Intersectional Approaches to the Experiences of parents of a child with a disability in Aotearoa New Zealand

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Abstract

This study aims to investigate the intersectional experiences of parents caring for a child with a disability in Aotearoa New Zealand, highlighting the challenges faced by these parents. Drawing on critical race theory, social constructionism, and interpretative phenomenological analysis, the research delves into the unique context of New Zealand, uncovering issues such as pathologized difficulties like depression and anxiety, the poverty trap, communication barriers, experiences of solo mothers, racism, housing insecurity, and relinquishment. The findings highlighted an intricate cyclical process reflecting the experiences faced by parents of children with disabilities and communication difficulties. The analysis builds on previously discussed findings to elucidate the "Repeat" cycle, a construct encompassing seven interconnected elements: pathologising difficulties, the poverty trap, loss and isolation, racial discrimination, housing insecurity, the inclination to capitulate, and the perpetuation of the cycle. The interconnectivity of the findings reveals that the parents' experiences embody a cyclical process. The "Repeat" cycle underscores the manner in which one aspect of their experience can give rise to another, culminating in a self-sustaining cycle that perpetuates and intensifies the challenges faced by these parents. The study proposes practical recommendations to address the issues of families with children with disabilities, including depathologising the difficulties, eradicating poverty, fostering inclusive practices, abolishing punitive approaches to disability for solo parents, promoting anti-racism, and ensuring accessible and affordable housing solutions. This study contributes to the existing literature on the intersectional experiences of parents of children with disabilities and offers valuable insights into the unique context of Aotearoa New Zealand, paving the way for a more inclusive and supportive society for families with children with disabilities. The research acknowledges its limitations and encourages further exploration of additional perspectives to better support these families in the future.

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Overview of the chapter

This chapter is to provide an introduction, scope, and the aims of the study. The chapter then moves to a review of the parental experiences of caring for children with disabilities, child disabilities, communication difficulties, parental communication difficulties, and relevant social practices and academic exclusion.

Introduction to the study

Communication is a key function of human interaction, enabling individuals to express their thoughts, feelings, and emotions through verbal, written, and non-verbal forms of communication in everyday life (Key, 2011; Mortensen 1972). Some can communicate, some have difficulties communicating, and some may attempt to communicate but not in a clear way. Children with a disability can often have communication difficulties associated with a range of issues, such as medical and psychological conditions (Klefbeck, 2021; Pinborough-Zimmerman et al., 2007). Children with disabilities and additional needs may have difficulty communicating their needs clearly, making it challenging for parents to care for them. When the parents also struggle with communication, it can be challenging to understand the difficulties they experience, making it difficult to examine their experiences. Caring for children with communication difficulties becomes more challenging, as communication difficulties act as a barrier to understanding their needs, communicating with others involved in their care, and accessing relevant information.

I have a child with Autism Spectrum Disorder (ASD) with an intellectual disability; he cannot speak and has communication difficulties. I find it really difficult that I cannot communicate with him, resulting in me feeling isolated in my home as he is my only family member and making it difficult to find the care I provide for him meaningful or rewarding. In addition to the other difficulties associated with his disability in caring for him, I thought it was my personal experience of finding the absence of communication between my son particularly difficult as it made caring harder for him and finding the work I put in not very meaningful.

Yet my two previous projects looking at migrant parental experiences of children with disabilities indicated that communication was a common theme.

> "*My child can't communicate… I don't know what he is thinking… how his day was*…" (Kim, 2022,p. 24)

> "*I can't speak English, my child can't speak anything at all, what are we supposed to do*?" (Kim, 2022, p. 27)

My previous research on parental experience in caring for a child with a disability and my personal experience motivated me to develop my interest in this topic My previous research examined the migrants' experiences and what was interesting was that the parental ability to communicate and their difficulties in communication played an important role in their sense making, their experiences and how they were feeling (as seen in the quotes from my honours research above). The meaning of communication was considered to be understood as the ability to communicate in a spoken form of English among the interviewed participants. This helped me with two important ideas that motivated this research. First, the communication difficulties were not a fixed idea, as they underlie a range of views, such as communication is a way to communicate through a verbal English format and communication as expressing feelings and thoughts. Second, communication difficulties are not understood as a clearly defined term among the parents of children with disabilities. Rather, it underpinned more of a embodied understanding, such as one's experiences of having difficulties in communicating rather than having a certain condition or meeting diagnostic criteria. From this, I wanted to examine the parental experiences of children with disabilities with communication difficulties throughout their narratives.

Study aims

The focus of this study is the primary caregivers of children with disabilities with communication difficulties in Aotearoa New Zealand (AOTEAROA). As Aotearoa is one of the most ethnically and culturally diverse places, the study may capture the differences and similarities in experiences among parents from a range of different backgrounds. In particular, it may also examine the parental understanding of the communication difficulties for their children and the experiences of parents who understand themselves to have communication difficulties. Although the study aims to look at the parental experience of caring for children with disabilities and communication difficulties, it also looks at the parental communication difficulties, if any, and how their own communication difficulties shape and impact the parental experiences, especially when caring for children with disabilities.

Disability in Aotearoa New Zealand

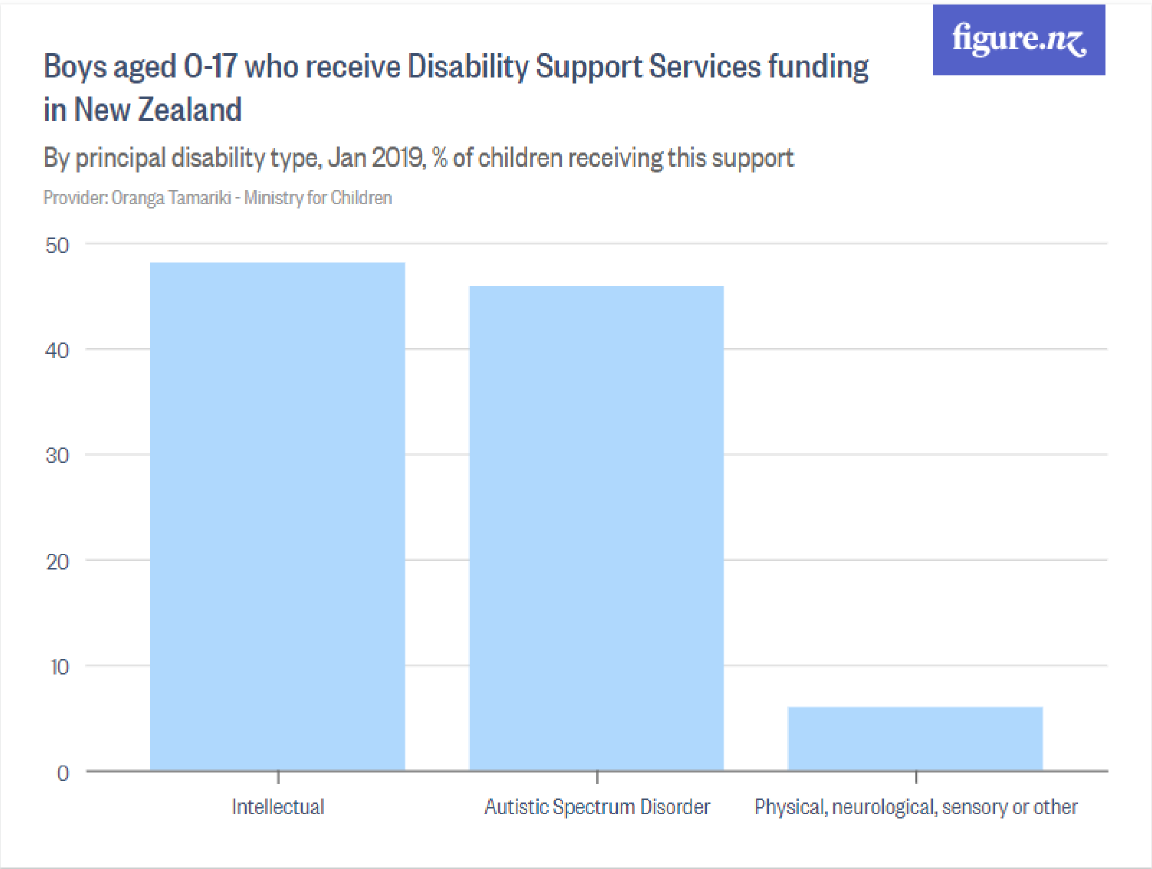
From the 2013 Disability Survey it was estimated that 24% of New Zealanders identified as disabled. Children under the age of 15 years with a disability was found to be 11%. Six percent of children, 52 percent of disabled children, had difficulty learning. While there has not been a survey since 2013, the Office for Disability Issues a Disability Action Plan 2019-2023 and a Minister for Disability Issues. There are eight key outcome areas that the disability action plan focuses on: education, employment, health and wellbeing, rights protection and justice, accessibility, attitudes, choice and control, and leadership. Currently for every single indicator disabled people are doing worse than non-disabled (Office for Disability Issues, MoSD, 2020). Clearly there is a lot more work to do for both adults and children.

It is difficult to get good statistics on disability for children however, the two figures from Figure.nz illustrate what funding is being given for, for young people. Number of parents using sign language or other forms of communication with their children is even harder to access.

Girls aged 0-17 who receive Disability Support Services funding in New Zealand

By principal disability type, Jan 2019, % of children receiving this support

Provider: Oranga Tamariki - Ministry for Children



Boys aged 0-17 who receive Disability Support Services funding in New Zealand

By principal disability type, Jan 2019, % of children receiving this support

Provider: Oranga Tamariki - Ministry for Children

The chapter will first explore the parental experience of caring for a child with a disability, then discuss the child's disability with communication difficulties and parental communication difficulties. Relevant social practices and the academic exclusion of voices of disability, especially those who have communication difficulties in Aotearoa, will be reviewed.

Literature Review

Parental experience of caring for a child with a disability

Parental experience of caring for a child with a disability has long been known to be characterised by the hardship that is associated with it, such as high levels of stress, anxiety, and depression, financial strains, social exclusion, and challenges in marital and social relationships (Currie & Szabo, 2020; Parish et al., 2008; Scherer et al., 2019; Singhi et al., 1990).

Psychological difficulties

Parents of children with disabilities often face a range of psychological difficulties, including stress, depression, and anxiety, which have consistently been reported to be higher than those of parents of children without disabilities (Lessenberry & Rehfeldt, 2004; Lindo et al., 2016). These psychological difficulties can be complex and multifaceted, which may require in-depth examination (Deater-Deckard et al., 2016; Hassall et al., 2020). Yet these studies have suggested that these difficulties can be particularly pronounced as parents may feel overwhelmed by the additional responsibilities and challenges that come with supporting their children throughout their lifespan from early childhood education and transition into adulthood (Burke et al., 2016). Parental psychological distress is often associated with multiple challenges in caring for the child, such as the hard-to-navigate process of seeking advice on the children's condition, getting an official diagnosis, and accepting and understanding the children's disabilities (Ooi et al., 2016; Mitchell & Holdt, 2014; Taylor et al., 2021). The psychological experiences they experience may also stem from the ongoing stress and uncertainty that comes with caring for a child with special needs, as well as from feelings of guilt and shame that some parents may experience if they feel that they are not doing enough to help their child (Farzianestanagh et al., 2020; Findler et al., 2016; Saricam et al., 2020).

