M., Gorter, J., Langezaal, L., Visser-Meily, J., & Ketelaar, M. (2016). Parents' perceptions of the services provided to children with cerebral palsy in the transition from preschool rehabilitation to school-based services. *Child: Care, Health and Development*, 42(4), 455-463. <https://doi.org/10.1111/cch.12341>
- Amatya, B., & Khan, F. (2011). Rehabilitation for cerebral palsy: Analysis of the Australian rehabilitation outcome dataset. *Journal of Neurosciences in Rural Practice*, 2(1), 43-49. <https://doi.org/10.4103/0976-3147.80097>

- Appleton, J. V., & King, L. (2002). Journeying from the philosophical contemplation of constructivism to the methodological pragmatics of health services research. *Journal of Advanced Nursing*, 40(6), 641-648. <https://doi.org/10.1046/j.1365-2648.2002.02424.x>
- Askeland, S., Guise, V., Aase, K., & Sogstad, M. K. R. (2025). Families' strategies for navigating care for their child with cerebral palsy: A qualitative study. *Health Expectations*, 28(2), e70197. <https://doi.org/10.1111/hex.70197>
- Australian and New Zealand Cerebral Palsy Strategy Collaboration. (2020). *Australian and New Zealand Cerebral Palsy Strategy, 2020* <https://cerebralpalsystategy.com.au/>
- Azizah, N., Rahmawati, R., & Purwanta, E. (2023). Transition program for young children with special needs: Parents' experiences. *Jurnal Obsesi: Jurnal Pendidikan Anak Usia Dini*, 7(1), 1055-1062. <https://doi.org/10.31004/obsesi.v7i1.4053>
- Badawi, N., Honan, I., Finch-Edmondson, M., Hogan, A., Fitzgerald, J., & Imms, C. (2020). The Australian & New Zealand Cerebral Palsy Strategy. *Developmental Medicine and Child Neurology*, 62(8), 885-885. <https://doi.org/10.1111/dmcn.14554>
- Baird, G., McConachie, H., & Scrutton, D. (2000). Parents' perceptions of disclosure of the diagnosis of cerebral palsy. *Archives of Disease in Childhood*, 83(6), 475-480. <https://doi.org/10.1136/adc.83.6.475>
- Barlow, A., & Humphrey, N. (2012). A natural variation study of engagement and confidence among parents of learners with special educational needs and disabilities. *European Journal of Special Needs Education*, 27(4), 447-467. <https://doi.org/10.1080/08856257.2012.711959>
- Beauchamp, M. L., Amorim, K., Wunderlich, S. N., Lai, J., Scolah, J., & Elsabbagh, M. (2022). Barriers to access and utilization of healthcare services for minority-language speakers with neurodevelopmental disorders: A scoping review. *Frontiers in Psychiatry*, 13, 915999. <https://doi.org/10.3389/fpsy.2022.915999>
- Berger, R. (2015). *Now I see it, now I don't: Researcher's position and reflexivity in qualitative research* (Vol. 15). SAGE.
- Berkey, F., Wiedemer, J., & Vithalani, N. (2018). Delivering bad or life-altering news. *American Family Physician*, 98(2), 99-104.
- Bettany-Saltikov, J., & McSherry, R. (2016). *How to do a systematic literature review in nursing: A step-by-step guide* (2nd ed.). Elsevier.

- Blair, E. (2010). Epidemiology of the cerebral palsies. *Orthopedic Clinics of North America*, 41(4), 441-455. <https://doi.org/10.1016/j.ocl.2010.06.004>
- Bourke-Taylor, H., Cotter, C., Johnson, L., & Lalor, A. (2018). Belonging, school support and communication: Essential aspects of school success for students with cerebral palsy in mainstream schools. *Teaching and Teacher Education*, 70, 153-164. <https://doi.org/10.1016/j.tate.2017.11.016>
- Bourke-Taylor, H., Cotter, C., Lalor, A., & Johnson, L. (2018). School success and participation for students with cerebral palsy: A qualitative study exploring multiple perspectives. *Disability and Rehabilitation*, 40(18), 2163-2171. <https://doi.org/10.1080/09638288.2017.1327988>
- Bourne, L. (2007). A story of transition to school. *Kairaranga*, 8(1), 31-33. <https://doi.org/10.54322/kairaranga.v8i1.79>
- Bowden, N., Kokaua, J., & Murray, S. (2015). *Ethnic inequalities in children and young people's access to disability-related support*. <https://apo.org.au/sites/default/files/resource-files/2020-03/apo-nid307973.pdf>
- Bradley, A. (2022). *Child wins five-year battle with ACC for birth-related injury cover*. Radio New Zealand. <https://www.rnz.co.nz/news/national/460058/child-wins-five-year-battle-with-acc-for-birth-related-injury-cover>
- Braun, V., & Clarke, V. (2012). Thematic analysis. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbook of research methods in psychology, Vol. 2. Research designs: Quantitative, qualitative, neuropsychological, and biological* (pp. 57–71). American Psychological Association. <https://doi.org/10.1037/13620-0>
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11(4), 589-597. <https://doi.org/10.1080/2159676X.2019.1628806>
- Braun, V., & Clarke, V. (2022). Conceptual and design thinking for thematic analysis. *Qualitative Psychology*, 9(1), 3. <https://doi.org/10.1037/qap0000196>
- Bray, L., Carter, B., Sanders, C., Blake, L., & Keegan, K. (2017). Parent-to-parent peer support for parents of children with a disability: A mixed method study. *Patient Education and Counseling*, 100(8), 1537-1543. <https://doi.org/10.1016/j.pec.2017.03.004>

- Brekke, I., & Alecu, A. (2023). The health of mothers caring for a child with a disability: A longitudinal study. *BMC Women's Health*, 23(1), 639.
<https://doi.org/10.1186/s12905-023-02798-y>
- Broll, J., Schäfer, S. K., Lüdecke, D., Nickel, S., Lieb, K., & Helmreich, I. (2025). Effects of micro-and macro-stressors and resilience factors on the mental health of parents caring for chronically ill and disabled children and adolescents. *BMC Nursing*, 24(1), 489. <https://doi.org/10.1186/s12912-025-03125-6>
- Brossard-Racine, M., Hall, N., Majnemer, A., Shevell, M., Law, M., Poulin, C., & Rosenbaum, P. (2012). Behavioural problems in school age children with cerebral palsy. *European Journal of Paediatric Neurology*, 16(1), 35-41.
<https://doi.org/10.1016/j.ejpn.2011.10.001>
- Byrne, E., Brugha, R., Clarke, E., Lavelle, A., & McGarvey, A. (2015). Peer interviewing in medical education research: Experiences and perceptions of student interviewers and interviewees. *BMC Research Notes*, 8(1), Article 513.
<https://doi.org/10.1186/s13104-015-1484-2>
- Camargo, N., Lima, M., Brietzke, E., Mucci, S., & Góis, A. (2019). Teaching how to deliver bad news: A systematic review. *Revista Bioética*, 27, 326-340.
<https://doi.org/10.1590/1983-80422019272317>
- Cantero-Garrito, P. A., Moruno-Miralles, P., & Flores-Martos, J. A. (2020). Mothers who take care of children with disabilities in rural areas of a Spanish region. *International Journal of Environmental Research and Public Health*, 17(8), 2920.
<https://doi.org/10.3390/ijerph17082920>
- Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum*, 41(5), 545-547.
<https://doi.org/10.1188/14.ONF.545-547>
- Celik, P., & Kara Uzun, A. (2023). Stressful experiences and coping strategies of parents of young children with Down syndrome: A qualitative study. *Journal of Applied Research in Intellectual Disabilities*, 36(4), 881-894.
<https://doi.org/10.1111/jar.13108>
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. SAGE.

- Chavez, C. (2015). Conceptualizing from the inside: Advantages, complications, and demands on insider positionality. *Qualitative Report*, 13(3), 474-494.
<https://doi.org/10.46743/2160-3715/2008.1589>
- Chiluba, B. C., & Moyo, G. (2017). Caring for a cerebral palsy child: A caregivers perspective at the University Teaching Hospital, Zambia. *BMC Research Notes*, 10(1), 724.
<https://doi.org/10.1186/s13104-017-3011-0>
- Chu, S.-Y., Wen, C.-C., & Weng, C.-Y. (2022). Gender differences in caring for children with genetic or rare diseases: A mixed-methods study. *Children*, 9(5), 627.
<https://doi.org/10.3390/children9050627>
- Claydon, L., S. (2015). Rigour in quantitative research. *Nursing standard (Royal College of Nursing (Great Britain): 1987)*, 29(47), 43-48.
<https://doi.org/10.7748/ns.29.47.43.e8820>
- Corbin, J., & Strauss, A. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (4th ed.). SAGE.
- Cottrell, D., & Summers, K. (1990). Communicating an evolutionary diagnosis of disability to parents. *Child: Care, Health and Development*, 16(4), 211-218.
<https://doi.org/10.1111/j.1365-2214.1990.tb00655.x>
- Craig, E., Reddington, A., Adams, J., Dell, R., Jack, S., Oben, G., Wicken, A., & Simpson, J. (2016). *The health of pacific children and young people with chronic conditions and disabilities in New Zealand (2013)*. New Zealand Child and Youth Epidemiology Service. <https://ourarchive.otago.ac.nz/esploro/outputs/report/The-Health-of-Pacific-Children-and/9926479010101891>
- Creswell, J. (2003). *Research design: Qualitative, quantitative, and mixed methods approaches*. SAGE.
- Creswell, J. (2013). *Qualitative inquiry & research design: Choosing among five approaches*. SAGE.
- Crettenden, A., Lam, J., & Denson, L. (2018). Grandparent support of mothers caring for a child with a disability: Impacts for maternal mental health. *Research in Developmental Disabilities*, 76, 35-45. <https://doi.org/10.1016/j.ridd.2018.02.004>
- Cypress, B. S. (2015). Qualitative research: The “what,” “why,” “who,” and “how”! *Dimensions of Critical Care Nursing*, 34(6), 35-45.
<https://doi.org/10.1097/DCC.0000000000000150>

- Dagenais, L., Hall, N., Majnemer, A., Birnbaum, R., Dumas, F., Gosselin, J., Koclas, L., & Shevell, M. (2006). Communicating a diagnosis of cerebral palsy: Caregiver satisfaction and stress. *Pediatric Neurology*, 35(6), 408-414.
<https://doi.org/10.1016/j.pediatrneurol.2006.07.006>
- DalPezzo, N. (2009). Nursing care: A concept analysis. *Nursing Forum*, 44(4), 256-257.
<https://doi.org/10.1111/j.1744-6198.2009.00151.x>
- Dambi, J., M., & Jelsma, J. (2014). The impact of hospital-based and community based models of cerebral palsy rehabilitation: A quasi-experimental study. *BMC Pediatrics*, 14(1), 301. <https://doi.org/10.1186/s12887-014-0301-8>
- Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., Davern, M., & Reddihough, D. (2010). The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers. *Child Care Health Development*, 36(1), 63-73.
<https://doi.org/10.1111/j.1365-2214.2009.00989.x>
- Davis, E., Shelly, A., Waters, E., Mackinnon, A., Reddihough, D., Boyd, R., & Graham, H. K. (2009). Quality of life of adolescents with cerebral palsy: Perspectives of adolescents and parents. *Developmental Medicine and Child Neurology*, 51(3), 193-199.
<https://doi.org/10.1111/j.1469-8749.2008.03194.x>
- Daynes-Kearney, R., & Gallagher, S. (2023). Online support groups for family caregivers: Scoping review. *Journal of Medical Internet Research*, 25, e46858.
<https://doi.org/10.2196/46858>
- Dempsey, L., Dowling, M., Larkin, P., & Murphy, K. (2016). Sensitive interviewing in qualitative research. *Research in Nursing and Health*, 39(6), 480-490.
<https://doi.org/10.1002/nur.21743>
- Denman, S. (2014). Parents as experts on children with disabilities: Being prepared for the long-haul. *International Journal of Disability, Development and Education*, 61(4), 434-440. <https://doi.org/10.1080/1034912X.2014.956003>
- Denzin, N. K., & Lincoln, Y. S. (2000). *Handbook of qualitative research*. SAGE.
- Dezoti, A., Alexandre, A., de Souza Freire, M., des Mercês, N., & de Azevedo Mazza, V. (2015). Social support to the families of children with cerebral palsy. *Acta Paulista de Enfermagem*, 28(2), 172-176. <https://doi.org/10.1590/1982-0194201500029>