The other known contributing factors to the psychological difficulty that parents of children with disabilities may face include a lack of informal and formal support, as any parent may feel that their friends and family members do not understand the unique challenges they are facing, may not be able to provide the emotional support and practical assistance that they need, and the constant need to advocate for their child's rights and needs (Boyd, 2022; Cuzzocrea et al., 2016; Taderea & Hall, 2017). This can involve frequent interactions with educational officials, therapists, and health professionals, as well as navigating complex education, health legal, and financial systems (Cole et al., 2016; Lindsay et al., 2017). Additionally, many parents of children with disabilities feel stressed as they are not being heard or understood by the people around them, which can further contribute to feelings of frustration and isolation (Boshoff et al., 2018 & Lundeby et al., 2008).

Despite the difficulties the parent experiences, Gupta and Singhal (2004) reported the positive cognitive process of reframing the difficulties as resilience and hope. Similarly, Paster et al. (2009) further supported the differences in the cognitive process and, in particular, coping strategies between parents of children with and without disabilities, suggesting that seeking social support, positive reappraisal, and avoidance were more common for the parents with children with disabilities. From understanding the difficulties and differences, some psychological support approaches have been reported. For example, Farzivanestanagh et al. (2020) reported that self-compassion education might help with the parents' feelings of shame and guilt. Similarly, Peer and Hillman (2014) suggested identified contributing factors such as supporting coping strategies and seeking social support to foster resilience for parents with children with intellectual and/or developmental disabilities. Although some studies have identified positive factors in the parental psychological difficulties and recommended some ways to support the parents, the remaining high levels of stress and prevalence of psychological difficulties among the parents suggest that changes in approach to reduce or eliminate parental distress due to children's disabilities may be required (Kuper et al., 2019; Scherer et al., 2019).

Importantly, although there has been extensive literature on the field of parenting children with disabilities, most of the studies were conducted overseas, making it difficult to understand parents' psychological difficulties and identify and brainstorm the ways in which to address parental psychological distress in AOTEAROA. For example, Shepherd et al. (2021) reported a clinically significant level of anxiety among the parents of children with ASD, suggesting that parenting stress was a predictor and mediator variable for the severity of the children's ASD symptoms and mental health issues. Yet an in-depth examination of the parental psychological distress of children with disabilities, such as both qualitative and quantitative data exploring the perspectives of diverse caregivers, including gender, race, ethnicity and socioeconomic status, have been overlooked, suggesting that this area requires further research.

Financial distress and strain

Financial distress is another negative consequential distress associated with parenting a child with a disability, which can have a significant impact on their well-being and ability to provide for their children's needs (Saunders et al., 2015; Shahat & Greco, 2021). Previously, the concept of financial distress was understood as an associated factor for families (Singhi et al., 1990; Knussen & Sloper, 1992). For example, Knussen and Sloper (1992) suggested the lack of financial resources as a coping response associated with problem-solving styles to cope with distress through a multivariable analysis. Similarly, Singhi and et al. (1990) employed questionnaires and standardised scales to identify financial stress as a psychosocial problem, suggesting that financial distress is a problem that needs to be managed within rehabilitation programmes. Additionally, financial stress has been identified as a psychosocial problem that needs to be addressed within rehabilitation programs (Singhi et al., 1990). Although this approach continues to be employed in recent research such as Gerco's report in 2021 and Totsika et al. in 2020, this approach has two limitations: first, it only demonstrates the common difficulties among families, not the specific ways in which factors contribute to parental experiences, and second, it ignores wider social factors, such as ethnicity, sexuality, and parental disabilities.

Recent studies on financial distress and parenting a child with a disability, such as those conducted by Allgood et al. (2011), Goudie et al. (2014), and McConnell et al. (2015), have sought to incorporate a more nuanced understanding of the complexities and multifaceted nature of the issues at hand by incorporating wider social factors into their examination of distress factors, including financial stress. These studies have contributed to a more comprehensive understanding of the financial strain experienced by parents of children with disabilities and how it is linked to broader societal practices and policies. In particular, McConnel et al. (2015) advocated for a re-evaluation of the traditional research framework for studying distress factors among families with children with disabilities, which has traditionally focused on the individual family unit. Instead, they suggested a more holistic approach that takes into account that socioeconomic factors should be adopted for the purpose of planning and suggesting adequate services. These studies have provided a deeper understanding of financial distress rather than simply categorising it as a commonly experienced factor.

The literature on the significant financial difficulties faced by families with children with disabilities is well-established. However, van der Mark and et al. (2017) sought to expand upon this understanding by reviewing literature published between 1995 and 2015 and theorising the impact of poverty on parental care for children with disabilities. The authors highlight the need for poverty eradication efforts and further research to improve the lives of these children and their family members. This research is particularly relevant in the context of Aotearoa New Zealand, where the rate of child poverty is relatively high compared to other OECD nations, and the prevalence of children's disabilities is significant, with 24% of the population being identified as disabled and 11% of that population being under the age of 15 (Goodyear-Smith & Ashton, 2019; Stats NZ, 2020; 2021).

Aotearoa New Zealand's parental experiences of financial distress within the context of the educational system have been explored by Hamilton (2016). The study presented the narratives of parents who struggled to pay for official diagnoses and ongoing assessments, support, and treatment for their children with disabilities due to inadequate public education support. However, this study primarily focused on the parents' experiences within the educational setting and did not fully capture the complexities and nuances of financial distress in everyday life. Additionally, the study did not include the experiences of parents who could not afford any services or who withdrew their children from school, thereby leaving out the perspectives of the most vulnerable population. Further research, such as investigating the role of cultural and societal factors in shaping financial difficulties and how they can shape the parental perception of financial capabilities and access requirements, may be needed to understand the financial difficulties faced by families with children with disabilities in-depth and the impact on their daily lives in Aotearoa New Zealand.

Social exclusion

In this section, the concept of social exclusion will be defined as the inability to access resources, opportunities, and rights that are available to others in society, such as educational, employment, health, political, and housing opportunities and accessibility, as proposed by Sen (2000) and Silver (1994). To distinguish it from the concept of social isolation, the feeling of loneliness, being socially isolated, and exclusion from social activities will be referred to as social isolation in this discussion. The topic of social isolation will be further addressed in a subsequent section.

Children with disabilities and their family members often face barriers to accessing quality education, including parents and siblings. This can include a lack of appropriate accommodation and support for parents and siblings to care for children with additional needs and in the classroom for children with disabilities (Hayden et al., 2019; Singal et al., 2020). Similarly, a lack of inclusive education policies and practices has been identified as a barrier for them to access education. Lopez et al. (2015) and Sánchez-Díaz et al. (2022) reported accessibilities issues in higher education have been reported, suggesting that students with disabilities experience social exclusion at their universities. In addition, discrimination from teaching staff and professional, heteronormativity, and racism toward students with disabilities and their parents have also been identified as barriers, making it difficult for them to be inclusive (Bastart et al., 2021; Duncan et al., 2020; Miller & Smith, 2021).

Although the exclusion of disabilities around education has been around for some time now, the recent COVID-19 pandemic highlights their invisibility of them in the education setting. Many scholars such as Rotarou et al. (2021), Jeste et al. (2020), and Asbury et al. (2021), have illustrated how children with disabilities and their families are excluded from the educational setting, highlighting the need to address the issues with educational access and opportunities for them. Despite that, this is a well-establish area of research, and the remained barriers and non-inclusive educational settings suggest that different approaches to address this may be necessary. Also, it may be important to acknowledge that one important area that has been overlooked can be how children's disabilities impact parental social exclusion in the educational setting, which can be related to other domains of social exclusion.

Employment is another important domain of social exclusion as parents of children with disabilities often face discrimination in the workforce, are less likely to be employed or have stable and secure employment, and are more likely to earn less income (Brown & Clark, 2017; Saunders et al., 2015; Stabile & Allin, 2012). A number of barriers associated with this have been identified, such as a perceived lack of their availability, lack of availability of flexible positions, as they often require taking children to appointments and meetings, stigmatisation from colleagues and employers, and a lack of support in caring for their children, which often requires them to take time off (Ntinda & Hianze, 2015; Saunders et al., 2015). Although the laws and rights of parents of children with disabilities have been established in many places, such as the United States, Canada, the United Kingdom, and Aotearoa, parental difficulties with employment have been consistently reported internationally through numerous studies and literature (Chung, 2020; Friendly & Prentice, 2016; Hewett & Newson, 2017; Kinnear et al., 2016; Wilkins et al., 2015). These barriers are also associated with financial strain and hardship, making it difficult for the parents to provide for their families and likely to be at risk of poverty, which again can be contributing factors for further stigmatisation and marginalisation (Gibson & Martin III, 2019; Samuel et al., 2018).

Parents and families of children with disabilities also often have significant obstacles when attempting to participate in political participation, namely issues with doing justice for people with disabilities, accessibility, representation, and resources, which can lead them to not be involved in the political decision-making process and not have their voices heard (Nussbaum, 2006; Simplican, 2015; Slee, 2019). As Nussbaum suggested (2006), people with cognitive impairments are often not able to express their voices, and parents or caregivers not being able to exercise their political rights any more than they can do as an individual thinking agency (not two including their children) leads the voices of people who cannot express their voices and people whose lives have been affected by the conditions of people that they care for to not be counted for them, thus making them less represented in the current democratic thinking-frame. In addition to the issues with democracy and justice, practical barriers such as accessibility issues, including mobility issues and physical accessibility of places where parents have to accompany children when participating, lack of resources such as having alternative caring labour options to allow them to have time to participate and lack of representation as these barriers work together also contribute to the political underrepresentation of them, which may result in their not having adequate representation in the political sphere, and their issues and concerns may not be addressed (Madanipour, 2015; Marsack & Perry, 2018; Munn, 2018; Schwanen et al., 2015).

They also often experience social exclusion in housing accessibility and face barriers such as issues with accessing appropriate housing for their children's needs, affordability, and discriminative and negative attitudes from landlords, property management, and neighbours (Baker et al., 2016; Grotti et al., 2018; Murchie & Pang, 2018). In addition, the absence of policies or regulations for accessible housing that is reflective of the population, minimal governmental support in housing modification for people with disabilities, and the lack of availability of accessible housing make it difficult for parents to secure housing that meets their children's needs (Baker et al., 2016; Grotti et al., 2018). Furthermore, issues with affordability are often closely associated with financial strain and compromised employment and educational opportunities, highlighting the multidimensional difficulties and inequities the parents face (Emerson & Hatton, 2007; Hughes & Avoke, 2010). In Aotearoa, numerous works of literature have consistently reported housing accessibility and inequality issues for people with disabilities and made suggestions such as an introduction of housing standards and increasing housing support for people with disabilities, yet these issues still remain unresolved (Callaway et al., 2022; Mills et al., 2015; Murray & Loveless, 2021; Yeung et al., 2022).