- Dickinson, C., Sheffield, J., Mak, C., Boyd, R., & Whittingham, K. (2023). When a baby is diagnosed at high risk of cerebral palsy: Understanding and meeting parent need. *Disability and Rehabilitation*, 45(24), 4016-4024.
<https://doi.org/10.1080/09638288.2022.2144491>
- Dlamini, M. D., & Chang, Y.-J. (2025). Caregiver burden in caring for children with cerebral palsy: A concept analysis. *International Journal of Health, Medicine and Nursing Practice*, 7(1), 1-23.
- Duncan, G. (2019). National's fortunate failure to deregulate accident compensation. *New Zealand Sociology*, 34(2), 253-277.
<https://search.informit.org/doi/10.3316/informit.901282524110059>
- Eaves, Y. (2001). A synthesis technique for grounded theory data analysis. *Journal of Advanced Nursing*, 35(5), 654-663. <https://doi.org/10.1046/j.1365-2648.2001.01897.x>
- Education Review Office. (2008). *Partners in learning: Good practice*.
<https://ero.govt.nz/sites/default/files/2021-05/pil-gp-sep08.pdf>
- Elangkovan, I., T, & Shorey, S. (2020). Experiences and needs of parents caring for children with cerebral palsy: A systematic review. *Journal of Developmental and Behavioral Pediatrics*, 41(9), 730-739. <https://doi.org/10.1097/DBP.0000000000000880>
- EmploySure. (2021). *Accident Compensation Act 2001*.
<https://employsure.co.nz/guides/important-legislation/accident-compensation-act-2001>
- Enabling Good Lives. (2021). *EGL background*. <https://www.enablinggoodlives.co.nz/about-egl/enabling-good-lives-context/egl-background/>
- Faccioli, S., Pagliano, E., Ferrari, A., Maghini, C., Siani, M. F., Sgherri, G., Cappetta, G., Borelli, G., Farella, G. M., & Foscan, M. (2023). Evidence-based management and motor rehabilitation of cerebral palsy children and adolescents: A systematic review. *Frontiers in Neurology*, 14, 1171224. <https://doi.org/10.3389/fneur.2023.1171224>
- Falkmer, M., Anderson, K., Joosten, A., & Falkmer, T. (2015). Parents' perspectives on inclusive schools for children with autism spectrum conditions. *International Journal of Disability, Development and Education*, 62(1), 1-23.
<https://doi.org/10.1080/1034912X.2014.984589>

- Fallowfield, L., & Jenkins, V. (2004). Communicating sad, bad, and difficult news in medicine. *The Lancet*, 363(9405), 312-319. [https://doi.org/10.1016/S0140-6736\(03\)15392-5](https://doi.org/10.1016/S0140-6736(03)15392-5)
- Farajzadeh, A., Dehghanizadeh, M., Maroufizadeh, S., Amini, M., & Shamili, A. (2021). Predictors of mental health among parents of children with cerebral palsy during the COVID-19 pandemic in Iran: A web-based cross-sectional study. *Research in Developmental Disabilities*, 112, 103890. <https://doi.org/10.1016/j.ridd.2021.103890>
- Fernandez-Alcantara, M., Garcia-Caro, M. P., Laynez-Rubio, C., Perez-Marfil, M. N., Marti-Garcia, C., Benitez-Feliponi, A., Berrocal-Castellano, M., & Cruz-Quintana, F. (2015). Feelings of loss in parents of children with infantile cerebral palsy. *Disability and Health Journal*, 8(1), 93-101. <https://doi.org/10.1016/j.dhjo.2014.06.003>
- Fitzgibbon, G. (2006). *The impact of resilience on the experience of parents raising a disabled child* [Master's thesis, Auckland University of Technology]. Tuwhera. <https://openrepository.aut.ac.nz/handle/10292/11277>
- Flanagan, D., Gaebler, D., Bart-Plange, E., & Msall, M. (2021). Addressing disparities among children with cerebral palsy: Optimizing enablement, functioning, and participation. *Journal of Pediatric Rehabilitation Medicine*, 14(2), 153-159. <https://doi.org/10.3233/PRM-210015>
- Foliaki, S., Kokaua, J., Schaaf, D., & Tukuitonga, C. (2006). Pacific People. In M. A. Oakley Browne, J. E. Wells, & K. M. Scott (Eds.), *Te Rau Hinengaro: The New Zealand Mental Health Survey* (pp. 180). Ministry of Health.
- Gao, Z. (2011). Delivering bad news to patients—the necessary evil. *Journal of Medical Colleges of PLA*, 26(2), 103-108. [https://doi.org/10.1016/S1000-1948\(11\)60033-6](https://doi.org/10.1016/S1000-1948(11)60033-6)
- Goertz, G., & Mahoney, J. (2012). Concepts and measurement: Ontology and epistemology. *Social Science Information*, 51(2), 205-216. <https://doi.org/10.1177/0539018412437108>
- Gold, J. (2016). *Parent experiences and coping processes when raising children with Asperger syndrome: Challenges, turning points and building resilience* [Doctoral thesis, Victoria University of Wellington]. <http://hdl.handle.net/10063/4990>
- Gomes, G., de Jung, B., Nobre, C., de Oliveira Norberg, P., Hirsch, C., & Dresch, F. (2019). Social support network of the family for the care of children with cerebral palsy. *Revista Enfermagem UERJ*, 27(e40274), 1-6. <https://doi.org/10.12957/reuerj.2019.40274>

- Goodyear-Smith, F., & Ashton, T. (2019). New Zealand health system: Universalism struggles with persisting inequities. *The Lancet*, *394*(10196), 432-442.
[https://doi.org/10.1016/S0140-6736\(19\)31238-3](https://doi.org/10.1016/S0140-6736(19)31238-3)
- Goudie, A., Narcisse, M.-R., Hall, D. E., & Kuo, D. Z. (2014). Financial and psychological stressors associated with caring for children with disability. *Families, Systems, & Health*, *32*(3), 280. <https://doi.org/10.1037/fsh0000027>
- Gray, L., Ng, H., & Bartlett, D. (2010). The gross motor function classification system: An update on impact and clinical utility. *Pediatric Physical Therapy*, *22*(3), 315-320.
<https://doi.org/10.1097/PEP.0b013e3181ea8e52>
- Greene, M. J. (2014). On the inside looking in: Methodological insights and challenges in conducting qualitative insider research. *Qualitative Report*, *19*(29), 1-13.
<https://doi.org/10.46743/2160-3715/2014.1106>
- Greiner, A., & Conklin, J. (2015). Breaking bad news to a pregnant woman with a fetal abnormality on ultrasound. *Obstetrical & Gynecological Survey*, *70*(1), 39-44.
<https://doi.org/10.1097/OGX.0000000000000149>
- Gruebner, O., van Haasteren, A., Hug, A., Elayan, S., Sykora, M., Albanese, E., Naslund, J., Wolf, M., Fadda, M., & von Rhein, M. (2022). Digital platform uses for help and support seeking of parents with children affected by disabilities: Scoping review. *Journal of Medical Internet Research*, *24*(12), e37972. <https://doi.org/10.2196/37972>
- Guba, E., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). SAGE.
- Gupta, V. B., Mehrotra, P., & Mehrotra, N. (2012). Parental stress in raising a child with disabilities in India. *Disability, CBR & Inclusive Development*, *23*(2), 41-52.
<https://doi.org/10.5463/dcid.v23i2.119>
- Guttmann, K., Flibotte, J., & DeMauro, S. (2018). Parental perspectives on diagnosis and prognosis of neonatal intensive care unit graduates with cerebral palsy. *The Journal of Pediatrics*, *203*, 156-162. <https://doi.org/10.1016/j.jpeds.2018.07.089>
- Hayles, E., Harvey, D., Plummer, D., & Jones, A. (2015). Parents' experiences of health care for their children with cerebral palsy [Grounded Theories]. *Qualitative Health Research*, *25*(8), 1139-1154. <https://doi.org/10.1177/1049732315570122>

- Health and Disability System Review. (2020). *Health and Disability System Review – Final report – Pūrongo Whakamutunga*. <https://www.systemreview.health.govt.nz/assets/Uploads/hdsr/health-disability-system-review-final-report.pdf>
- Hitchcock, B., Hocking, C., & Jones, M. (2020). The perceptions and concerns of mothers raising a child with developmental coordination disorder. *New Zealand Journal of Occupational Therapy*, 67(3), 23.
<https://search.informit.org/doi/10.3316/informit.580882897600837>
- Hood, N., & Hume, R. (2024). *The illusion of inclusion: The experiences of neurodivergent children and those supporting them in Aotearoa New Zealand's education system*.
<https://www.theeducationhub.org.nz>
- Huang, Y. P., Kellett, U., & St John, W. (2012). Being concerned: Caregiving for Taiwanese mothers of a child with cerebral palsy. *Journal of Clinical Nursing*, 21(1-2), 189-197.
<https://doi.org/10.1111/j.1365-2702.2011.03741.x>
- Huang, Y. P., Kellett, U. M., & St John, W. (2010). Cerebral palsy: Experiences of mothers after learning their child's diagnosis. *Journal of Advanced Nursing*, 66(6), 1213-1221.
<https://doi.org/10.1111/j.1365-2648.2010.05270.x>
- Hunt, M. R. (2009). Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative Health Research*, 19(9), 1284-1292.
<https://doi.org/10.1177/1049732309344612>
- Inan Budak, M., Küçük, L., & Civelek, H. Y. (2018). Life experiences of mothers of children with an intellectual disability: A qualitative study. *Journal of Mental Health Research in Intellectual Disabilities*, 11(4), 301-321.
<https://doi.org/10.1080/19315864.2018.1518502>
- Janus, M., Kopechanski, L., Cameron, R., & Hughes, D. (2008). In transition: Experiences of parents of children with special needs at school entry. *Early Childhood Education Journal*, 35, 479-485. <https://doi.org/10.1007/s10643-007-0217-0>
- Johnston, C., Tracey, D., Mahmic, S., & Papps, F. (2013). *Getting the best from disability care Australia: Families, information and decision making: Report of a project undertaken for the practical design fund department of families, housing, community services and indigenous affairs*.
<https://researchdirect.westernsydney.edu.au/islandora/object/uws:26945>

- Jonsson, U., Eek, M., Sunnerhagen, K., & Himmelmann, K. (2019). Cerebral palsy prevalence, subtypes, and associated impairments: A population-based comparison study of adults and children. *Developmental Medicine and Child Neurology*, *61*(10), 1162-1167. <https://doi.org/10.1111/dmcn.14229>
- Kaplan, G., & Celik, P. (2023). Intersectionality of disability and cultural/linguistic diversity in the UK: A literature review. *Frontiers in Education*, *8*, 1239777. <https://doi.org/10.3389/educ.2023.1239777>
- Kearney, A. (2016). The right to education: What is happening for disabled students in New Zealand? *Disability Studies Quarterly*, *36*(1). <https://doi.org/10.18061/dsq.v36i1.4278>
- Kelly, K., Doucet, S., Luke, A., Azar, R., & Montelpare, W. (2022). Exploring the use of a facebook-based support group for caregivers of children and youth with complex care needs: Qualitative descriptive study. *JMIR Pediatrics and Parenting*, *5*(2), e33170. <https://doi.org/10.2196/33170>
- Kouther, D. A., Shakir, M. O., Alhumaidah, R. A., Jamaluddin, H. A., Jaha, A. Y., Alshumrani, M. J., & Hakami, A. Y. (2022). Factors influencing the mental health of caregivers of children with cerebral palsy. *Frontiers in Pediatrics*, *10*, 920744. <https://doi.org/10.3389/fped.2022.920744>
- Kuper, H., Gatta, D. R., Rotenberg, S., Banks, L. M., Smythe, T., & Heydt, P. (2024). Building disability-inclusive health systems. *The Lancet Public Health*, *9*(5), e316-e325. [https://doi.org/10.1016/S2468-2667\(24\)00042-2](https://doi.org/10.1016/S2468-2667(24)00042-2)
- Kurtuncu, M., Akhan, L. U., Yildiz, H., & Demirbag, B. C. (2015). Experiences shared through the interviews from fifteen mothers of children with cerebral palsy. *Sexuality and Disability*, *33*(3), 349-363. <https://doi.org/10.1007/s11195-014-9373-5>
- Lee, J. (2019). *Single-mother led families with disabled children in Aotearoa New Zealand* [Master's thesis, Massey University]. <http://api.digitalnz.org/records/45465135/source>
- Legg, H., & Tickle, A. (2019). UK parents' experiences of their child receiving a diagnosis of autism spectrum disorder: A systematic review of the qualitative evidence. *Autism*, *23*(8), 1897-1910. <https://doi.org/10.1177/1362361319841488>
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. SAGE.

- Lincoln, Y. S., & Guba, E. G. (2016). *The constructivist credo*. Routledge.
<https://doi.org/10.4324/9781315418810>
- Lincoln, Y. S., Lynham, S., & Guba, E. G. (2011). Paradigmatic controversies, contradictions, and emerging confluences, revisited. In N. Denzin & Y. Lincoln (Eds.), *The Sage handbook of qualitative research* (4th ed., pp. 97-128). SAGE.
- Liu, F., Shen, Q., Huang, M., & Zhou, H. (2023). Factors associated with caregiver burden among family caregivers of children with cerebral palsy: A systematic review. *BMJ Open*, 13(4), e065215. <https://doi.org/10.1136/bmjopen-2022-065215>
- Low, F., Gluckman, P., & Poulton, R. (2021). *Intergenerational disadvantage: Why maternal mental health matters*. Koi Tū: The Centre for Informed Futures.
<https://informedfutures.org/wp-content/uploads/pdf/Intergenerational-disadvantage-maternal-mental-health.pdf>
- Mackey, A., Sorhage, A., Alzahr, A., & Stott, S. (2022). *The New Zealand cerebral palsy register report*. N.Z.C.P. Register. https://cerebralpalsy.org.nz/wp-content/uploads/2022/09/NZCPR-Report-2022-8Sept_FINAL.pdf
- Manuel, J., Naughton, M., Balkrishnan, R., Paterson Smith, B., & Koman, L. (2003). Stress and adaptation in mothers of children with cerebral palsy. *Journal of Pediatric Psychology*, 28(3), 197-201. <https://doi.org/10.1093/jpepsy/jsg007>
- Masi, A., Mendoza Diaz, A., Tully, L., Azim, S. I., Woolfenden, S., Efron, D., & Eapen, V. (2021). Impact of the COVID-19 pandemic on the well-being of children with neurodevelopmental disabilities and their parents. *Journal of Paediatrics and Child Health*, 57(5), 631-636. <https://doi.org/10.1111/jpc.15285>
- Matziou, V., Manesi, V., Vlachioti, E., Perdikaris, P., Matziou, T., Chliara, J. I., & Mpoutopoulou, B. (2018). Evaluating how paediatric nurses perceive the family-centred model of care and its use in daily practice. *British Journal of Nursing*, 27(4). <https://doi.org/10.12968/bjon.2018.27.14.810>
- McCann, D., Bull, R., & Winzenberg, T. (2012). The daily patterns of time use for parents of children with complex needs: A systematic review. *Journal of Child Health Care*, 16(1), 26-52. <https://doi.org/10.1177/1367493511420186>
- McDowell, B. (2008). The gross motor function classification system – expanded and revised. *Developmental Medicine and Child Neurology*, 50(10), 725.
<https://doi.org/10.1111/j.1469-8749.2008.03104.x>

- McKay, M., & Hensey, O. (1990). From the other side: Parents' views of their early contacts with health professionals. *Child: Care:Health and Development*, 16(6), 373-381.
<https://doi.org/10.1111/j.1365-2214.1990.tb00670.x>
- McNaughton, H., & McPherson, K. (2000). New Zealand and the ACC: A noble experiment that failed? *The Australian Journal of Rehabilitation Counselling*, 6(2), 86-95.
<https://doi.org/10.1017/S1323892200000922>
- Mhuru, M. (2020). *The educational experiences of disabled learners*.
www.education.govt.nz/goto/whakaaro
- Michael-Asalu, A., Taylor, G., Campbell, H., Lelea, L., & Kirby, R., S. (2019). Cerebral palsy: Diagnosis, epidemiology, genetics, and clinical update. *Advances in Pediatrics*, 66, 189-208. <https://doi.org/10.1016/j.yapd.2019.04.002>
- Milbrath, V. M., Cecagno, D., Soares, D. C., Amestoy, S. C., & Heckler de Siqueira, H. C. (2008). Being a woman, mother to child with cerebral palsy [Original]. *Acta Paulista de Enfermagem*, 21(3), 427-431. <https://doi.org/10.1590/S0103-21002008000300007>
- Ministry of Education. (2021). *The education and disability legislation guiding our approach to learning support*. <https://www.education.govt.nz/school/student-support/special-education/education-disability-legislation/>
- Ministry of Education. (2024). *Transitions in early learning*
<https://www.education.govt.nz/early-childhood/teaching-and-learning/transitions-in-early-learning/>
- Ministry of Education. (n.d.). *Inclusive practices toolkit*.
<https://wellbeingatschool.org.nz/inclusive-toolkit>
- Ministry of Health. (2012). *Service specification (national) child development services*.
<https://www.health.govt.nz/system/files/documents/pages/service-specification-child-development-services.pdf>
- Ministry of Health. (2017). *The New Zealand health and disability system: Handbook of organisations and responsibilities*.
<https://www.beehive.govt.nz/sites/default/files/2017-12/Health%20-%20Organisations%20and%20Responsibilities%200.pdf>

- Ministry of Health. (2018a). *Contracting and working disability support services*.
<https://www.health.govt.nz/our-work/disability-services/contracting-and-working-disability-support-services/>
- Ministry of Health. (2018b). *Faiva Ora 2016–2021 National Pasifika disability plan*.
<https://www.health.govt.nz/publications/faiva-ora-2016-2021-national-pasifika-disability-plan>
- Ministry of Health. (2018c). *Whāia Te Ao Mārama 2018 To 2022: The Māori disability action plan*. <https://www.health.govt.nz/publications/whaia-te-ao-marama-2018-to-2022-the-maori-disability-action-plan>
- Ministry of Justice. (2020). *Constitutional issues and human rights*. The New Zealand Government. <https://www.justice.govt.nz/justice-sector-policy/constitutional-issues-and-human-rights/human-rights/international-human-rights/crc/>
- Ministry of Social Development. (n.d). *Transition from school service for people with a disability or health condition*. <https://www.msds.govt.nz/what-we-can-do/disability-services/transition-from-school-service-for-people-with-a-disability-or-health-condition.html>
- Moen, R. D. (n.d.). *What is cerebral palsy?: How is the severity of CP classified?* Retrieved March 16, 2024, from <https://www.madeformovement.com/all-you-need-to-know-about-cerebral-palsy#scroll4>
- Mohamed Madi, S., Mandy, A., & Aranda, K. (2019). The perception of disability among mothers living with a child with cerebral palsy in Saudi Arabia. *Global Qualitative Nursing Research*, 6, 1-11. <https://doi.org/10.1177/2333393619844096>
- Mohanty, M., Beaulieu, F., Sampath, S., Tambunan, D., Kataria, S., & Rosman, N. (2021). “Your child has cerebral palsy”: Parental understanding and misconceptions. *Journal of Child Neurology*, 36(8), 648-654. <https://doi.org/10.1177/0883073821991300>
- Mokhtari, M., & Abootorabi, F. (2019). Lived experiences of mothers of children with cerebral palsy in Iran: A phenomenological study. *Child and Youth Services*, 40(3), 224-244. <https://doi.org/10.1080/0145935x.2019.1594757>
- Monden, K., Gentry, L., & Cox, T. (2016). Delivering bad news to patients. *Baylor University Medical Center Proceedings*, 29(1), 101-102.
<https://doi.org/10.1080/08998280.2016.11929380>

- Moon, M. (2019). Triangulation: A method to increase validity, reliability, and legitimation in clinical research. *Journal of Emergency Nursing*, 45(1), 103-105.
<https://doi.org/10.1016/j.jen.2018.11.004>
- Moorfield, J. C. (n.d-a). *Māori*. <https://maoridictionary.co.nz/search?idiom=&phrase=&proverb=&loan=&histLoanWords=&keywords=maori>
- Moorfield, J. C. (n.d-b). *Pākehā*. <https://maoridictionary.co.nz/search?idiom=&phrase=&proverb=&loan=&histLoanWords=&keywords=pakeha>
- Morgan, C., Fetters, L., Adde, L., Badawi, N., Bancale, A., Boyd, R., O., C., Cioni, G., Damiano, D., & Darrah, J. (2021). Early intervention for children aged 0 to 2 years with or at high risk of cerebral palsy: International clinical practice guideline based on systematic reviews. *JAMA Pediatrics*, 175(8), 846-858.
<https://doi.org/10.1001/jamapediatrics.2021.0878>
- Morse, J. (1994). *Critical issues in qualitative research methods*. SAGE.
<http://catdir.loc.gov/catdir/enhancements/fy0734/93034535-b.html>
- Muller-Kluits, N., & Slabbert, I. (2018). Caregiver burden as depicted by family caregivers of persons with physical disabilities. *Social Work*, 54(4), 493-502.
<https://doi.org/10.15270/54-4-676>
- Neuwelt-Kearns, C., Murray, S., Russell, J., Lee, J., & St, W. (2020). 'Living well'?: Children with disability need far greater income support in Aotearoa. Child Poverty Action Group.
- New Zealand Government. (n.d). *The history of New Zealand, Treaty of Waitangi*.
<https://nzhistory.govt.nz/politics/treaty-of-waitangi>
- New Zealand Public Health & Disability Act 2000.
- Nimbalkar, S., Raithatha, S., Shah, R., & Panchal, D. A. (2014). A qualitative study of psychosocial problems among parents of children with cerebral palsy attending two tertiary care hospitals in western India. *International Scholarly Research Notices*, 2014, 769619. <https://doi.org/10.1155/2014/769619>
- Novak, I., McIntyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., & Goldsmith, S. (2013). A systematic review of interventions for children with cerebral palsy: State of the evidence. *Developmental Medicine and Child Neurology*, 55(10), 885-910.
<https://doi.org/10.1111/dmcn.12246>

- Novak, I., Morgan, C., Fahey, M., Finch-Edmondson, M., Galea, C., Hines, A., Langdon, K., Namara, M. M., Paton, M. C., & Popat, H. (2020). State of the evidence traffic lights 2019: Systematic review of interventions for preventing and treating children with cerebral palsy. *Current Neurology and Neuroscience Reports*, 20, 1-21.
<https://doi.org/10.1007/s11910-020-1022-z>
- Novak, I., Morgan, C., McNamara, L., & Te Velde, A. (2019). Best practice guidelines for communicating to parents the diagnosis of disability. *Early Human Development*, 139, 104841. <https://doi.org/10.1016/j.earlhumdev.2019.104841>
- Ntre, V., Papanikolaou, K., Amanaki, E., Triantafyllou, K., Tzavara, C., & Kolaitis, G. (2022). Coping Strategies in mothers of children with autism spectrum disorder and their relation to maternal stress and depression. *Psychiatriki*, 33(3), 210-218.
<https://doi.org/10.22365/jpsych.2022.068>
- Nyante, G., G., & Carpenter, C. (2019). The experience of carers of children with cerebral palsy living in rural areas of Ghana who have received no rehabilitation services: A qualitative study. *Child Care Health and Development*, 45(6), 815-822.
<https://doi.org/10.1111/cch.12706>
- Office for Disability Issues. (2016). *New Zealand Disability Strategy 2016-2026*. Ministry for Social Development. <https://www.odi.govt.nz/assets/New-Zealand-Disability-Strategy-files/pdf-nz-disability-strategy-2016.pdf>
- Office for Early Childhood Education. (n.d.). *Glossary*.
<https://oece.nz/public/information/terminology/glossary/>
- Olmos-Vega, F. M., Stalmeijer, R. E., Varpio, L., & Kahlke, R. (2023). A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Medical Teacher*, 45(3), 241-251. <https://doi.org/10.1080/0142159X.2022.2057287>
- Olney, S., & Dickinson, H. (2019). Australia's new national disability insurance scheme: Implications for policy and practice. *Policy Design and Practice*, 2(3), 275-290.
<https://doi.org/10.1080/25741292.2019.1586083>
- Olusanya, B., Kancherla, V., Shaheen, A., Ogbo, F., & Davis, A. (2022). Global and regional prevalence of disabilities among children and adolescents: Analysis of findings from global health databases. *Frontiers in Public Health*, 10, 977453.
<https://doi.org/10.3389/fpubh.2022.977453>