This section explored the social exclusion of parents of children with disabilities in important domains of the lives of the parents and also the children. It found that, issues are not new but still strongly present, as also found in the current international and local literature. This suggests that more actions and research for the effectiveness of actions should be encouraged for the development of more inclusive and equitable policies and practices to reduce social exclusion.

Children with communication difficulties

Communication difficulties

Communication difficulties refer to the challenges an individual may experience when trying to effectively convey or understand information through verbal or nonverbal means. In this study, it is important to acknowledge the two ways in which communication difficulties are understood: the medical model and the phenomenological lived experience model in the literature (Finlay, 2009).

The medical model of communication difficulties framework views these difficulties as a pathological or clinical condition, where an individual's communication abilities are evaluated against a set of pre-determined norms and standards, focusing on identifying and treating the underlying causes of communication difficulties, such as speech disorders or cognitive impairments (Pound et al., 2018). Although this framework has been beneficial for the development of many important approaches to communication difficulties, it has a limitation of not being able to capture people's experiences and the meaning understood by them.

On the other hand, the phenomenological lived experience paradigm of communicative disorders may offer to posit that a comprehensive comprehension and appreciation of the subjective experiences of individuals grappling with communicative impairments can be useful in this study as this theoretical framework acknowledges the complexity and multidimensional nature of communication, which is influenced by various factors such as social, cultural, and personal experiences (Cwirynkato et al., 2022; Maxfield et al., 2022). Importantly, it can also recognise the profound impact that communicative difficulties can have on an individual's self-perception and their ability to actively engage in their surroundings (Heidegger, 2005; Moustakas, 1994).

The significance of this approach is rooted in its capacity to offer a more comprehensive and inclusive comprehension of these difficulties, acknowledging that communicative impairments are not merely a pathological problem to be diagnosed and treated but rather a multifaceted and complex phenomenon shaped by various personal, social and cultural factors. Additionally, it enables an understanding of the lived experiences of individuals experiencing communicative disorders and other conditions that are associated with communication difficulties and their family members and the ramifications these have on their daily existence, in the hope that the understanding may contribute to the implementation of efficacious and appropriate interventions and support for them.

Associated conditions

Communication disabilities, also known as communicative disorders, refer to a wide range of impairments that affect an individual's ability to effectively use and understand spoken and written language (Hemsley & Balandin, 2014; Simeonsson et al., 2012). These impairments can manifest in various forms, such as difficulty with articulation, fluency, voice, and language comprehension. They can also arise from a variety of causes including neurological disorders, hearing loss, cognitive impairment, and developmental delays (Hemsley & Balandin, 2014; Simeonsson et al., 2012).

Communicative impairments can be understood as categories of neurological disorders and speech-language disorders. Neurological disorders associated with social communication, such as autism spectrum disorder, developmental delays, cerebral palsy, and traumatic brain injury that are associated with cognitive impairment and developmental delays have a profound impact on an individual's cognitive and linguistic abilities, including their ability to process and understand language, as well as their capacity to produce speech and nonverbal communication (Lancioni et al., 2020).

Speech-language disorders, such as dysarthria and apraxia of speech, refer to impairments in the motor and phonetic aspects of speech production (Chenausky et al., 2019; Chu et al., 2019). These disorders can impede an individual's ability to articulate speech sounds correctly, as well as their capacity to form coherent sentences and convey meaning effectively for a range of reasons, including developmental or acquired disorders (Chenausky et al., 2019).

In Aotearoa, Keith and colleagues (2019) reported the estimated prevalence of auditory processing disorders among children to be around 6.2%, yet there are no current data or studies on the prevalence of young children with communication disabilities. Although older adults do not represent the epidemiological understanding of children, McAuliffe et al. (2019) reported that approximately 30 to 36 % of older adults are known to face one type of communication difficulty, with the prevalence being higher among Māori, Pasifika, and Asian compared to European and other ethnicities, suggesting that there may be differences in the prevalence among children from an ethnic minority background. Further local studies are required to understand child communication cultures, disabilities and/or difficulties.

Parental experiences of compromised communication and interaction with children

The compromised communication and interaction between parent and child with communication disabilities and difficulties can be a complex and nuanced one, as it involves difficulties in understanding the child's verbal or nonverbal expressions, difficulties in initiating or maintaining conversational exchanges, and difficulties in effectively conveying one's own needs and expectations to the child (Drew et al., 2002). In addition, feelings of frustration and helplessness among parents, stemming from the perception of not being comprehended or attended to by the child, were often among the parents, which may exacerbate feelings of isolation and alienation, especially for the parents feeling that they are not receiving adequate support or understanding from their social network (Daumgardner, 2019; Zulfia, 2020). Furthermore, parents may experience a sense of guilt or inadequacy in regard to their perceived inability to provide adequate support for their child's communication development, which is associated with a negative self-perception and a lack of confidence in their parenting abilities (Meirsschaut et al., 2010).

In regard to parental experiences, Feldman (2002) examined the level of life satisfaction among the mothers of children with intellectual disabilities and reported that the mothers were adversely stressed and socially isolated. In particular, the positive interaction between the children and the parent had a significant correlation with positive life satisfaction. In addition, a similar effect of the abovementioned mitigating factors of social support, including informal support networks such as family members and friends and formal support such as health and educational support was also observed, as the mothers who had available and accessible social support reported less level of social isolation and also better life satisfaction compared to the mothers who did not, indicating that the stress associated with the compromised parent-child interaction could be reduced by social support. Cuzzocrea and et al. (2016) further supported the role of social support in parenting a child with communication difficulties as they reported that the parents of children low functioning autism had difficulties interacting with their children. They also reported higher level of stress than the parents of children with other disabilities without communication difficulties and lower levels of stress when they received more social support.

Despite these challenges, parents are often reported to take proactive steps to improve communication and interaction with their child, such as seeking out specialised support from speech therapists, special education teachers, or other professionals who are trained in addressing communication difficulties through parental education, in-home therapy, and parent-child therapies (Armstrong et al., 2015; Chengappa et al., 2017; Yang, 2016). Furthermore, Aggazzi et al. (2017) found that access to and accessing these known effective interventions for child-parenting is associated with less parental stress, anxiety, and depression, and more positive children's behaviour and parenting outcomes. Parents also reported that participation in support groups or networking with other parents of children with communication difficulties and/or disabilities can provide a valuable source of information, validation, and emotional support (Lei & Kantor, 2021; Shepherd et al., 2020). Still, many parents reported common barriers to accessing specialised support and social networks, such as not having enough money, time and appropriate transportation, indicating that support to remove these identified barriers can be beneficial for both parents and children. These findings highlight how parents are often willing to access social support and already well-established and available effective interventions, which often lead to a positive outcome for both parents and children, yet the barriers still make it difficult for the parents to access them and achieve the positive outcomes.

Parental communication difficulties

Communication difficulties among parents of children with disabilities can take various forms associated with a range of factors. There are two types of parental communication difficulties that are relevant to this study - difficulties related to conditions compromising the ability to communicate and difficulties related to English as a second language. Understanding parental communication difficulties in regard to compromised ability to communication difficulties may be crucial as Lederberg et al (2013) and Kanto (2013) theorised the important role the parental ability to communicate plays in parenting, children's language development, and challenges and strengths among parents with communication difficulties of children with and without communication difficulties.

Exploring parental communication difficulties in relation to the parental ability to speak the dominant language of a place – English in Aotearoa – also provides helpful insight into examining the experiences of parents with children with disabilities as parents who do not speak English were found to have the lowest rate of accessing and the higher rate of having difficulties in accessing parenting information in England (2001). Similarly, Amant et al. (2018) identified not having a proficient level in English as a barrier for non-English speaking parents to access disability-related services.

However, difficulties in researching the population with communication difficulties, such as not being able to communicate, and difficulties with the participants and researchers understanding each other, have been consistent barriers, with minimal attempts to address these issues. This has resulted in no known knowledge of the population.

Relevant social practices in Aotearoa

Aotearoa has solidified the legal rights of individuals with disabilities by ratifying the relevant legal obligations, including the United Nations Convention on the Rights of Persons with Disabilities (2006), as well as the New Zealand Bill of Rights Act (1990) and the Human Rights Act (1993), which provide for the protection and promotion of the rights of people with disabilities. Regarding the provision of assistance for families with children with disabilities, various forms of government support are available in the areas of social welfare, health, and education.

The social welfare policies and programmes related to families are outlined and offered by the Ministry of Social Development (MSD) through their agencies, such as Work and Income (WINZ) and the Office of Disability Issues. MSD also provides a range of community programmes for families, such as community activities, employment training, public transportation discounts, and transitioning into community services (MSD, 2022a). Currently, various financial assistance options are available from WINZ, such as a child disability allowance (52.79 NZD per week), which is not income tested, and income tested disability allowance, which is a maximum of 70.04 NZD per week depending on the household income (WINZ, 2022a; WINZ, 2022b). In addition to the weekly payment, MSD provides care in the community disability welfare fund for the financial year of 2022 and 2023, in which 176 applicants were successful nationwide (MSD, 2022b).

Although these social services are available, there are barriers and challenges when accessing them including administrative and bureaucratic barriers. These include assumptions that they can communicate effectively, have time to seek services during business hours, are well aware of the eligibility and services and can thereby easily prepare relevant documentations and applications form to apply, and the stigmatisation and stereotyping of the normalised assumptions of the parental responsibilities of their own children with disabilities (Casebolt, 2020; Mitchell, 2015; Tracy & McDonald, 2015). In addition, it may be also questionable as to whether the current support is sufficient to support the families and accessible for all, especially for cultural, social and ethnical minority groups (Hall, 2010; Liasidou, 2014).

For health-related support, New Zealand Government outlines that Aotearoa provides a diverse array of health-related resources and support options for parents and families with children who have disabilities (New Zealand Government, 2022). These include assessment and intervention services such as occupational, rehabilitative, and behavioural support, as well as daily living support, medication, and respite care through Te Whatu Ora (TWO) and the Ministry of Health (TWO, 2022a). In 2022, TWO publicly stated its objective of offering a holistic approach to meet the social, physical, cultural, emotional, and spiritual requirements of those it serves (TWO, 2022b).