- Ones, K., Yilmaz, E., Cetinkaya, B., & Caglar, N. (2005). Assessment of the quality of life of mothers of children with cerebral palsy (primary caregivers). *Neurorehabilitation and Neural Repair*, 19(3), 232-237. <https://doi.org/10.1177/1545968305278857>
- Oskoui, M., Coutinho, F., Dykeman, J., Jette, N., & Pringsheim, T. (2013). An update on the prevalence of cerebral palsy: A systematic review and meta-analysis. *Developmental Medicine and Child Neurology*, 55(6), 509-519. <https://doi.org/10.1111/dmcn.12080>
- Oskram, J. (2020). *One parent's advice to another: An exploration of self-care for parents of children with high-needs disabilities and the development of a psychoeducational resource* [Doctoral thesis, Massey University]. <https://mro.massey.ac.nz/handle/10179/15648>
- Ostojic, K., Karem, I., Paget, S., Mimmo, L., Berg, A., Scott, T., Burnett, H., McIntyre, S., Smithers-Sheedy, H., & Azmatullah, S. (2024). A qualitative study investigating the experiences of unmet social needs for children with cerebral palsy and their families: Perspectives of parents and clinicians. *Disability and Rehabilitation*, 47(9), 2278-2287. <https://doi.org/10.1080/09638288.2024.2391557>
- Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997). Gross motor function classification system for cerebral palsy. *Developmental Medicine and Child Neurology*, 39(4), 214-223. <https://doi.org/10.1111/dmcn.1997.39>
- Palmer, G. (1994). New Zealand's accident compensation scheme: Twenty years on. *University of Toronto Law Journal* 44, 223. <https://doi.org/10.2307/825757>
- Patton, M. Q. (2015). *Qualitative research & evaluation methods: Integrating theory and practice* (4th ed.). SAGE
- Paulson, A., & Vargus-Adams, J. (2017). Overview of four functional classification systems commonly used in cerebral palsy. *Children*, 4(4), 30. <https://doi.org/10.3390/children4040030>
- Pelchat, D., Levert, M.-J., & Bourgeois-Guérin, V. (2009). How do mothers and fathers who have a child with a disability describe their adaptation/transformation process? *Journal of Child Health Care*, 13(3), 239-259. <https://doi.org/10.1177/1367493509336684>
- Pelentsov, L. J., Laws, T. A., & Esterman, A. J. (2015). The supportive care needs of parents caring for a child with a rare disease: A scoping review. *Disability and health journal*, 8(4), 475-491. <https://doi.org/10.1016/j.dhjo.2015.03.009>

- Peters, S. (2010). Literature review: Transition from early childhood education to school. *Report to the Ministry of Education, New Zealand*.
https://ece.manukau.ac.nz/_data/assets/pdf_file/0008/85841/956_ECELitReview.pdf
- Pfeifer, L., Silva, D., Lopes, P., Matsukura, T., Santos, J., & Pinto, M. (2014). Social support provided to caregivers of children with cerebral palsy. *Child: Care, Health and Development*, 40(3), 363-369. <https://doi.org/10.1111/cch.12077>
- Polit, D., F., & Beck, C., T. (2006). *Essentials of nursing research: Methods, appraisal, and utilization* (6th ed.). Lippincott Williams & Wilkins.
- Postma, A., Ketelaar, M., van Nispen Tot Sevenaer, J., Downs, Z., van Rappard, D., Jongmans, M., & Zinkstok, J. (2024). Exploring individual parent-to-parent support interventions for parents caring for children with brain-based developmental disabilities: A scoping review. *Child: Care, Health and Development*, 50(3), e13255.
<https://doi.org/10.1111/cch.13255>
- Pousada, M., Guillamón, N., Hernández-Encuentra, E., Muñoz, E., Redolar, D., Boixadós, M., & Gómez-Zúñiga, B. (2013). Impact of caring for a child with cerebral palsy on the quality of life of parents: A systematic review of the literature. *Journal of Developmental and Physical Disabilities*, 25(5), 545-577.
<https://doi.org/10.1007/s10882-013-9332-6>
- Provost, L. (2014). *Accident Compensation Corporation: Using a case management approach to rehabilitation*. Office of the Auditor-General.
- Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S., Russell, D., Swinton, M., Zhu, B., & Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, 115(6), e626-e636. <https://doi.org/10.1542/peds.2004-1689>
- Ratima, K., & Ratima, M. (2007). Māori experience of disability and disability support services. In B. Robson & R. Harris (Eds.), *Hauora: Māori standards of health IV: A study of the years 2000-2005* (pp. 189-194). Te Rōpū Rangahau Hauora a Eru Pōmare, School of Medicine and Health Sciences, University of Otago.
https://www.otago.ac.nz/_data/assets/pdf_file/0028/329806/chapter-12-maori-experience-of-disability-and-disability-support-services-067751.pdf

- Ratima, M., Durie, M., Allan, G., Morrison, P., Gillies, A., & Waldon, J. (1995). *He anga whakamana: A framework for the delivery of disability support services for Maori*. National Advisory Committee on Core Health and Disability Support Services.
- Reichman, N. E., Corman, H., & Noonan, K. (2008). Impact of child disability on the family. *Maternal and Child Health Journal, 12*(6), 679-683. <https://doi.org/10.1007/s10995-007-0307-z>
- Reid, A., Imrie, H., Brouwer, E., Clutton, S., Bartlett, D., Evans, J., & Russell, D. (2011). 'If I knew then what I know now': Parents' reflections on raising a child with cerebral palsy. *Physical and Occupational Therapy in Pediatrics, 31*(2), 169-183. <https://doi.org/10.3109/01942638.2010.540311>
- Reid, P., Paine, S.-J., Curtis, E., Jones, R., Anderson, A., Willing, E., & Harwood, M. (2017). Achieving health equity in Aotearoa: Strengthening responsiveness to Māori in health research. *The New Zealand Medical Journal (Online), 130*(1465), 96-103.
- Reid, S. M., Carlin, J. B., & Reddihough, D. S. (2011). Using the gross motor function classification system to describe patterns of motor severity in cerebral palsy. *Developmental Medicine and Child Neurology, 53*(11), 1007-1012. <https://doi.org/10.1111/j.1469-8749.2011.04044.x>
- Rentinck, I. C., M, K., Jongmans, M. J., & Gorter, J. W. (2007). Parents of children with cerebral palsy: A review of factors related to the process of adaptation. *Child Care Health and Development, 33*(2), 161-169. <https://doi.org/10.1111/j.1365-2214.2006.00643.x>
- Resch, J., A, Elliott, T., R., & Benz, M., R. (2012). Depression among parents of children with disabilities. *Families, Systems, and Health, 30*(4), 291-301. <https://doi.org/10.1037/a0030366>
- Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., & Bax, M. (2007). A report: The definition and classification of cerebral palsy April 2006. *Developmental Medicine and Child Neurology,, 49*, 8-14. <https://doi.org/10.1111/j.1469-8749.2007.tb12610.x>
- Rudebeck, S., R. (2020). The psychological experience of children with cerebral palsy. *Paediatrics and Child Health, 30*(8), 283-287. <https://doi.org/10.1016/j.paed.2020.05.003>

- Ryan, S., & Salisbury, H. (2012). 'You know what boys are like': Pre-diagnosis experiences of parents of children with autism spectrum conditions. *British Journal of General Practice*, 62(598), e378-e383. <https://doi.org/10.3399/bjgp12X641500>
- Saarijärvi, M., & Bratt, E., L. (2021). When face-to-face interviews are not possible: Tips and tricks for video, telephone, online chat, and email interviews in qualitative research. *European Journal of Cardiovascular Nursing*, 20(4), 392-396. <https://doi.org/10.1093/eurjcn/zvab038>
- Sadowska, M., Sarecka-Hujar, B., & Kopyta, I. (2020). Cerebral palsy: Current opinions on definition, epidemiology, risk factors, classification and treatment options. *Neuropsychiatric Disease and Treatment*, 1505-1518. <https://doi.org/10.2147/NDT.S235165>
- Sainsbury, W., Bowden, C., Carrasco, K., Whitehouse, A., & Waddington, H. (2023). Parent experiences of their children's diagnosis with autism, attention deficit hyperactivity disorder, or both conditions. *International Journal of Developmental Disabilities*, 1-11. <https://doi.org/10.1080/20473869.2023.2166197>
- Sandelowski, M., Barroso, J., & Voils, C. (2007). Using qualitative metasummary to synthesize qualitative and quantitative descriptive findings. *Research in Nursing and Health*, 30(1), 99-111. <https://doi.org/10.1002/nur.20176>
- Sandle, M., Sheppard, A., Fletcher, A., Berry, M., & DeVries, N. (2020). Early identification of infants at risk of cerebral palsy: Developing the use of general movement assessment in routine clinical practice in a tertiary neonatal unit in New Zealand. *The New Zealand Medical Journal (Online)*, 133(1514), 63-66.
- Santos, A., Braz, P., Folha, T., Machado, A., & Matias-Dias, C. (2023). Parents of children diagnosed with congenital anomalies or cerebral palsy: Identifying needs in interaction with healthcare services. *Children*, 10(6), 1051. <https://doi.org/10.3390/children10061051>
- Sbaraini, A., Carter, S., M., Evans, R. W., & Blinkhorn, A. (2011). How to do a grounded theory study: A worked example of a study of dental practices. *BMC Medical Research Methodology*, 11(1), 128. <https://doi.org/10.1186/1471-2288-11-128>
- Schischka, J., Rawlinson, C., & Hamilton, R. (2012). Factors affecting the transition to school for young children with disabilities. *Australasian Journal of Early Childhood*, 37(4), 15-23. <https://doi.org/10.3390/children10061051>

- Schöpfel, J. (2010). Towards a Prague definition of grey literature. In twelfth international conference on Grey literature: Transparency in grey literature. *Grey Tech Approaches to High Tech Issues*, 11-26.
- Schwandt, T. (1994). Constructivist, interpretivist approaches to human inquiry. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 113-138). SAGE.
- Sharma, P., Gupta, M., & Kalra, R. (2023). Recent advancements in interventions for cerebral palsy—A review. *Journal of Neurorestoratology*, 11(3), 100071.
<https://doi.org/10.1016/j.inrt.2023.100071>
- Shevell, A., & Shevell, M. (2013). Doing the “talk” disclosure of a diagnosis of cerebral palsy. *Journal of Child Neurology*, 28(2), 230-235.
<https://doi.org/10.1177/0883073812471430>
- Shevell, M., Dagenais, L., & Hall, N. (2009). The relationship of cerebral palsy subtype and functional motor impairment: A population-based study. *Developmental Medicine and Child Neurology*, 51(11), 872-877. <https://doi.org/10.1111/j.1469-8749.2009.03269.x>
- Shields, L., Pratt, J., & Hunter, J. (2006). Family centred care: A review of qualitative studies. *Journal of Clinical Nursing*, 15(10), 1317-1323. <https://doi.org/10.1111/j.1365-2702.2006.01433.x>
- Siddiqua, A., & Janus, M. (2017). Experiences of parents of children with special needs at school entry: A mixed method approach. *Child: Care, Health and Development*, 43(4), 566-576. <https://doi.org/10.1111/cch.12443>
- Singogo, C., Mweshi, M., & Rhoda, A. (2015). Challenges experienced by mothers caring for children with cerebral palsy in Zambia. *South African Journal of Physiotherapy*, 71(1), 274. <https://doi.org/10.4102/sajp.v71i1.274>
- Skok, A., Harvey, D., & Reddihough, D. S. (2006). Perceived stress, perceived social support, and wellbeing among mothers of school-aged children with cerebral palsy. *Journal of Intellectual and Developmental Disability*, 31(1), 53-57.
<https://doi.org/10.1080/13668250600561929>
- Smith, M., & Blamires, J. (2022). Mothers' experience of having a child with cerebral palsy. A systematic review. *Journal of Pediatric Nursing*, 64, 64-73.
<https://doi.org/10.1016/j.pedn.2022.01.014>