Despite promising plans and proposed services for individuals with disabilities and their families, a significant body of literature has consistently reported that these services are either unavailable or inaccessible. Anderson et al. (2020) have highlighted a gap between the support currently available and the support that is required. Additionally, challenges related to access to relevant information about available services and difficulties encountered in advocating for access have been identified. Murray (2018) has argued that the insufficient level of governmental support and assistance available has resulted in families of children with disabilities being trapped in poverty. This is because these families often prioritise the care of their children, preventing them from being able to work and earn a sustainable income.

Mont (2019) has discussed the complex yet significant relationship between child poverty and disability, indicating that available disability support may play a crucial role in the well-being of children with disabilities and their families. Access to services has been identified as a greater issue for minority and marginalised communities as Shrestha-Ranjit and colleagues (2020) emphasized the increased challenges faced by refugee women in accessing disability services. Similarly, Zhang (2021) noted that families from diverse cultural backgrounds and low incomes encountered obstacles in accessing intervention services and perceived the existing services to be limited.

For education support, the Ministry of Education (MoE) provides a range of disability support aimed at providing inclusive to ensure equal access for all such as individualised education plans, assistive technology, and teacher aid support (MoE, 2022a). One important support is the ongoing resourcing scheme, which provides funding for students with significant needs. The MoE also provide relevant training and services for teaching staff members, a range of teaching providers and facilities and parents to support them in further supporting children with disabilities (MoE, 2022b).

Despite the MoE assertion that they offer comprehensive support to meet the educational needs of children and ensure inclusive enrolment, Selvaraj (2015, 2016) and Zhang (2021) have highlighted the reality of an inaccessible and exclusive learning environment for children with disabilities in Aotearoa. Their research suggests that the inclusive learning environment that the Ministry aims to provide is far from the actual learning setting, leaving many children without necessary learning support and some forced to stay home due to insufficient support in their learning environment (Selvaraj, 2015; Tiso & Stace, 2016). Kearney (2016) similarly reported that students with disabilities face exclusion from their learning environment, citing barriers such as educators lacking knowledge about the conditions of students, insufficient funding and teacher aide time, and negative attitudes from educators. As such, Kearney recommends that reforms be made to relevant legislation, policy, and practices to address these identified barriers, highlighting the needs and urgency of addressing the compromised educational opportunities for Aotearoa children with disabilities.

The findings indicate that there are services available that appear to be somewhat suitable. However, the adequacy of these services remains in question, and their accessibility and appropriateness of approach are uncertain, and the issues and their implications may be greater for marginalised groups.

Racial disparities

Understanding the issue of racial disparities and inequalities among parents of children with disabilities is a crucial area of examining the parental experiences, as it is understood that there are racial disparities among people with disabilities and the parents of children with disabilities (Fazil et al., 2002; Magaña et al., 2015; Morgan et al., 2015), and these racial disparities are often associated with equity and inequality, social and cultural issues, and the matters of professions involved in the care of children that the parents face (Fish, 2019; Magaña et al., 2012; 2015).

Fazil et al. (2002) examined the narratives of the Pakistani and Bangladeshi parents of children with disabilities in England and found that the parents were severely disadvantaged in accessing services and resources for their children. Based on the parent’s narratives, Fazil et al. (2002) suggested that parents of children with disabilities add an additional layer of institutional racism, especially for ethnical minority and immigrant families and offered insights into the multi-dimensional and structural inequalities underpinned by race and disability. Although these studies offered an understanding of the intersection between race, ethnicity, and disability, not many studies have attempted to further explore this intersection. For example, Selman et al. (2016) reported the perceived stigmatisation of Somalian parents of children with ASD in the United Kingdom, yet the concept of racism or the parental ability to communicate was not explicitly explored in this study.

However, the idea of an association between racial disparities and the parental ability to communicate has gained some attention and contributed to the understanding of the experiences of difficulties that ethnic minority families face, such as racism and lack of proficiency in the language of their host nation (Magaña et al, 2015; Zuckerman et al., 2014; Morgan et al., 2015). Although there may be a distinction and explanation of race and ethnicity, it is important to acknowledge that in understanding the ethnic minority parents, the overlapping and intertwining areas of understanding race and ethnicity will offer a framework to examine the ethnic minority groups who are often in the ethnic or racial minority or both of them (Brondolo et al., 2009; Richardson & Norris, 2010). For example, Amant et al. (2018) reported that in the United States, children with ASD whose parents speak English as a primary language received substantially more services, including individualised educational plans and one-on-one service hours than the children with ASD parents' primary language was not English. In regard to ethnicity, Magaña and et al. (2015) and Elliot et al. (2022) reported disparities between European and non-European populations in the quality and accessibility of received health care and intervention, respectively. These findings highlight the importance of the role of ethnicity, race, their intersectionality when understanding parental experiences, and the significance of accounting for the complexities of these concepts when doing so.

When examining the issue of racial disparities in Aotearoa, it is essential to recognise the legal obligations and guidance of Aotearoa for achieving racial equality in health, including disability, as outlined by Te Tiriti o Waitangi (1980), the United Nations Convention on the Rights of Persons with Disabilities (2006), the New Zealand Bill of Rights Act (1990), and the Human Rights Act (1993). Te Tiriti o Waitangi establishes the principles of Tino rangatiratanga (Māori self-determination), Pātuitanga (partnership with Māori), Mana Taurite (equity for Māori), Whakamarumaru Tanga (protection of Māori), and Kōwhiringa (Māori rights to pursue their own personal direction, whether or not it aligns with tikanga Māori), which are intended to ensure equal health outcomes for Māori and non-Māori. Both the Waitangi Tribunal (2019) and the Ministry of Health (2022) have recognised the importance of these principles. Similarly, in accordance with the United Nations Convention on the Rights of Persons with Disabilities (2006), the New Zealand Bill of Rights Act (1990), and the Human Rights Act (1993), which were mentioned in the previous section, any observed racial disparities should be reduced, if not eliminated altogether.

Yet racial disparities related to disability in Aotearoa continue to be reported. Wyeth et al. (2019) found that Māori face greater challenges in accessing post-injury disability services and experience poorer post-injury disability outcomes. Similarly, Mortensen et al. (2014) highlighted racial disability disparities among refugee communities in Aotearoaand provided recommendations on how to improve this. They reported that refugee families with disabled members are not familiar with available disability-related health services and struggle to understand the available disability support. Cultural caseworkers who provide culturally responsive approaches to navigate the disability support system appear to be helpful for these families.

One crucial factor contributing to the existing racial disparities among families with children with disabilities is the lack of comprehensive understanding of the underlying phenomena. For instance, according to a report by CCS Disability Action (2015), Māori and Pasifika children are less likely to receive necessary resources, thereby underscoring the racial inequalities faced by these families. However, a thorough exploration of this issue has yet to be undertaken. Similarly, a report by New Zealand (2020) revealed that Māori families with disabilities are over three times more likely to experience financial difficulties in meeting basic needs than Māori without disabilities, revealing the multiple layers of challenges that the indigenous population faces. Nevertheless, this report fails to highlight the differences among various ethnic groups, and an in-depth explanation of how these challenges interrelate and impact the Māori population is absent. These findings illustrate the lack of understanding that may be closely linked to the inadequate efforts to comprehend the complexities of racial disparities in the disability sector, such as in academic and public research. This could be a consequence of the academic exclusion of relevant groups, which will be discussed in the following chapter.

Academic exclusion

Academic exclusion can be understood as the systematic hindrance of the marginalised such as people with disability and their family members, from fully participating in the academic research process, specifically in regard to the production of knowledge, which can be a pervasive problem that negatively affects marginalised populations (Scheurich & Young, 1997; Holmes et al., 2006). This exclusion can be seen in a range of forms, such as underrepresentation in the literature and studies, and their underlying epistemology, ontology, and methodology resulting in the exclusion of the worldviews and perspectives of the population relevant to academic exclusion (Scheurich & Young, 1997; Holmes et al., 2006).

In relation to disability academic exclusion, hermeneutic phenomenology of disability as a topic and people with disability and their family members as research conductors, contributors and participants limit human knowledge construction of people with disabilities (Russo & Beresford, 2015). One population that is particularly encapsulated in academic exclusion is children with disabilities and their family members, particularly those of children with communication difficulties.

The academic exclusion of children with disabilities and their family members can be understood by the barriers that they face, such as the children’s inability to express their voices due to their communication difficulties, inaccessible and discriminatory educational opportunities that compromise any potential opportunities of the children in knowledge construction, the parental difficulties in understanding the thoughts of the children, and the lack of resources of children to have the capacity to participate in academic knowledge generation due to the additional required resources in caring for the children (Doell & Clendon, 2018; Ferri & Connor, 2005; Kitchin, 2010; Olsen et al., 2020). In particular, Ferri and Connor (2005) also highlighted that race is an element of academic exclusion in a way disability serves as a component of academic exclusion when suggesting disability as a contributing issue in academic exclusion, which raises the question of how race and disability may work together for those of whom have a disability and are in an ethnic minority as well as highlight the needs of exploring the complexities of the intersection between race and disability (Annamma et al., 2018). These findings are well reflective of the academic exclusion of children with disabilities that impact knowledge construction in the field of disability sector Aotearoa.

For example, Morton et al. (2012) reported a longitudinal study of young children and families looking at the factors associated with the children's well-being, but the disabilities have been minimally looked at as a part of the report, highlighting that the study required the resources to look at the long-term well-being of children overlooked the children with disabilities, whose well-being is significantly more likely to be compromised, outlining the urgency of research strategies that acknowledge the invisibility of children with disability and their family members. Another report published in 2017 (Morton et al., 2017) looked at the well-being of the young children and their family members, including physical health in Aotearoa, using a longitudinal study. However, this also minimally looks at and considers disability and long-term illness, suggesting that the attempts to understand disability when assessing the overall well-being of children has continued to be excluded.

Of particular note, both of the reports look at the school and early childhood centre enrolment among the children without acknowledgment of the issues with the inaccessible Aotearoa educational setting, which has been well known to the Aotearoa education literature (Kearney, 2016; Morrison et al., 2022; Purdue et al., 2011; Twiss et al., 2013). Whilst the reports capture the overall information of young children and families in Aotearoa, excluding disability as an issue or topic to be looked at or discussed furthers the exclusion of children with disabilities and families and contributes to the continuous challenges in understanding them as it may blind them as the members of Aotearoa society.

In the context of race, when Kasilingam et al. (2019) examined the mismatch between the services that parents of children with ASD hope to receive and what children actually receive, which contributes to more understanding of children with disability and their parents. However, the consideration of the issues regarding race and ethnicity was not carefully explored despite the well-established understanding of the importance of considering race and ethnicity with unique historical and current influences, such as colonisation, migration, and racism in health inequities in Aotearoa (Moewaka & McCreanor, 2019). While Kasilingam et al.(2019) noted that they could not find a statistically significant relationship between child characteristics, which include ethnicity and the parental preferred support received, this approach may not be suitable to examine the complexities in existing issues in race and disability as it could not capture important issues such as how participants had arrived at the determination of their preferring certain types of intervention, receiving the intervention, barriers in understanding and sense-making process in children's disability and intervention, navigating health and educational system process, and complexities in the intersection between race and disability.