- Smith, M., Blamires, J., & Foster, M. (2022). The impact of policies and legislation on the structure and delivery of support services for children with cerebral palsy and their families in Aotearoa New Zealand: A professional perspective. *Nursing Praxis in New Zealand*, 38(3), 1-10. <https://doi.org/10.36951/001c.38925>
- Smythe, L. (2012). Discerning which qualitative approach fits best. *New Zealand College of Midwives Journal*(46), 5-12.
- Social Security Act 1964 (NZ).
- Sorhage, A., Keenan, S., Chong, J., Blackmore, M., Byrnes, C., Hill, T., Mackey, A., & Stott, S. (2022). Identifying and addressing respiratory health inequities for indigenous Maori children and young adults with cerebral palsy in Aotearoa New Zealand. *Pediatric Pulmonology*, 57, S111-S112. <https://doi.org/10.1002/ppul.25963>
- Spittle, A., Orton, J., Anderson, P., Boyd, R., & Doyle, L. (2015). Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. *Cochrane Database of Systematic Reviews* (11). <https://doi.org/10.1002/14651858.CD005495.pub4>
- St-Yves, M. (2013). The psychology of rapport: Five basic rules. In T. Williamson (Ed.), *Investigative interviewing* (pp. 87-106). Willan.
- Starship. (2019a). *New Zealand cerebral palsy register*. <https://starship.org.nz/health-professionals/cerebral-palsy-research/>
- Starship. (2019b). *Youth transition, frequently asked questions*. <https://starship.org.nz/frequently-asked-questions/>
- Statistics New Zealand. (2014). *Disability survey: 2013*. <https://www.stats.govt.nz/assets/Uploads/Disability-survey/Disability-survey-2013/Disability-survey-2013-additional-documents/Disability-Survey-2013.pdf>
- Statistics New Zealand. (2024). *2023 Census population counts (by ethnic group, age and Māori descent) and dwelling counts*. <https://www.stats.govt.nz/information-releases/2023-census-population-counts-by-ethnic-group-age-and-maori-descent-and-dwelling-counts/>
- Stephens, R. (2004). Horizontal equity for disabled people: Incapacity from accident or illness. *Victoria University Wellington Law Review*, 35, 783.

- Stretton, C., Chan, W.-Y., & Wepa, D. (2022). Demystifying case management in Aotearoa New Zealand: A scoping and mapping review. *International Journal of Environmental Research and Public Health*, 20(1), 784. <https://doi.org/10.3390/ijerph20010784>
- Ström, H., Kreuter, M., & Rosberg, S. (2012). Quality of life in parents/caretakers of children with cerebral palsy in Kampong Cham, Cambodia. *Journal of Tropical Pediatrics*, 58(4), 303-306. <https://doi.org/10.1093/tropej/fmr077>
- Sukhera, J. (2022). Narrative reviews: Flexible, rigorous, and practical. *Journal of Graduate Medical Education*, 14(4), 414-417. <https://doi.org/10.4300/JGME-D-22-00480.1>
- Sutter, E. N., Francis, L. S., Francis, S. M., Lench, D. H., Nemanich, S. T., Krach, L. E., Sukal-Moulton, T., & Gillick, B. T. (2021). Disrupted access to therapies and impact on well-being during the COVID-19 pandemic for children with motor impairment and their caregivers. *American Journal of Physical Medicine and Rehabilitation*, 100(9), 821-830. <https://doi.org/10.1097/PHM.0000000000001818>
- Taikura Trust. (n.d.). *What we do*. <https://www.taikura.org.nz/what-we-do/>
- te Velde, A., Morgan, C., Novak, I., Tantsis, E., & Badawi, N. (2019). Early diagnosis and classification of cerebral palsy: An historical perspective and barriers to an early diagnosis. *Journal of Clinical Medicine*, 8(10), 1599-1611. <https://doi.org/10.3390/jcm8101599>
- Teodoro, I., de Cássia Félix Rebouças, V., Thorne, S., de Souza, N., de Brito, L., & Alencar, A. (2018). Interpretive description: A viable methodological approach for nursing research. *Anna Nery School Journal of Nursing / Escola Anna Nery Revista de Enfermagem*, 22(3), 1-8. <https://doi.org/10.1590/2177-9465-EAN-2017-0287>
- The Education Hub. (n.d.). *Our mission is to improve opportunities and outcomes for young people by bridging the gap between research and practice in education*. <https://theeducationhub.org.nz/>
- Thompson Burdine, J., Thorne, S., & Sandhu, G. (2021). Interpretive description: A flexible qualitative methodology for medical education research. *Medical Education*, 55(3), 336-343. <https://doi.org/10.1111/medu.14380>
- Thorne, S. (2008). *Interpretive description*. Left Coast Press.
- Thorne, S. (2009). The role of qualitative research within an evidence-based context: Can metasynthesis be the answer? *International Journal of Nursing Studies*, 46(4), 569-575. <https://doi.org/10.1016/j.ijnurstu.2008.05.001>

- Thorne, S., Canam, C., Dahinten, S., Hall, W., Henderson, A., & Kirkham, S. R. (1998). Nursing's metaparadigm concepts: Disimpacting the debates. *Journal of Advanced Nursing*, 27(6), 1257-1268. <https://doi.org/10.1046/j.1365-2648.1998.00623.x>
- Thorne, S., E. (2016). *Interpretive description: Qualitative research for applied practice* (2nd ed.). Routledge.
- Thorne, S., Kirkham, S. R., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing and Health*, 20(2), 169-177. [https://doi.org/10.1002/\(SICI\)1098-240X\(199704\)20:2<169::AID-NUR9>3.0.CO;2-I](https://doi.org/10.1002/(SICI)1098-240X(199704)20:2<169::AID-NUR9>3.0.CO;2-I)
- Thorne, S., Stephens, J., & Truant, T. (2016). Building qualitative study design using nursing's disciplinary epistemology. *Journal of Advanced Nursing*, 72(2), 451-460. <https://doi.org/10.1111/jan.12822>
- Thorne, S. E. (1997). Phenomenological positivism and other problematic trends in health science research. *Qualitative Health Research*, 7(2), 287-293-293. <https://doi.org/10.1177/104973239700700208>
- Topia, M. (2015). *The lived experience of mothering a young child with severe multiple disability* [Master's thesis, Auckland University of Technology]. Tuwhera. <https://openrepository.aut.ac.nz/handle/10292/9099>
- Torres, M. A., & Ohajunwa, C. O. (2025). Care perspectives: Mothers of children with disabilities in a peri-urban setting in South Africa. *African Journal of Disability (Online)*, 14, 1-9. <https://doi.org/10.4102/ajod.v14i0.1589>
- Tucker, P. (2004). *The parental experience of caring for a child who experiences disability and has high care needs* [Master's thesis, Massey University]. <https://mro.massey.ac.nz/handle/10179/6349>
- Vadivelan, K., Sekar, P., Sruthi, S. S., & Gopichandran, V. (2020). Burden of caregivers of children with cerebral palsy: An intersectional analysis of gender, poverty, stigma, and public policy. *BMC Public Health*, 20(1), 645. <https://doi.org/10.1186/s12889-020-08808-0>
- van Eyk, C. L., Fahey, M. C., & Gecz, J. (2023). Redefining cerebral palsies as a diverse group of neurodevelopmental disorders with genetic aetiology. *Nature Reviews Neurology*, 19(9), 542-555. <https://doi.org/10.1038/s41582-023-00847-6>

- van Manen, M. (1997). *Researching lived experience: Human science for an action sensitive pedagogy*. Taylor & Francis Group.
- Waitangi Tribunal. (2019). *Hauora: Report on stage one of the health services and outcomes Kaupapa inquiry (Report no. WAI 2575)*.
https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_152801817/Hauora%20W.pdf
- Wallace-Watkin, C., Sigafos, J., Woods, L., & Waddington, H. (2023). Parent reported barriers and facilitators to support services for Autistic children in Aotearoa New Zealand. *Autism*, 27(8). <https://doi.org/10.1177/13623613231168240>
- Weber, P., Bolli, P., Heimgartner, N., Merlo, P., Zehnder, T., & Kätterer, C. (2016). Behavioral and emotional problems in children and adults with cerebral palsy. *European Journal of Paediatric Neurology*, 20(2), 270-274. <https://doi.org/10.1016/j.ejpn.2015.12.003>
- Whaikaha Ministry of Disabled People. (2022a). *Child development services*.
<https://www.whaikaha.govt.nz/types-of-support/specific-disability-services/child-development-services>
- Whaikaha Ministry of Disabled People. (2022b). *Who can get support*.
<https://www.whaikaha.govt.nz/types-of-support/specific-disability-services/child-development-services>
- Whaikaha Ministry of Disabled People. (2024). *Education support*.
<https://www.disabilitysupport.govt.nz/disabled-people/support-and-services/education-and-employment/education-support/>
- Whaikaha Ministry of Disabled People. (n.d.). *Contracts and service specifications*.
<https://www.whaikaha.govt.nz/for-service-providers/contracts-and-service-specifications>
- Whittingham, K., Wee, D., Sanders, M. R., & Boyd, R. (2013). Sorrow, coping and resiliency: Parents of children with cerebral palsy share their experiences. *Disability and Rehabilitation*, 35(17), 1447-1452. <https://doi.org/10.3109/09638288.2012.737081>
- Williams, S. A., Alzahr, W., Mackey, A., Hogan, A., Battin, M., Sorhage, A., & Stott, N. S. (2021). "It should have been given sooner, and we should not have to fight for it": A mixed-methods study of the experience of diagnosis and early management of cerebral palsy. *Journal of Clinical Medicine*, 10(7), 1398.
<https://doi.org/10.3390/jcm10071398>

- Williams, S. A., Mackey, A., Sorhage, A., Battin, M., Wilson, N., Spittle, A., & Stott, N. S. (2021). Clinical practice of health professionals working in early detection for infants with or at risk of cerebral palsy across New Zealand. *Journal of Paediatrics and Child Health*, 57(4), 541-547. <https://doi.org/10.1111/jpc.15263>
- Woodgate, R. L., Edwards, M., Ripat, J. D., Borton, B., & Rempel, G. (2015). Intense parenting: A qualitative study detailing the experiences of parenting children with complex care needs. *BMC Pediatrics*, 15, 1-15. <https://doi.org/10.1186/s12887-015-0514-5>
- Worcester, J. A., Nesman, T. M., Raffaele Mendez, L. M., & Keller, H. R. (2008). Giving voice to parents of young children with challenging behavior. *Exceptional Children*, 74(4), 509-525. <https://doi.org/10.1177/001440290807400406>
- Wynd, D. (2015). *It shouldn't be this hard: Children, poverty and disability*. Child Poverty Action Group. <https://static1.squarespace.com/static/60189fe639b6d67b861cf5c4/t/612f0339069b3a2ef4929e88/1630470970540/150317ChildDisability.pdf>
- Zhang, K. C., & Li, Q. (2021). "It would be harder without faith": An exploratory study of low-income families' experiences of early childhood inclusive education in New Zealand. *Journal of Religion and Health*, 60(6), 4151-4166. <https://doi.org/10.1007/s10943-021-01270-1>

Appendices

Appendix A: Smith and Blamires (2022). Link to article [here](#)

Appendix B: Smith, Blamires, and Foster (2022). Link to article [here](#)