Similarly, when Morrison et al. (2020) examined the understanding of belonging in places in Aotearoa society which are understood to be built upon ableism in this study, they acknowledged other factors associated with discrimination within the disability sector such as ethnicity and age. However, the crucial role of race in this space has not been explored with the aim of understanding the relationship between ethnicity and discrimination within the disability sector, which can lead to the enhancement of the understanding of the intersection.

To address the academic exclusion of marginalised populations in Aotearoa, such as parents of children with disabilities, particularly those with communication difficulties, it is important for researchers to adopt decolonising methodologies (Smith, 2021; Leavy, 2022). These include community-based participatory research, storytelling, and autoethnography, which centre on the voices and experiences of marginalised groups and disrupt dominant narratives (Barker et al., 2021; Leavy, 2022). Additionally, considering the research community's obligation and commitment to Te Tiriti o Waitangi, it is important for researchers to adopt a decolonising ontology, which recognises the ways in which colonialism has shaped their understanding of the world and their research questions, and actively seeks to centre the perspectives and experiences of marginalized groups in their research (Baker et al., 2021; Silcock & Hocking, 2021). Therefore, this study will aim to explore the narratives of parents of children with disability and communication difficulties. It will consider the findings in this section and the absence of their narratives, with the aim of exploring the intersectionality of race and disability in the current literature in Aotearoa (Baker et al., 2021). By centring the voices and experiences of them, this study seeks to address the academic exclusion of parents of children with disabilities and contribute to a more academic understanding of the complexities of race and disability that are reflective of, represented and inclusive of their own experiences and perspectives.

In addition, to address the issues of the exploration of the intersection between disability and race, Annamma (2016) and Annamma et al. (2018) provided the framework of disability critical race theory. This framework allows the exploration of the intersection while acknowledging that the issues around disability are an independent issue but are intricately connected to the issues of race and ethnicity in disability issues. Other factors involved in the intersections around disability and race, such as sexuality, gender and class, worldviews of others that are outside of the Western worldviews, the urgency of inclusion of all who have been traditionally excluded in the knowledge generation process and promotion of empowerment of them in their everyday lives, will also be addressed in this study (Smith, 2016). This framework alongside the academic position of privileging people’s narratives to explore the gaps in the current research explored by the findings, will be explored in the next chapter.

Chapter 2

Overview of the chapter

This chapter is to provide the framework and methods of the study. Critical Race Theory, Social Constructionism, Interpretative Phenomenological Analysis, ethical considerations, participants, and procedures are discussed.

Theoretical Framework

Critical Race Theory (CRT) has been the chosen framework of this study as I aim to explore the parental experiences of children with disabilities and communication in Aotearoa. This is because intersectionality is essential in understanding their experiences. The experiences of these people whose lives have been impacted by their disability or their family members, their experiences, and their race, gender, and class (Annamma et al., 2018; Ladson-Billings & Tate, 1995).

CRT is a theoretical position on the premise that race and racism, and social power dynamics shape the experiences of marginalised groups such as parents and families of children with disabilities (Annamma et al., 2018). CRT acknowledges that racism and racial hierarchies and their power dynamics intersect with other social factors such as class, gender, and disability, contributing to marginalization and discrimination. They are also embedded in societal structures and systems, how these structures and systems perpetuate racial inequalities and the importance of examining the ways in which people experience and resist and challenge the racial inequalities manifested and maintained by the structures and systems (Annamma et al., 2018; Gillborn, 2015). CRT aims to critically examine the role of race and racism in shaping society, institutions, and individual experiences by exploring the counter-narratives and challenges the traditional understanding of race as a biological category by emphasising its social and historical construction. It also seeks to expose and dismantle racial inequality and promote social justice through a critical lens that acknowledges the systemic nature of racism (Annamma et al., 2018; Gillborn, 2015).

In the context of researching the experience of parents of children with disabilities, CRT provides a framework for understanding the ways in which race and racism intersect with ability and disability and communication difficulties by how these intersections shape these parents' experiences (Annamma et al., 2018; Graham et al., 2011). This will allow me to explore the ways in which race, disability and parenting interact with systemic racism in societal structures and systems that are relevant to these parents, such as educational and healthcare systems, and how they perpetuate racial disparities and inequalities in access to opportunities, resources and support among these parents.

In the context of Aotearoa, CRT is particularly important, given the country's colonial history. The colonial history of Aotearoa has resulted in the displacement and marginalisation of Māori, and this marginalisation is reflected in the current socio-economic disparities experienced by Māori (Came, 2014; Hylton, 2012). By incorporating CRT, this study acknowledges the historical and contemporary racial disparities in Aotearoa and seeks to understand how these disparities may influence the experiences of parents in the study. Furthermore, CRT can help to uncover the ways in which colonial legacies continue to shape the experiences of both Māori and non-Māori parents raising children with disabilities and communication difficulties (Came, 2014; Hylton, 2012).

However, it is important to acknowledge Critical Disability Studies (CDS) (Goodley & Lawthom, 2019; Goodley et al., 2017), which shifts the focus to disability, emphasising the intersectionality of race, gender, and other factors that contribute to the experiences of individuals with disabilities. CDS also recognises that the ways in which society perceives and interacts with disability are intertwined with other social constructs, and thus, it is essential to examine these aspects concurrently. By privileging the intersectional nature of these experiences, CDS seeks to illuminate the complexities and challenges faced by individuals with disabilities and their families, highlighting the interconnectedness of various forms of marginalization and oppression.

However, it seems that positioning CRT , CRT seems to be especially relevant and essential to Aotearoa, as the persisting and growing racial disparities in Aotearoa New Zealand indicate that centering race may be necessary to address these issues and given the multicultural diversity of Aotearoa with historical and ongoing migrations, which also shape Aotearoa's structures and systems that are intertwined with the migrant populations who are often from the ethnic, cultural, and social minority groups in Aotearoa (Moffitt et al., 2019). In this study, although the acknowledgement and the population of the minority groups such as non-heterosexual, migrant, and a range of religious populations have exponentially grown, the minority groups are defined to be socially, culturally, and politically minor groups that may differ from those of the socially, culturally, and politically dominant population (Moffitt et al., 2019; Oritz & Jani, 2010; Shelton, 2018). By using CRT as a framework, I can gain a deeper understanding of the complexities and nuances of the experiences of these families and may be able to identify the racial inequalities and potential barriers to support and resources, ultimately contributing to inform policies and practices that aim to promote equity and justice for all families of children with disabilities.

CRT and Social Constructionism

Social constructionism provides a theoretical framework proposing a reality that is not fixed and challenges the idea of objective reality by contending that our understanding of phenomena, such as disability and race is subject to the interpretive processes inherent in human interaction and communication (Andrews, 2012; Burr, 1998; Burr & Dick, 2017). It posits that reality is constructed, understood, and shaped within society and influenced by societal factors such as culture, history, politics, language, social institutions, and people and therefore the reality is not to be objectively discovered. This framework provides ways to construct knowledge as knowledge is socially constructed, acknowledging that knowledge is not the one truth that is universally accepted, and understanding that knowledge itself is shaped by people who generate and understand the knowledge within the society (Andrews, 2012; Burr, 1998; Burr & Dick, 2017).

Whilst social constructionism highlights how reality is not fixed and constructed, the role of race and racism embedded in the societal structure and systems may have not been centred in this framework (Hernández, 2016; Pulliam, 2017). However, social constructionism fits well with CRT as both theories emphasise the role of social structures and institutions in shaping individual experience. It can be understood that CRT and social constructionism are both theoretical frameworks that focus on how people’s everyday lives and their experiences are intertwined and shaped by the societal structures and systems, which manifest and maintain inequities and unequal power dynamics (Hernández, 2016; Pulliam, 2017). This combined framework acknowledges the influence of social constructions of race and disability on parents' experiences while also considering the impact of racial inequality and discrimination. By integrating these two perspectives, the study can better explore the complex interplay between individual experiences and broader social forces that shape the lives of parents and their children (Hernández, 2016; Pulliam, 2017).

The ontological position of this study is relativism as this, alongside CRT and social constructionism, allows me to generate knowledge of the parental experiences of children with disabilities while looking at the societal factors and the individuals who interact and are intertwined with society (Hylton, 2008; Treviño et al., 2008). The methodologies of this study will include methods that look at the parental experiences through in-depth interviews that allow me to have a deeper understanding of the way in which parents understand their experiences and also to understand my own position in the society that shapes my understanding and meaning and knowledge construction process, using my reflexivity (Hernández, 2016; Hylton, 2008).

In addition, it is also important to note that the parental experiences of children with disabilities and communication difficulties can be individual and challenging, and their experiences can be shaped by societal structures and power dynamics (Farrugia, 2009; Lalvani & Polvere, 2013). Therefore, using qualitative approaches rather than collecting numerical data without in-depth context, can be helpful to see their experience and how they navigate and make sense of their experiences. This will then inform the inclusive and effective adjustments in the existing system that are meant to support them, and also reduce or eradicate the difficulties that they may experience (Resch et al., 2010).

It is possible to argue that qualitative data may lack reliability and validity and that the researcher's interpretation may not accurately represent the collected data (Noble & Smith, 2015). However, given the complexity and nuance of the experiences of parents of children with disabilities, I intend to be reflexive throughout each stage and use the strengths of CRT to explore the experiences of migrant parents with a child with a disability (Annamma et al., 2018; Moffitt et al., 2019). This will enable a comprehensive understanding of the experiences of parents of children with disabilities in Aotearoa acknowledging that there are multiple truths. I am a researcher who is a member of an ethnic minority group, a social and political minority group as a solo parent, and a parent of children with disabilities which will be a helpful position within this research but will require on-going reflexivity.

I note that the combined framework of CRT and social constructionism may result in a loss of clarity or focus, making it more challenging to examine these parents' experiences. Also, the critical nature of CRT may lead to a focus on negative experiences and challenges faced by parents, potentially overlooking the resilience and strengths that these families demonstrate (Moffitt et al., 2019). Despite these limitations, the benefits of using a combined theoretical framework of CRT outweigh the potential weaknesses as it provides a more holistic understanding of parents' experiences, accounting for the complex interplay between individual, social, and systemic factors. By acknowledging the potential weaknesses of this combined framework, I can take steps to mitigate these issues, such as maintaining a clear focus on the research objectives and ensuring that both positive and negative aspects of parents' experiences are considered.

Acknowledging the sense-making and meaning-making process of individuals and their social context, I will examine how existing societal features in Aotearoa interact with and shape parental experiences by utilising CRT and social constructionism (Hernández, 2016; Zuberi, 2010). Ultimately, this study will seek to provide a thorough and nuanced understanding of the experiences of parents of children with disabilities and communication difficulties in Aotearoa from the perspective of a researcher with multiple marginalised identities.

Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is a methodological approach employed to analyse qualitative data, with a focus on individuals' subjective psychological experiences (Eatough & Smith, 2017; Smith et al., 2009; Smith, 2011). By emphasizing the idiographic nature of research, IPA enables the generation of rich, contextually grounded insights that contribute to a broader understanding of psychological phenomena. This approach illuminates how individuals make sense of their subjective world. Smith et al. (2009) suggested IPA as a suitable method for examining complex and nuanced psychological phenomena through a detailed idiographic focus. To appreciate the strengths of IPA in research, it is crucial to consider its epistemological, ontological, and methodological positions (Smith et al., 2009).

Epistemologically, IPA is rooted in phenomenology and hermeneutics (Smith et al., 2009). Phenomenology underscores the importance of understanding individuals' lived experiences, while hermeneutics emphasises the interpretative nature of human understanding (Laverty, 2003; Lindseth & Norberg, 2004). In IPA, researchers acknowledge that knowledge is co-constructed by both the participant and researcher, necessitating recognition of the researcher's preconceptions and influence on the research process (Smith et al., 2009). IPA adopts a subjective epistemology, recognising that no single, objective reality exists; rather, multiple interpretations of the same phenomenon emerge, which facilitates deep exploration of participants' unique experiences and highlights the researcher's role in generating meaningful insights through interpretation (Smith et al., 2009).

Ontologically, IPA is characterized by its commitment to examining individuals' subjective experiences (Eatough & Smith, 2017). This approach aligns with a constructivist ontology, which maintains that reality is socially constructed and understood through individuals' meanings and interpretations. IPA acknowledges the complexity of human experience, emphasizing the significance of context and language in shaping individuals' understanding of their world (Eatough & Smith, 2017).

Methodologically, IPA is characterised by a rigorous, iterative process of data collection and analysis. Researchers conduct in-depth, semi-structured interviews with participants to elicit rich and complex narratives (Eatough & Smith, 2017). Data analysis in IPA is an iterative and interpretative process, involving multiple stages of coding and theme development to reveal the essence of participants' experiences (Smith et al., 2009).

However, it is important to acknowledge the criticisms of Interpretative Phenomenological Analysis (IPA) in order to understand its limitations and to ensure a balanced view of the methodology (Brocki & Wearden, 2006; Smith, 2011). First, IPA relies heavily on the researcher's interpretation of the data. This means that the researcher's own beliefs, experiences, and perspectives can significantly influence the analysis process, potentially leading to bias. Second, the subjective nature of IPA makes it difficult to generalise the findings to larger populations. The analysis is based on a small number of participants and their unique experiences, meaning that the results may not be applicable to other individuals or groups (Brocki & Warden, 2006; Smith, 2011).

Despite these criticisms, IPA remains valuable for examining the parental experiences of children with disabilities and communication difficulties as it can offer a way to explore complex and nuanced experiences in depth, which can provide valuable insights into the meaning that people attach to their own experiences (Smith, 2011). This is particularly important in fields like psychology, where understanding individual experiences can contribute to broader theoretical development. In addition, as IPA emphasises the researcher (who is also a parent of a child with a disability with communication difficulties) and the participants' meaning-making processes, it will allow me to better understand how individuals make sense of their experiences (Eatough & Smith, 2017). This can help inform interventions or support systems that are tailored to the unique needs of individuals or groups.

The potential for researcher bias and the subjective nature of the analysis will be addressed by my trustworthiness and the in-depth exploration of reflexivity (Rodham et al., 2015; Shaw, 2010). I will conduct member checking, a technique used to validate the accuracy of the findings by sharing preliminary results with the participants (Curtin & Fossey, 2007; Smith & McGannon, 2018). This process allows participants to review and confirm my interpretations of their experiences. By engaging in this iterative process, I can ensure that the data analysis accurately represents the participants' perspectives, thereby enhancing the credibility of the study as I aim to produce credible, reliable, and valid findings that contribute to the understanding of the unique challenges and experiences faced by these parents. I will solicit feedback from supervisors. These supervisors, experienced in IPA and the study's subject matter, will assess the research design, data collection methods, and data analysis to ensure their appropriateness and rigour. Reviewing will help identify any potential weaknesses or biases in the study and contribute to the overall trustworthiness of the findings (Rodham et al., 2015; Smith, 2011).

Triangulation involves the use of multiple sources, methods, or researchers to corroborate findings. In this study, I will employ methodological triangulation by collecting data through multiple methods, including in-depth interviews, participant observation, and review of relevant information (Andrews, et al., 2015; Larkin et al., 2019). By comparing and contrasting findings from different data sources, I can enhance the study's validity and reduce the potential for bias or misinterpretation.

I will build trust and rapport with the participants, allowing for a deeper understanding of their experiences. Prolonged engagement enhances the credibility of this study, as it provides the opportunity to gain a more comprehensive and nuanced understanding of the participants' perspectives (Maggs-Rapport, 2000; Shinebourne, 2011). This process will involve regular communication, follow-up check-ins, and the continuous refining of data analysis, ensuring that the findings genuinely represent the participants' experiences.

In addition, reflexivity is a critical aspect of qualitative research, particularly in studies employing IPA, as it acknowledges the researcher's influence on the research process and findings (Smith, 2011). To ensure the trustworthiness of a study exploring the parental experiences of raising children with disabilities, I will address reflexivity through self-awareness and self-reflection (Eatough & Smith, 2017). Self-awareness involves acknowledging my positionality, personal experiences, and potential biases that may influence the study. Therefore, I will openly acknowledge any personal experiences of being a parent of a child with disabilities and communication difficulties, beliefs of racial disparities among the parents, or assumptions shaped by my experiences and beliefs related to parenting children with disabilities or the research in general. This disclosure will allow me and others to recognise potential biases that may influence data collection, analysis, and interpretation (Eatough & Smith, 2017). Furthermore, throughout the research process, I will maintain a reflexive journal to document personal thoughts, feelings, and reactions to the data and the research process. This practice will help me identify further potential biases and their influence on the study (Miller et al., 2018; Vicary et al., 2017).

Self-reflection involves the ongoing evaluation of my role in the research process and the effects of their biases and assumptions on the findings. To promote self-reflection in this study, I will critically reflect on my role in the research process regularly throughout the research process and document it in the reflexive journal (Miller et al., 2018; Vicary et al., 2017). I will also share the reflexive journal context and preliminary findings with the supervisor, soliciting feedback on potential biases and their impact on this study. This feedback will help me to recognise any overlooked biases and promote greater self-reflection (Miller et al., 2018; Vicary et al., 2017). I will discuss my reflexivity process in the research supervision, providing transparency about their role in the research process and the potential impact of my biases and assumptions on the study's findings, which will contribute to the study's credibility and trustworthiness (Miller et al., 2018; Vicary et al., 2017).

My intention is to utilise the strategies I have discussed and apply these techniques to generate findings that are both trustworthy and credible. I aim to contribute to the comprehension of the distinct challenges and experiences that parents of children with disabilities and communication difficulties encounter. By doing so, I will ensure the reliability and validity of this IPA study.

Ethics

The present study, which obtained ethical approval from Massey University's Northern Ethics Committee (NOR 22/17), is aimed to investigate the experiences of parents raising a child with a disability and communication difficulty. Given the sensitive nature of the research topic, a comprehensive application was submitted to address potential ethical concerns, including the emotional distress of participants, privacy and confidentiality, and adherence to Te Tiriti o Waitangi.

Participants may experience emotional distress while discussing the challenges associated with caring for their children and confronting issues such as racism and communication difficulties. Despite this possibility, it was determined that the potential emotional distress was unlikely to be prolonged or significant, as the study included several safeguards, such as a list of agencies and support resources provided to participants, and detailed information on the study's aims and purposes allowed them to make informed decisions about their participation. Furthermore, the study's potential benefits, which were absent in existing literature, were deemed to outweigh the potential harms. By improving our understanding of these parents' experiences, the study could contribute to the development of effective psychological support strategies.

To ensure participant safety and minimise the risk of distress, participants were recruited from their existing support networks, where they could potentially access other relevant services. This approach allowed for the identification of individuals who were already engaged in seeking support and were more likely to be comfortable discussing their experiences.

In adherence to Te Tiriti o Waitangi, the study consulted with the ethics committee, the research supervisor, and a cultural advisor. Each research process, including recruitment, data collection, and data analysis, was reviewed by Māori researchers and community members to ensure the well-being of Māori participants and cultural sensitivity throughout the study.

Considering the close-knit nature of the disability parental support community, especially among ethnic-specific parents of children with disabilities, measures were taken to protect participants' privacy. Identifying information, such as names of schools and specific suburbs, was omitted, and pseudonyms were used to maintain the anonymity of all participants and children involved in the study.

The provision of a $30 Koha gift card for each participant was approved by the university's ethics committee and the School of Psychology. This compensation demonstrated appreciation for the participants' time and contributions to the study.

By addressing ethical considerations such as emotional distress, participant safety, Te Tiriti o Waitangi commitment, privacy, and confidentiality, the present study ensured that the investigation of parental experiences in raising a child with a disability and communication difficulty was conducted responsibly and sensitively. This approach not only protected the well-being of participants but also contributed to the trustworthiness and credibility of the study's findings.

Participants

Participants were required to meet the following criteria to be eligible for this study. First, they must be a caregiver or a parent of at least one child with a disability. Second, the child(ren) must have an official diagnosis. Third, the child must require supplementary resources such as assistive devices (e.g., computers, tablets, iPads, or other assistive technology), cochlear implants, or utilize sign language, or have limited language ability. Fourth, participants must reside in New Zealand at the time of the interview. Fifth, given the consent, competency, and assent considerations, they must be over 18 years of age.

Exclusion criteria for this study encompassed parents with children who do not have an official diagnosis of a disability and those not residing in New Zealand at the time of the interview. For each participant, the following demographic information was collected, and the information included age, gender, area of residence, types of communication difficulties experienced by children and parents if any, race/ethnicity, self-reported social class, and relationship status.

Participants were recruited through the following organisations and support groups, with permission obtained from Autism New Zealand, Auckland Whanau Special Needs Support Group Inc, Māori Autism Support Group, Pasifika Autism Support Group (PASG), Auckland Central New Zealand Sign Language Learning Group and VIPS - Equity in Education NZ. These organisations and groups have Facebook pages and/or community notice boards where the study was advertised. I provided information about the study to the organizations and support groups listed above and sought their permission to advertise the study and promote participant recruitment. Upon receiving approval, I provided an advertisement that included information about the study, the inclusion criteria, and my contact details (email address and phone number) for interested participants. Potential participants contacted the researcher via email or phone. Those who expressed interest in participating received an information sheet and a consent form to review.