Appendix C: Literature Review Part 3 – Seven Key Documents

Summary of key characteristics of relevant documents	
The United Nations Convention Rights of the Persons with Disabilities (United Nations, 2022) (UNCRPD)	<ul style="list-style-type: none"> Lays out the expectations of what countries need to do to ensure people living with disabilities have the same rights as everybody else. Promote, protect, and ensure people living with disabilities have the following: <ul style="list-style-type: none"> Enjoyment of all human rights and fundamental freedoms. Respect for their inherent dignity. Equal opportunities and access. Children living with a disability are respected. Duty of care to ensure they are not discriminated against.
The United Nations Convention Rights of the Child (Ministry of Justice, 2020a).	<ul style="list-style-type: none"> All children are equal and have the same rights. Every child has the right to have his or her basic needs fulfilled. Every child has the right to protection from abuse and exploitation. Every child has the right to express his or her opinion and to be respected.
Te Tiriti o Waitangi (The Treaty of Waitangi) (Ministry of Justice, 2020b).	<ul style="list-style-type: none"> Significant founding human rights document signed in 1840 between the British Crown and Māori. Intention to establish governance by the Crown and to protect Māori rights, sovereignty & land. Difference in the meaning of the English and Māori versions of Te Tiriti o Waitangi have had significant negative impacts on all aspects of Māori life, health, and wellbeing. As with many aspects of society, Te Tiriti o Waitangi also guides decision making for how disability services should be delivered within this unique cultural context.
New Zealand Disability Strategy 2016-2026 (Office for Disability Issues, 2016) (NZDS)	<ul style="list-style-type: none"> High-level picture of how the NZ government will do what it has committed to at the UN Convention on the Rights of Persons with Disabilities. Underpinned on eight key outcomes: education, jobs & money, health & wellbeing, accessibility, disabled people as leaders, disabled people having choices & control over their own lives, protecting the rights of disabled people, attitudes towards disability.
The New Zealand Disability Action Plan (Office for Disability Issues, 2019).	<ul style="list-style-type: none"> Action plan for the NZDS presented as 25 work programmes that simultaneously work to achieve the Strategy's outcomes. They are spread across the eight key outcomes and include: <ul style="list-style-type: none"> The Ministry of Education learning support action plan (education). The Ministry of Social Development disability employment action plan (employment). Improving accessibility across the NZ housing system
Whāia Te Ao Mārama (Māori Disability Action Plan) 2018-2022 (MoH, 2018b).	<ul style="list-style-type: none"> Based on the principles of Te Tiriti o Waitangi. Reflects NZ's obligations to the UNCRPD. Connected with other Māori outcome improvement work across Government, such as He Korowai Oranga (Māori Health Strategy), Whānau Ora and the NZDS. Provides pathway for supporting Māori with disabilities (tāngata whaikaha) and their whānau. Aims to reduce barriers and improve the health outcomes. Six goals: to participate in the development of health and disability services; to have control over their disability support; to participate in Te Ao Māori (Māori world view); to participate in their community; to receive disability support services that are responsive to Te Ao Māori; and to have informed responsive communities.
Faiva Ora: National Pasifika Disability Plan 2016-2021 (MoH, 2017a).	<ul style="list-style-type: none"> Developed to help address the under representation of disabled people that identify as Pacifica. The plan's goals are to improve health outcomes; encourage better engagement and support with Pacific communities; ensure disability services and supports meet the needs of Pacific people; and encourage key stakeholders to work in partnerships to address challenges experienced by Pacific disabled people and their families.

MoH: Ministry of Health; NZ: New Zealand; NZDS: New Zealand Disability Service; UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

Appendix D: Literature Review Part 3 – Five Significant Legislative Acts

Summary of key characteristics of 5 relevant legislation	
The Health and Disability Commissioner Act 1994.	<p>This Act mandated the Health and Disability Commissioner (HDC) to promote and protect the rights of health consumers and disability consumers.</p> <p>The Act is established to ensure:</p> <ul style="list-style-type: none"> • secure the fair & efficient resolution of complaints relating to infringements of rights. • have a HDC to investigate complaints against providers. • a Health and Disability Services Consumer Advocacy Service. • provide for the promulgation of a Code of Health and Disability Services Consumers' Rights.
New Zealand Public Health and Disability Act 2000.*	<p>The Act:</p> <ul style="list-style-type: none"> • Established the structure for public sector funding and the organisation of health and disability services, including DHBs and other Crown entities. • Mandated the NZ Health Strategy and NZ Disability Strategy. <p>Two key positions for the disability sector are described within this Act:</p> <ol style="list-style-type: none"> 1. The Minister of Health: overall responsibility for setting strategic direction for HDS and MoH; establishing and reporting on health strategies. 2. Minister for Disability Issues: establish and report on the NZ Disability Strategy, and to advocate for disability issues and their specific duties are laid out in this Act.
The Social Security Act, 2018.	<p>The main purpose of this act is to provide financial and other support as appropriate.</p> <p>Of significant is two financial provisions it allows for:</p> <ol style="list-style-type: none"> 1. Child Disability Allowance (CDA) - issued Irrespective of the level of disability or financial status of the family and is available through the MSD to the main carer of a child under 18 years. It's a fortnightly payment of approximately \$100 and paid in recognition of extra care needed. 2. Disability allowance - has the same qualifying criteria as CDA except that it is means tested. A person may be eligible to receive both allowances.
The Children's Act 2014.	<p>This act was designed to:</p> <ul style="list-style-type: none"> • Protect and improve the lives of vulnerable children • Ensure the Police, Ministries of Health, Education, Justice, Social Development, and children work together and be held accountable for protecting and improving the lives of vulnerable children
The Accident Compensation Corporation Amendment Act 2010.	<p>This legislation guides the law with regards to:</p> <ul style="list-style-type: none"> • Preventing injuries. • Rehabilitation and entitlements of injured people. • The Act provides a framework for the ACC to work within to ensure that it provides comprehensive, no-fault personal injury cover for all New Zealanders.

*Note that the New Zealand Public Health and Disability Act 2000 was repealed in July 2022 and replaced by the Pae Ora (Healthy Futures) Act 2022.

ACC: Accident Compensation Corporation; CDA: Child Disability Allowance; HDC: Health and Disability Commissioner; HDS: Health Disability Service; MSD: Ministry Social Development; NZ: New Zealand

Appendix E: Excerpts From Reflective Journal

Interview Two, December 21st, 2022.

This is the second interview that I have done. I didn't know the mother I interviewed today, but she seemed relaxed and present. She came across as a mother that was very determined to give her daughter the best possible opportunities in life. She had made considerable sacrifices to do so including a very significant financial sacrifice to pay for surgery. She had experienced a premature labour, and she recounted her experience in a solemn slow way. She seemed both sad and pragmatic. When she talked about her time in hospital with a premature baby and knowing something was wrong with her baby but not getting clear answers, she became emotional. She talked about the emotional toll of the first few years of her child life, and the juggle of also having other children and having to keep searching and asking for a diagnosis. She talked quite slowly, with lots of pauses and I'm not sure if that's because she had to really think about what she was saying or whether that's how she normally communicates, but I was aware of having to slow down my pace to match hers. I found I really needed to make sure she had finished her sentences as sometimes I noticed I talked when it was a pause as opposed to ensuring she had finished what she had to say. When this happened, I stopped immediately, apologised, and asked her to continue. I made a note to myself to allow for pauses. Her voice seemed calm, and she appeared thoughtful. I found myself asking additional questions when I felt I did not fully understand her answers, or they didn't quite make sense, and she seemed happy to clarify and talk.

On listening back to this interview. I noticed that this mother came across as quite matter of fact but also at times became emotional when relaying stories such as her labour and early days in hospital, battles with school and ACC. I also noticed that I do not always finish my sentences and that I could ask my questions more simply, so this is something that I will definitely work on. I will do this by endeavouring to fully formulate a question in my head before asking it and give myself permission to take time to do this as opposed to feeling like I must start asking a question before it is fully formed. Also, I will try and incorporate "tell me more about that" into my interviewing as there were times when she made a comment, but I felt there was more to her experience. I will add in a question about jobs and the possible impact on work hours/job/career due to being the primary caregiver of a child with CP. I noticed that I tend to say 'wow' and 'gosh' a bit and I think that I need to use more neutral language like 'right' and 'okay.' I need to be aware of this because it occurs to me that 'wow' and 'gosh' have more emotion attached and could be seen as influencing a participant's answers or leaning towards a personal bias. I was aware of feeling connected to some of what this mother was saying as I could directly relate to it. I was also aware of needing to not show this and stay neutral and objective. I was able to do this by acknowledging these thoughts to myself and writing down on my notes 'stay objective.' I did say 'yes' several times, but not as much as the first interview.

This reflective journal entry was the start of an audit trail of analytic insights. After this interview and before the next interview I returned to the first interview to compare how the first mother had described her experiences and responded to aspects of her parenting journey such as receiving the diagnosis, how hard she found parenting, the time, and significant financial sacrifices she made, experiences with the healthcare and education

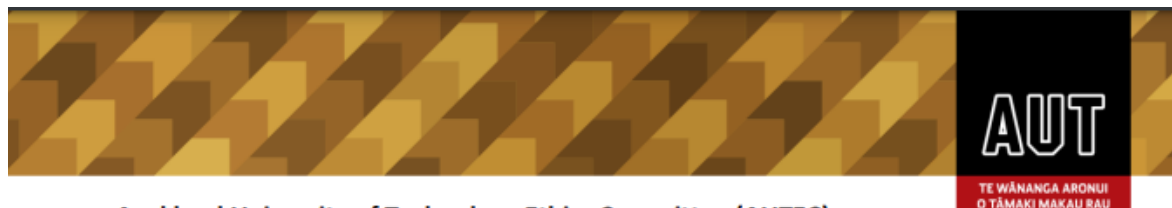
sectors, the challenges, and the positive aspects in comparison to the mother I interview second.

The observation about needing to ask simpler, more considered questions led me to refine my interview guide to better explore the experiences at the start from the labour, receiving the diagnosis and the emotional impact of parenting a child with CP, these areas later became part of the 'difficult start' theme. Similarly, the participant's slow, thoughtful way of speaking contrasted with more nervous responses in the first interview. This drew my attention to the variable way that these two mothers processed and conveyed their experiences. Recognising this contrast prompted me to consider communication pace and tone as additional interpretive cues during coding. Thus, this reflection triangulated with transcript data and field notes to shape the interpretive lens applied across the dataset. These insights also demonstrate how reflective journaling was not an isolated activity, but rather an ongoing analytic practice that enriched the rigour and trustworthiness of the study.

Interview 12, March 17th, 2023.

Today I interviewed the most incredible woman. I had not met or heard of this mother before. We met on zoom. When she came online, she was well presented and struck me as being a strong and resilient woman. Her voice was clear and confident. After I did my welcome and formalities, I asked her to tell me about her child with CP and that marked the start of an almost two-hour interview where she talked and talked, and I just guided her with questions here and there as appropriate. I have successfully reduced the number of little words I say (and seemed to say in earlier interviews). I am now very comfortable with not talking very much during interviews. I show my interest and engagement through eye contact, nodding etc as opposed to always feeling like I have to respond by saying something. This has also helped me to be fully present with listening. I feel more confident with asking my question's clearly and not stopping mid-sentence as I noticed I did in my first few interviews. There were many long periods where she spoke uninterrupted. I was humbled by how open and honest she was with me. She shared deeply personal information, for example her traumatic NICU experience, mental health challenges and her marriage break up. She talked about many struggles and challenges, but was also very optimistic and inspiring. I felt very humbled by her story and her strength. During the interview I became very mindful of needing to remain neutral so as not to influence her responses. I found myself having to be very intentional to remain as objective as possible. When I first had the thought that she was an incredible woman (probably about a third of the way through the interview), I wrote myself a note - it simply said 'be warm, objective and neutral.' I found this technique very helpful. I was really pleased with how the interview went. I definitely feel as though I've made progress with my interviewing technique.

Appendix F: Auckland University of Technology Ethics Committee Approval Letter



Auckland University of Technology Ethics Committee (AUTEC)

Auckland University of Technology
D-88, Private Bag 92006, Auckland 1142, NZ
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

29 November 2022

Julie Blamires
Faculty of Health and Environmental Sciences

Dear Julie

Re Ethics Application: **22/343 The experiences and perspectives of primary caregivers raising a school aged child with Cerebral Palsy in New Zealand.**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 29 November 2025.

Non-Standard Conditions of Approval

1. Amendment of the Information Sheet as follows:
 - a. Removal of all derivatives of 'anonymised' given that it is an interview;
 - b. Removal of the duplicate information in the sections on 'discomforts' and the section of 'how they will be alleviated'.

Note: It is noted that AUT Counselling is being offered, however the researcher may wish include other free options that might be better suited to the cohort of potential participants. Include details of these as appropriate.

Non-standard conditions must be completed before commencing your study. Non-standard conditions do not need to be submitted to or reviewed by AUTEC before commencing your study.

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the [Auckland University of Technology Code of Conduct for Research](#) and as approved by AUTEC in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard and that all the dates on the documents are updated.
8. AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact ethics@aut.ac.nz. The forms mentioned above are available online through <http://www.aut.ac.nz/research/researchethics>

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: megsmi03@autuni.ac.nz; mandie.foster@aut.ac.nz

Appendix G: Participant Recruitment Post

Published on the 'Cerebral Palsy Kids of NZ' Facebook Page



Meg Smith ▸ Cerebral Palsy Kids of NZ
November 30, 2022 · 🌐

Research study on having a child with CP

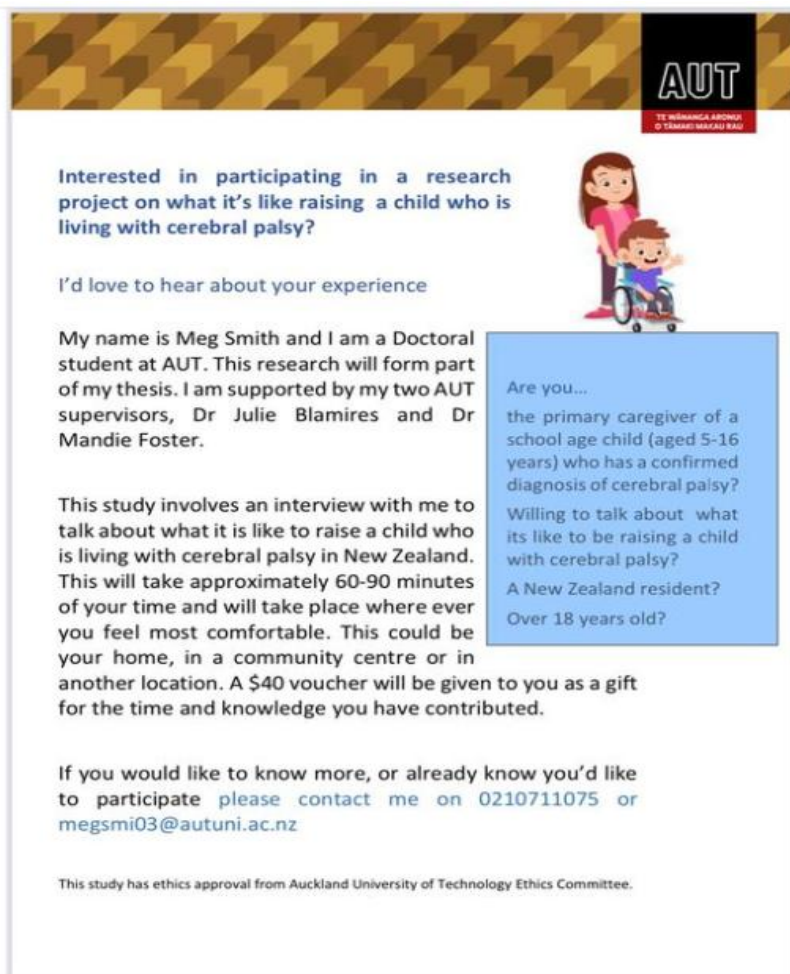
Kia ora koutou CP whanau,

Today is a long awaited and exciting day for me. I finally have the green light to go ahead and ask if anyone would be interested in being interviewed as part of my doctoral research on what it's like raising a child who is living with cerebral palsy in Aotearoa.

Here are the details.

Nga mihi

Meg



Interested in participating in a research project on what it's like raising a child who is living with cerebral palsy?

I'd love to hear about your experience

My name is Meg Smith and I am a Doctoral student at AUT. This research will form part of my thesis. I am supported by my two AUT supervisors, Dr Julie Blamires and Dr Mandie Foster.

This study involves an interview with me to talk about what it is like to raise a child who is living with cerebral palsy in New Zealand. This will take approximately 60-90 minutes of your time and will take place where ever you feel most comfortable. This could be your home, in a community centre or in another location. A \$40 voucher will be given to you as a gift for the time and knowledge you have contributed.

If you would like to know more, or already know you'd like to participate please contact me on 0210711075 or megsmi03@autuni.ac.nz

This study has ethics approval from Auckland University of Technology Ethics Committee.

AUT
TE WHANGA ARONGI
O'ŌTARANGA

Are you...
the primary caregiver of a school age child (aged 5-16 years) who has a confirmed diagnosis of cerebral palsy?
Willing to talk about what its like to be raising a child with cerebral palsy?
A New Zealand resident?
Over 18 years old?

Appendix H: Participant Information Sheet



Participant Information Sheet

Date Information Sheet Produced: 29th October 2022

Project Title

The experiences and perspectives of primary caregivers raising a school aged child with Cerebral Palsy in New Zealand.

An Invitation

Kia ora,

My name is Meg Smith and I would like to invite you to participate in my study. This would involve you and I meeting face to face (or on zoom or teams if you are out of Auckland) for about an hour so that I can ask you about your experience of being the primary caregiver of a school age child who is living with cerebral palsy in New Zealand. Would you be willing to help me?

About me

I am a doctoral student in Health Science at AUT and this research will form part of my thesis. I have a 12 year old daughter who lives with cerebral palsy. My paid employment is as a Clinical Nurse Director at Te Whatu Ora Counties Manukau. In a volunteer capacity I am currently the chair of the Cerebral Palsy Society executive board and co chair on the Cerebral Palsy Child Health Clinical Network as a consumer representative. This is a national network of health professionals and consumer representatives who are working together to improve the quality of clinical services for children and youth who are living with cerebral palsy.

What is the purpose of this research?

Cerebral Palsy is a lifelong condition that requires ongoing and complex management for you as the primary caregiver as well as your family. We would like to know about your experiences of raising and a school age child who is living with cerebral palsy in the hopes of giving you and your family as well as health care providers better information and tools to inform care. We also hope that this study will provide the Government with a clearer idea of how current disability supports are working. The findings of this research may be used for academic publications, presentations and in my doctoral thesis.

How was I identified and why am I being invited to participate in this research?

You are being invited to be part of this study because you responded to a recruitment flyer posted on social media or through a relevant network outlining the details of this study. In response you are now expressing an interest with a view to take part. You will be eligible to participate if you are over 18 years old and are the primary caregiver of a school aged child who has a confirmed diagnosis of cerebral palsy.

How do I agree to participate in this research?

This participant information sheet will help you decide if you'd like to take part. It sets out why I am doing the study, what your participation would involve, what the benefits and risks to you might be, and what will happen after the study ends. I will talk to you about the study and answer any questions you have. You can take a copy of this information sheet to think about it or talk about it



with your whānau and friends. Once you understand what the research is about and if you agree you would like to take part, we can arrange an interview. When we meet, I will ask you to complete a consent form which you will get a copy of. If we meet over zoom or teams there will be an oral consent process. Your participation in this research is voluntary (it is your choice) and whether you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

If you choose to participate, you will take part in an interview with me where you will be asked to describe your experiences of raising a child who is living with cerebral palsy. You are welcome to have a support person/people with you during the interview. The interview will take 60-90 minutes and will be recorded. They will take place in an environment that is private, suitable and convenient to you. The stories and comments from all the interviews will be used to find themes and patterns. If the initial interview is not completed, you may or may not be asked for a second interview. You do not have to agree to a second interview.

What are the discomforts and risks?

We do not expect any bad effects or risks for you in taking part in the study. It is entirely up to you what you wish to tell us about. If you don't want to answer some of the questions that is okay and if you want to stop the interview at any time that is okay as well.

How will these discomforts and risks be alleviated?

If you decide to join the study and then change your mind, the interview will be stopped, and you do not have to give a reason. Any information provided by you will be confidential and available only to the research team. If during the course of the interview you become upset by the topics discussed during the interview and would like to talk to someone for support and counselling then AUT Student Counselling and Mental Health is able to offer three free sessions of confidential counselling support to you. These sessions are only available for issues that have arisen directly as a result of participation in the research and are not for other general counselling needs. To access these services, you will need to drop into our centre at WB203 City Campus, email counselling@aut.ac.nz or call 921 9998. Simply let the receptionist know that you are a research participant, and provide the title of my research and my name and contact details as given in this information sheet. You can find out more information about AUT counsellors and counselling on <https://www.aut.ac.nz/student-life/student-support/counselling-and-mental-health>

What are the benefits?

It may be helpful for you to have a chance to tell someone about what it is like to raise a child who is living with cerebral palsy. It will be helpful for health professionals and the Government to know what matters the most to you. This will make sure they are looking after you, your child and family in the best way possible. This research is being undertaken to assist me with obtaining a Doctor in Health Science qualification.

How will my privacy be protected?

If you decide to participate in this research study, your participation would be confidential. This means that any information such as your name, and other personal information that could identify you will be removed from the transcripts by the interviewer. Interview recordings and transcripts will only be available to other members of the research team. All identifiable details will be held securely and accessible only to the interviewer; no information identifying you as a participant will be included in any of the project reports or publications. You will be able to indicate on the consent form if you would like to review and correct the

transcript and/or receive a summary of the results from this study. Information gathered from the interviews may be used for future research only upon your consent. Although every effort will be made to protect your privacy, absolute confidentiality of your information cannot be guaranteed. The risk of people accessing and misusing your information is currently very small. If you have any concerns regarding your rights, please contact any of the research team below.

What are the costs of participating in this research?

The only cost to you taking part in this research is your time. If you choose to take part, you will take part in a 60–90-minute interview with me. I will meet you at a place convenient for you. This could be your home or a mutually agreed community venue close to your home. A koha/gift of \$40 for the time and knowledge you have contributed will be gifted to you.

What opportunity do I have to consider this invitation?

I will touch base within one month of you receiving this information to check if you would like to participate in this study. If you do, we can set up an interview time.

Will I receive feedback on the results of this research?

You are welcome to a summary of the study findings. If you could like a summary, please indicate this during the consent process and make sure we have your contact details. Study findings will also be presented at different health forums and published in appropriate journals as well as doctoral thesis published in the AUT these repositories.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the research coordinator Meg Smith, megsmi03@autuni.ac.nz, ph 0210711075
Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEK, ethics@aut.ac.nz , (+649) 921 9999 ext 6038.

Whom do I contact for further information about this research?

If you are not able to get the information you require from me, then you are welcome to contact the project supervisors. The project supervisors' details are below. Please keep this information sheet for your future reference. The details for the research team are below.

Project Supervisor Contact Details:

Dr Julie Blamires is a senior lecturer at AUT University where she currently works full time running courses for new graduate nurses, and postgraduate nurses wanting to work with children and youth.
Dr. Julie Blamires; email: julie.blamires@aut.ac.nz, ph 0212387275

Dr Mandie Foster is a senior lecturer and emerging research scholar in children and young people's nursing, at AUT university. She has a passion to make a difference to the holistic health and wellbeing of children and families globally. Dr. Mandie Foster; email: mandie.foster@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on 29th November 2022, AUTEK Reference number 22/343.

Appendix I: Participant Consent Form



Consent Form

For use when interviews are involved.

Project title: The experiences and perspectives of primary caregivers raising a school aged child with Cerebral Palsy in New Zealand.