A target sample size of six to 10 participants was initially established for this study, as recommended by Braun and Clarke (2021), Smith (2004), and Smith et al. (2009) for the application of IPA and in consideration of the appropriate sample size for a university post-graduate level project. However, due to the increased interest from potential participants, a total of 14 individuals were ultimately included in the study. This larger sample size contributes to a robust representation of the study population, as the 14 participants come from diverse backgrounds and have varying demographic information, enriching the overall understanding of the research topic.

In this study, a total of 14 biological mothers participated, all of whom had children with disabilities and communication difficulties. The children ranged in ages from 5 to 32 years old, while the age range of the participants was 24 to 59 years old. All of the participants were living in Auckland at the time of the interview and identified themselves as Māori (n=3), Pasifika (n=3), New Zealand European (n=2), Chinese (n=2), Korean (n=2), South African (n=1), and English (n=1).

The children's disabilities included Autism Spectrum Disorder, intellectual disability, type 1 diabetes, Global Developmental Delay, Muscular Dystrophy, and brain damage. Two participants reported doing well socioeconomically, four reported not doing great but stable, and two reported struggling. Six participants reported severe struggles and not meeting their basic needs.

Regarding communication difficulties, eight participants reported not having any difficulties, one reported having some difficulties due to their proficiency in English, and three reported significant difficulties due to their proficiency in English. Seven participants were married or in a bona fide relationship, while seven were solo parents.

Although the eligibility criteria were clearly defined, four concerns emerged during the course of this study. First, there were expressions of interest from parents of children with disabilities who did not experience communication difficulties. I addressed this issue by informing these individuals that future opportunities to participate in relevant research might become available.

Second, the study's eligible population shared a common characteristic: all participants were women. While the recruitment materials clearly stated that participants could be a parent or caregivers, prevailing social and gender norms seemed to contribute to the participation of solely female caregivers. One male caregiver who initially expressed interest in the study deferred to his spouse, as he felt that the mother was the primary caregiver. I addressed this issue by consulting with peer scholars and supervisors and implementing strategies for including more non-female caregivers and by challenging the social and gender norms that heavily emphasised the role of women as carers among disability communities by sharing the findings.

Third, even though the study advertisement was displayed in deaf communities and indicated that a New Zealand Sign Language (NZSL) interpreter would be provided and the researcher had intermediate-level proficiency in NZSL, no deaf individuals ultimately participated in the study. Potential participants cited childcare arrangements and transportation issues as barriers to their involvement. To address this concern, I communicated to potential participants and the community that future research would aim to better accommodate their needs with robust support, ensuring that their voices are represented in research.

Lastly, this investigation endeavoured to engage participants from across Aotearoa, with the objective of including individuals who may have faced difficulties participating in prior research projects due to geographic constraints. I initially thought that utilising online advertising and removing location restrictions would attract study participants from outside Auckland. Regrettably, all respondents resided in Auckland, highlighting the necessity for alternative strategies to guarantee equal participation opportunities for individuals, irrespective of their regional location or internet accessibility. By acknowledging and addressing these concerns, I aim to improve the inclusivity and representation of diverse perspectives in future research efforts.

Once a participant expressed their interest in participating in the study, the date and location for the interview were scheduled according to their preferences. To prioritise safety, interview locations were selected in quiet public spaces, such as local libraries or cafes. Participants were provided with a printed version of the information sheet during the initial contact, and prior to the commencement of the interview process. All participants completed the informed consent form to ensure their understanding and agreement to participate in the study (See Appendix A for the information sheet and Appendix B for the consent form).

In cases where participants preferred to conduct the interview at home due to childcare or transportation issues, I travelled to their address accompanied by an additional safety person who waited in the car outside. The safety person was equipped with a safety alarm message set up on my phone. In case of any safety-related issues, I could tap the phone, alerting the safety person to provide support. However, this safety measure was not needed during the data collection process.

Procedure

During the recruitment phase, potential participants were informed that the interview process would entail a one to two-hour recorded session. This duration was chosen to provide ample time for open and thoughtful discussion, allowing participants to share their experiences and insights fully. Clear communication of the interview process aimed to establish expectations and foster a sense of trust between myself and the participants.

Prior to scheduling interviews, the researcher emphasized the importance of confidentiality and informed consent. Participants were assured that their personal information would remain protected, and their identities would not be disclosed in any resulting publications. Informed consent was obtained, ensuring that participants understood the nature of the study, their voluntary involvement, and their right to withdraw at any time without negative consequences.

To effectively delve into the complex and nuanced experiences of parents caring for children with disabilities and communication difficulties, in-depth interviews were deemed essential as I aimed to determine how participants made sense of their experiences and constructed the meaning. The in-depth interviews enabled me to explore participants' perspectives, emotions, and challenges, uncovering rich, detailed insights that may not have emerged through more superficial data collection methods such as surveys or questionnaires.

The interviews were conducted in Korean, English, and Chinese, as per the participants' preferences. To accommodate diverse linguistic needs, I informed participants that translation services were available if required. Colleagues proficient in various languages, such as Tongan, Te Reo, Tuvaluan, Samoan, Hindi, and French, generously offered their assistance. Despite the availability of translation options, the majority of participants opted to communicate in English.

During the introduction, participants were provided with a printed information sheet in English that outlined the interview process with a verbal explanation of the information in Korean and Chinese when the interview was conducted in Korean and Chinese, including the option to select their preferred language, audio recording procedures, the right to discontinue the study or take breaks during the interview if they felt distressed or uncomfortable. Participants willing to participate in the study were asked to provide their consent by signing the consent form prior to the interview.

In accordance with the participant’s consent, the interviews were recorded using a Galaxy Note 10 Plus device, which featured a built-in recording application (see Appendix C for the interview questions). The use of voice recording enabled me to accurately transcribe the context of the interviews for analysis purposes. In addition to voice recording, I also actively took notes on their understanding, thoughts, emotions, and reflections during the interviews.

The in-depth interview process considered the framework of this study combining critical race theory and social constructionism had phases of establishing rapport, contextualisation, exploration, discussion and conclusion (Cuadraz & Uttal, 1999; Laus, 2022). I began each interview by establishing a rapport with the participant, creating a comfortable and supportive atmosphere, and providing an overview of the study's objectives and the relevance of the participants' experiences. Open-ended questions were used to encourage participants to discuss their experiences in depth, focusing on their emotions, challenges, and coping strategies while caring for their children with disabilities and communication difficulties. I did not limit the time spent on the participants’ responses to the questions, thus allowing them to share their experiences in a way that felt natural to them. This approach allowed me to explore how participants perceived their experiences, emotions, and feelings, and how these were intertwined with societal factors through their unique perspectives.

Participants were also prompted to explore how societal attitudes, systemic barriers, and cultural norms may have shaped their experiences. This was achieved through open-ended questions that invited participants to discuss any racism or barriers they may have encountered outside of their individual circumstances. By using this approach, I was able to gain a deeper understanding of the participants' experiences and the various factors that influenced them. Then the conversation was expanded to cover support networks, resources, and services that participants had accessed or would like to have available to them. I provided an opportunity for participants to raise any additional concerns or share insights beyond the structured questions. After exploring all questions, I thanked the participants for their time and valuable input and provided information on any follow-up procedures or dissemination of research findings.

By adhering to this process, the study aimed to yield rich and comprehensive data, shedding light on the multifaceted experiences of parents caring for children with disabilities and communication difficulties within the context of critical race theory and social constructionism.

Data analysis

Interpretative Phenomenological Analysis (IPA) is a qualitative research methodology that concentrates on comprehending participants' lived experiences and the ways they interpret these experiences. By applying IPA, I aimed to offer a comprehensive exploration of the experiences of parents with children who have disabilities and communication difficulties. The following sections outline the systematic and rigorous step-by-step IPA process undertaken and explain of the analytic process and strategies employed.

The initial stage of the IPA process entailed that I immersed myself in the data. This immersion involved listening to audio recordings multiple times, transcribing the interviews, and making annotations on emerging patterns, ideas, and topics. Subsequently, I first listened to the recordings and created a note to make notes to comments, highlighting some of the topics, ideas, events, and thoughts about the research. Then I listened to the recording and produced a transcribed version of it. After confirmation of the accuracy of the participants’ transcription, I went back to the transcription and went through it with the recordings to make further notes. Once this stem was completed, I went back to the transcription and notes to become pioritized with the data. The initial stage was helpful for developing a deep understanding of the participants’ experiences and identifying potential avenues for further exploration and the coding process.

In the initial coding phase of the IPA process, I embarked on a thorough examination of each transcript, prioritized every line with keen attention to detail. This critical stage involved the identification and labelling of salient statements, phrases, and ideas that effectively captured the essence of the participants’ experiences. Throughout this phase, I remained deeply immersed in the participants’ language and narrative content, ensuring that the codes were both descriptive and grounded in the rich fabric of their personal stories.

The initial coding phase was characterised by a systematic, inductive approach that 47prioritized the data-driven analysis of the transcripts. I refrained from imposing the pre-planned theoretical framework for this study upon the data. Rather, I cultivated an open and exploratory mindset, aiming to explore the participants' unique voices and perspectives to guide the discovery of the initial emergent patterns and connections. This inductive approach laid the foundation for the subsequent emergence of themes that were firmly rooted in the data to enhance the authenticity and relevance of the findings. During this phase, I engaged in an iterative process of revisiting and revising the initial codes, continually refining and adjusting them to make them reflect the nuances and complexities of the participants' experiences more accurately. This cyclical process facilitated the development of a comprehensive and coherent coding structure that captured the richness and diversity of the participants' narratives while remaining grounded in their lived experiences. The initial coding phase also involved the creation of detailed analytical notes, where I documented my thoughts, reflections, and ideas as I engaged with the data. These notes served as a valuable resource for tracking the evolution of the analysis process, enabling me to trace my thoughts, reflections, and ideas, and the development of codes and themes over time and ensure their consistency and coherence with the data.

Upon completion of the initial coding phase, I began the active coding phase, a critical and dynamic stage of the IPA process that entailed a deeper and more sophisticated engagement with the data. At this juncture, I carefully reviewed the initial codes, focusing on discerning connections, patterns, and relationships that emerged from the rich tapestry of each participant’s narratives. This meticulous examination allowed me to identify clusters of interrelated codes, which formed the foundation for the development of emergent themes. These emergent themes, representing broader, more abstract concepts, encapsulated the essence of the participants' experiences, transcending the specificities of individual narratives while remaining firmly grounded in the data. The active coding phase was marked by a persistent sensitivity to the nuances, intricacies, and complexities of the participants' narratives, with me continually revisiting and refining the emergent themes to ensure their accuracy and authenticity. During this phase, I adopted a reflexive stance, actively engaging in critical self-reflection and documenting my thoughts, insights, and potential biases in a reflexive journal. This practice facilitated a heightened awareness of my role in shaping the analysis, promoting transparency and bolstering the credibility of the findings.