Project Supervisor: Dr Julie Blamires and Dr Mandie Foster

Researcher: Meg Smith

- I have read and understood the information provided about this research project in the Information Sheet dated 29th October 2022.
- I have had an opportunity to ask questions and to have them answered.
- I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- I understand that while every effort will be made to protect your identity there is a possibility of being identifiable due to the small community of caregiver within New Zealand?
- I agree to take part in this research
- Do you wish to receive a summary of the research findings? (Please tick one): Yes No
- Please confirm your name and contact details

Participants signature :

Participants name:

Participants Contact Details (if answered yes above)

.....
.....
.....
.....

Date :

Approved by the Auckland University of Technology Ethics Committee on 29th , AUTEK Reference number 22/343

Note: The Participant should retain a copy of this form.

Appendix J: Participant Oral Consent Form



Oral Consent Protocol

For use when interviews are being conducted by videoconference.

Project title: The experiences and perspectives of primary caregivers raising a school aged child with Cerebral Palsy in New Zealand.

Project Supervisor: Dr Julie Blamires and Dr Mandie Foster

Researcher: Meg Smith

The participant joins the videoconference

Do you agree to my recording your consent to participate?

If they agree, then the record function will be activated and they will be asked the following:

- Have you read and understood the information provided about this research project in the Information Sheet dated 29th October 2022?
- Do you have any questions about the research?
- Do you understand that notes will be taken during the interviews and that the interview will also be audio-recorded and transcribed?
- Do you understand that taking part in this study is voluntary (your choice) and that you may withdraw from the study at any time without being disadvantaged in any way.?
- Do you understand that if you withdraw from the study then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used? However, once the findings have been produced, removal of your data may not be possible.
- Do you understand that while every effort will be made to protect your identity there is a possibility of being identifiable due to the small community of caregiver within New Zealand?
- Do you agree to take part in this research?
- Do you wish to receive a summary of the research findings? (please tick one): Yes No
- Do you want me to send you a copy of the audio recording for this consent? Yes No
- Please confirm your name and contact details

Participants name:

Participants Contact Details (if appropriate):

.....
.....
.....

I will now turn off the recording of the Consent and then will start a separate recording for the interview.

Approved by the Auckland University of Technology Ethics Committee on 29th , AUTEK Reference number 22/343

Note: The Participant should retain a copy of this form.

Draft Guide for interviewing

The participants will be asked semi structured questions and be allowed to talk uninterrupted. Whether interviews are conducted in person or on video conference, the researcher will aim to ensure they are sitting at a comfortable distance from the participant and looking directly at them with open body language in a friendly, warm and relaxed manner that puts the participant at ease.

Interviews will start with some warmup questions such as:

- Tell me a little bit about yourself, and your life
 - your family?
 - other children?

Then move onto study related questions such as:

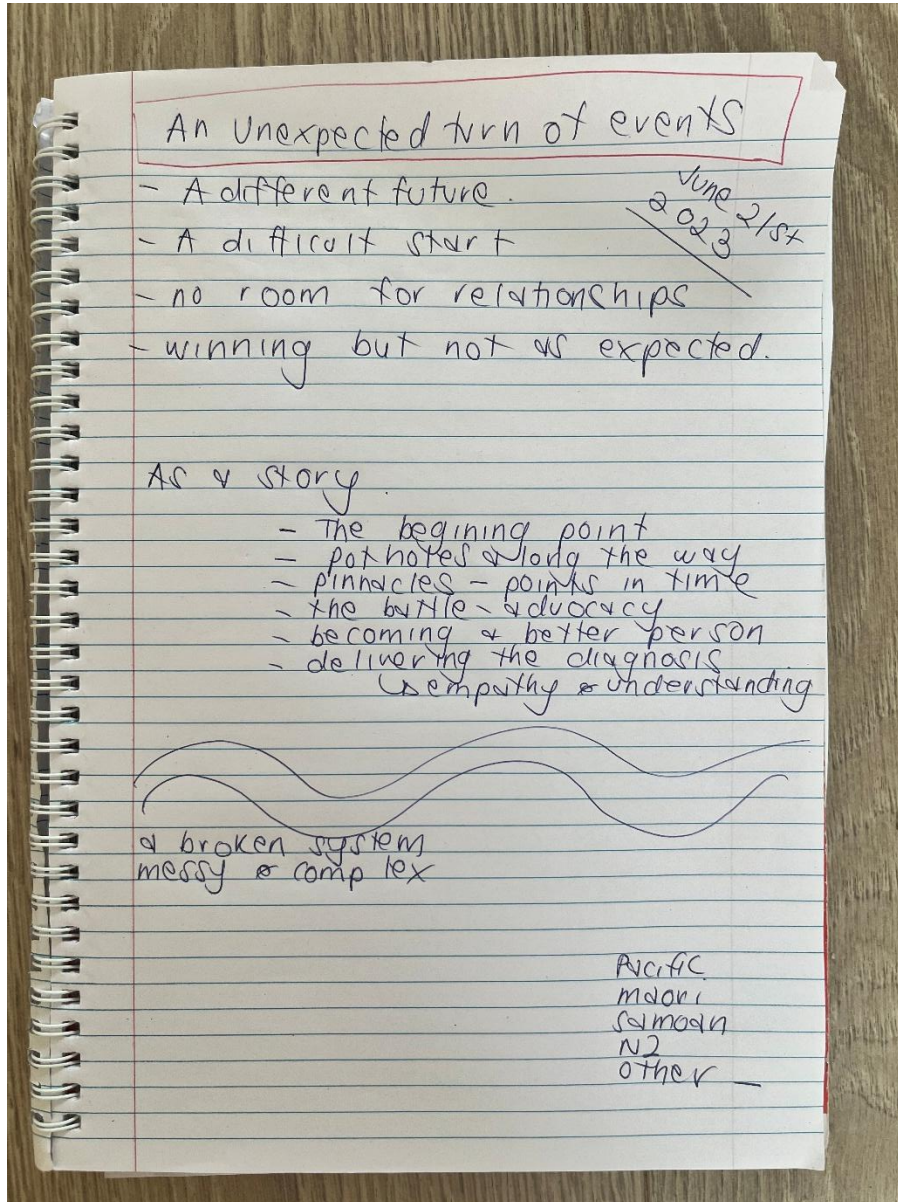
- Tell me about your child with cerebral palsy.
- Tell me about your daily life with your child.
- What does a typical day look like?
- Tell me about what it's like to be raising a child with cerebral palsy.
- When did you first know that your child had cerebral palsy?
- How does having a child with cerebral palsy affect your family
- Do you see your responsibilities as the primary care giver different from others primary care giver you know? If yes, why?
- Where do you get support from?
- What has been your experiences with the health system?
 - How do you find navigating the health system?
- What has been your experiences with the education system and schools?
- What has been your experience with social service such as Work and Income and Inland Revenue Department?
- What are the positive aspects to being the primary caregiver of a child with cerebral palsy?
- What are some of the biggest challenges you face as the primary caregiver of a child with cerebral palsy?
- What are your thoughts when you think about the future with your child with cerebral palsy?
- Is there anything else you would like me to know?

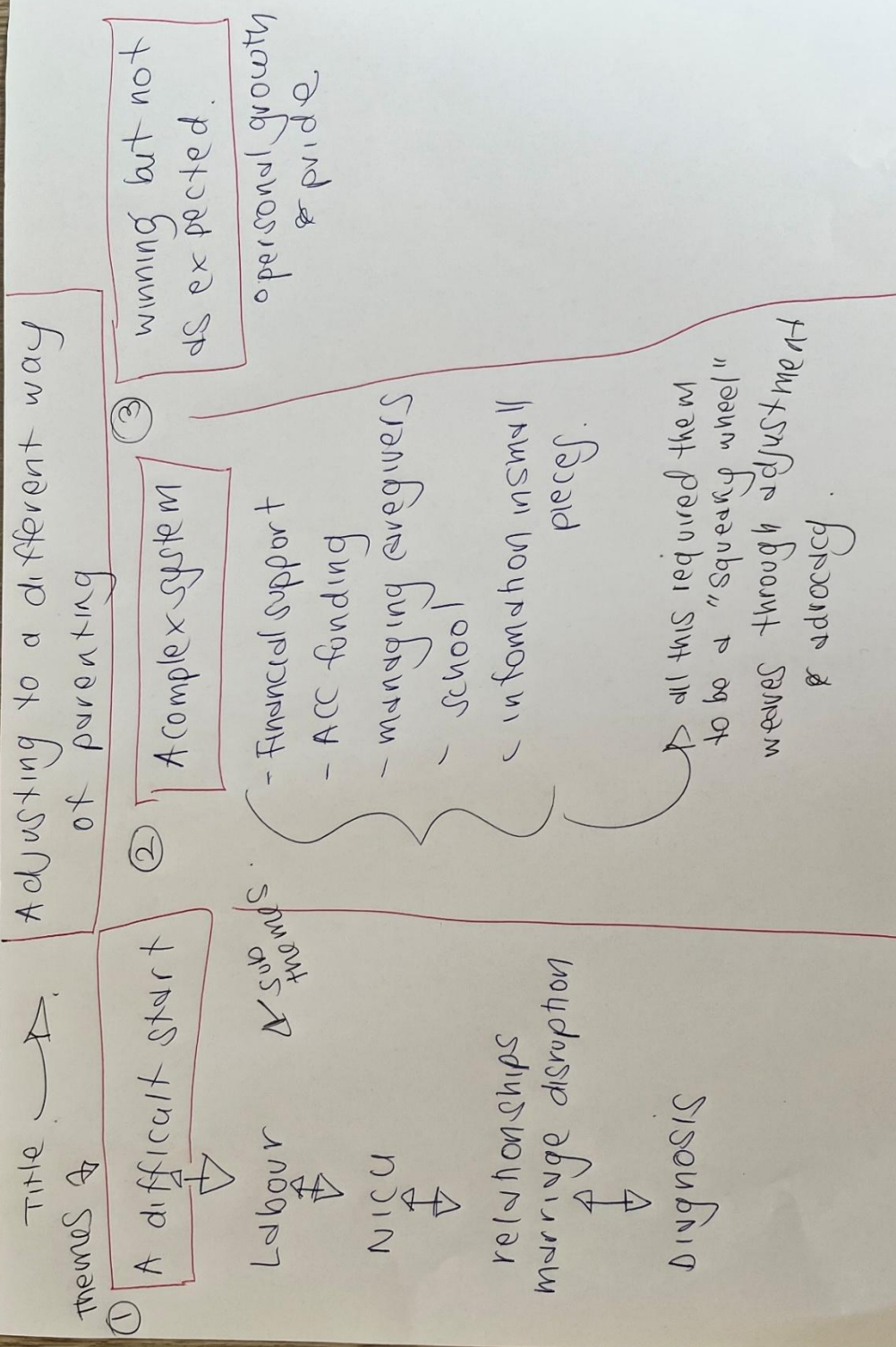
Prompts that could be used throughout the interview as indicated could be phrases such as

- Could you please tell me a bit more about that?
- When you say XYZ what do you mean? Could you please clarify XYZ?

Appendix L: Examples of Theme Development Process

June 21st, 2023





① An unexpected turn of events

- Receiving a diagnosis
 - no information / not knowing
 - being told to go home & google it
 - in appropriate transfer - no referrals / resources
- * Feeling lost -

- Parenting
 - being a caregiver not a parent
 - more time / attention w/ CP
 - every thing revolves around child
 - finding balance - squaring wheel
 - siblings - diff. parenting required

- Working but not as expected.
 - privileges of caring for CP child
 - new way of looking at things
 - personal growth
 - community support - deep connections

- Pivot - balance work & careers
 - ? finding a balance - digging work
 - ? under 'different future' - a nonworking child - less hours working

② Support

- mental health & wellbeing support
 - positive attributes
 - exercise
 - talking to people
- new support networks.
 - other mothers
 - facebook pages
 - social media
- other relationships.
 - lost friendships
 - and friends replaced or new friends.

note. 4 people or ACC
4/15 only one got ACC from birth

③ The system

- Health care changes.
 - understanding the disability
 - managing the disability
- Health care
 - surgery, hospital appointments
 - physio, OT, ACC vs non ACC
- School / education
 - changes in support
 - advocacy / fighting
 - no longer expert.