Throughout the active coding phase, I also engaged in regular debriefing sessions, seeking input and feedback from supervisors with expertise in health psychology, IPA, disability, critical race theory, and social constructivism. These collaborative exchanges fostered an environment of critical dialogue and constructive critique, further refining the emergent themes and enhancing the rigour and trustworthiness of the analysis.

As the active coding phase progressed, I revisited the analytical notes created during the initial coding phase, integrating these insights with the emergent themes to develop a holistic and nuanced understanding of the participants' experiences. This iterative and recursive approach allowed for constant refinement of the themes, ensuring they remained anchored in the data while providing a coherent and cohesive representation of the participants' lived experiences.

As the analysis advanced into the pivotal stage of connecting themes and developing superordinate themes, I immersed myself in the landscape of emergent themes that had been identified during the active coding phase. This was a crucial stage of the IPA that necessitated a thorough examination of the relationships, intersections, and commonalities that existed among the emergent themes, enabling me to discern overarching superordinate themes that encapsulated the broader conceptual dimensions of each participant’s experiences.

These superordinate themes, characterised by a higher level of conceptual abstraction, served to synthesise and integrate multiple emergent themes, offering a more comprehensive and coherent understanding of the participants’ experiences. Throughout this phase, I remained steadfast in my commitment to maintaining a strong connection to each participant's data. I also engaged in an iterative process of constant comparison and reflection to ensure the superordinate themes accurately captured the nuances and complexities of the individual narratives. In addition, I continued to engage in reflexive practices to contribute to the trustworthiness of the analysis and promoted transparency in the development of superordinate themes. The process of connecting themes and developing superordinate themes represented the groundwork laid during the initial and active coding phases. By maintaining a steadfast focus on each participant's data and engaging in an iterative process of constant comparison and reflection, I developed superordinate themes that represent the participants' lived experiences.

Upon completing the individual transcript analysis, I performed a cross-case analysis, comparing the themes identified across all 14 participants. This stage involved recognizing commonalities and differences in participants' experiences and highlighting shared themes and unique aspects of individual narratives. This analysis contributed to a more comprehensive understanding of the phenomenon under investigation, situated within the broader sociocultural context. Following the process of connecting themes and developing superordinate themes for each individual participant, I started the cross-case analysis phase involving a systematic comparison of the themes that emerged across the entire cohort of 14 participants, enabling me to identify overarching patterns and insights that transcended individual experiences while also acknowledging the unique aspects of each narrative.

The cross-case analysis required me to engage in a detailed examination of the commonalities and differences that emerged between the participants' experiences. By carefully juxtaposing and contrasting the themes, I was able to identify shared elements and discern the unique features that characterised individual narratives, fostering a deeper understanding of the multifaceted nature of their experiences. This process facilitated the development of a more comprehensive understanding of the experiences of parents of children with disabilities and communication difficulties, effectively situating the phenomenon within the broader sociocultural context. Furthermore, the cross-case analysis allowed me to establish connections between the emergent themes and the study's theoretical underpinnings, enabling a more nuanced interpretation of the data in light of critical race theory and social constructivism.

Upon the completion of the cross-case analysis stage, I was able to proceed to the phase of integrating the identified themes with the study's theoretical frameworks: critical race theory and social constructivism. This process facilitated the development of a more nuanced understanding of the parents' experiences, delving into the intricate ways in which systemic and institutional factors shaped their perceptions, coping strategies, and lived realities. Engaging in a thoughtful and scholarly integration process, I carefully examined the identified themes and conceptualised how race, ethnicity, culture, and societal norms might have influenced the participants' experiences. This comprehensive analysis extended beyond the immediate context of the individual narratives and addressed the broader sociocultural and systemic factors that underpin the phenomenon under investigation, as informed by critical race theory and social constructivism.

Reflexivity

During the data analysis stage reflexivity was essential to remain committed to maintaining methodological rigour and academic professionalism. The use of reflexive notes and debriefing supervision sessions were employed to ensure my interpretations were critically examined and contextualised within this study's theoretical frameworks. Additionally, I drew upon relevant literature to support the integration process, highlighting connections between the study's findings and existing scholarship. This process facilitated the development of a more nuanced understanding of the parents' experiences, uncovering the complex ways in which systemic and institutional factors intersect with race, ethnicity, culture, and societal norms to shape their lived realities.

In order to ensure the trustworthiness and validation of the findings from the previous phases of analysis, I adhered to employed triangulation, reflexivity, and member checking. Triangulation, a critical component in establishing trustworthiness, was achieved through the use of other sources reviewed in the literature review stage and analytic approaches. In addition to IPA, I employed Thematic Analysis and coding reliability techniques to corroborate the findings. The consistency of the findings across these methods served to strengthen the credibility and trustworthiness of the results. Yet, while Thematic Analysis and coding reliability techniques successfully identified commonalities across the participants' experiences, I acknowledged that these methods were limited in their ability to capture the rich and unique narratives of each participant. However, the researcher understood that this limitation highlights the strength of IPA, as it provides a more in-depth and nuanced understanding of individual experiences, which is essential in capturing the complexities of the participants' lives. This approach not only verified the consistency of the findings but also underscored the value of IPA in capturing the intricacies of the participants' experiences.

Reflexivity allowed me to examine my positionality as a parent of a child with a disability and difficulties and the potential influence of my biases and assumptions on data interpretation. By engaging in reflexive practices, including keeping a reflexivity journal and participating in debriefing sessions, the researcher critically examined my role in the research process, enhancing the credibility of the study's findings. Member checking involved sharing the identified themes with the participants and soliciting their feedback, which allowed me to confirm that the emergent themes accurately captured and reflected the participants' experiences, thus ensuring authenticity and credibility. By employing these strategies, I was able to ensure the trustworthiness and validation of the IPA findings, ultimately contributing to the rigour and robustness of the study. Following the abovementioned steps and the strategies of this research, I was able to prepare for the next steps, which involved the presentation and discussion of the findings within the broader context of the literature and the implications for practice, policy, and future research.

In the final step, I presented the findings in a coherent and accessible manner, providing a clear and concise narrative that accurately conveyed the participants' experiences. This included a thorough description of the superordinate and emergent themes, supported by verbatim quotes from the participants to illustrate and substantiate the findings. I also situated the results within the broader literature, examining the study's contributions to the existing knowledge base and discussed the implications for practice, policy, and future research.

After these steps, I acknowledged the study's limitations: potential biases in participant recruitment, the impact of any subjectivity, and the transferability of the findings to other contexts. By acknowledging these limitations, I encouraged a critical appraisal of the study's results and provided a foundation for further research to address any gaps or shortcomings. Additionally, based on the findings and limitations, I offered recommendations for future research, practice, and policy development related to the experiences of parents of children with disabilities and communication difficulties.

Chapter 3

Overview of the chapter

This chapter is to provide the findings of this study. It discusses the pathologised difficulties of depression and anxiety, poverty trap, can’t understand and can’t express, incarcerated solo mothers in circumstance, racism, housing insecurity, relinquishment, and the “Repeat” cycle. A supplementary section of Love, Joy, and Hope has been added, which is not categorised as a primary finding but deemed essential to be included in the findings section.

Pathologised difficulties as depression and anxiety

Many parents in this study revealed that the unique challenges they encountered while caring for their children with disabilities were often overlooked or misunderstood. Their emotional turmoil manifested through feelings of helplessness, guilt, and isolation. Parents often experienced helplessness as they navigated through the uncharted territory of raising a child with disabilities. The lack of clarity and predictability in their child's progress further intensified these feelings. For instance, Participant 1 shared her experience:

> *"Each day, I wake up with uncertainty. I don't know if my daughter will have a good day or if she'll struggle with even the simplest tasks. It's terrifying to feel so powerless, unable to control the unpredictable rollercoaster of her life."*

Guilt was another prominent emotion expressed by parents. They often felt guilt for their child's disability, questioning whether they could have done something differently during pregnancy or early childhood. Participant 2, revealed her feelings of guilt:

> *"I wonder if it is my fault. Did I miss something, or could I have done something differently to prevent this? These questions haunt me, I wonder if it's not my fault."*

Isolation also emerged as a significant issue for parents, as they often felt disconnected from their social circles due to the unique challenges they faced. The inability to participate in typical family activities or relate to other parents' experiences contributed to feelings of loneliness. Participant 1, mentioned earlier, further elaborated on her feelings of isolation:

> *"I see other families with their 'normal' lives, and it's like I'm living in a completely different world. I can't just take my daughter to the park or have a playdate. It feels like I'm just on my own, cut off from the rest of society."*

In addition, the misunderstandings and lack of awareness surrounding the challenges faced by parents of children with disabilities had a significant impact on their emotional well-being. They often felt unsupported and dismissed, which further intensified their feelings of helplessness, guilt, and isolation. For example, Participant 4 described her experience:

> *"My friends don't understand me. They just don't get me. They think I'm just always tired or stressed or lazy, but it's so much more than that. They just don't know what it is like, and it is just difficult to get them to understand, and even my own family don't understand."*

The participants emphasised the importance of empathy and understanding in alleviating their emotional turmoil. When their challenges were acknowledged and validated, they felt less isolated and more empowered to cope with their unique situations. As Participant 5 noted:

> *"When someone takes the time to truly listen to what I have to say, it makes me feel better even if they are not doing anything but just listening. It helps a lot. It reminds me that I'm not alone in this journey."*

Although participants expressed that being understood makes it better, they also faced difficulties with understanding their own children, and communication barriers were a common theme. The inability to understand and interpret their child's needs, expressions, or emotions only intensified their struggles. As participant 6 lamented:

> *"I feel so angry that I can't understand my son. I feel so stupid and frustrated that I can't understand what he wants and meet his needs."*

The inability to understand and interpret their child's needs, expressions, or emotions only intensified their struggles. There were various aspects of communication barriers and their impact on the parents' experiences caring for children communicate through Non-verbal

Communication, Limited or Delayed Language Development, and Augmentative and Alternative Communication (AAC) Devices.

Some children with disabilities heavily relied on non-verbal communication, such as gestures, facial expressions, or body language. However, interpreting these cues can be challenging for parents. Participant 3 shared her struggles:

> *"My son doesn't speak, so he communicates through his facial expressions. It is always a guessing game trying to figure out what he needs or how he feels."*

Some children with disabilities experience limited or delayed language development, making it difficult for parents to engage in typical verbal exchanges with their children. Participant 7, who has children with a speech delay, recounted his experience:

> *"It's so heart breaking when my boys try to talk to me, but I can't understand their words. I wish I could have a conversation with them like other parents do with their children."*

While AAC devices can provide valuable communication support for children with disabilities, parents may face challenges in learning to use and interpret these tools effectively. Participant 8 described her experience with an AAC device:

> *"My son uses the iPad, the device, the app thing that he uses. It is okay. I mean it is better than nothing, but it is still hard to understand. It is hard enough when he doesn't understand me, but when I can't understand him, there is nothing I can really do for him."*

The communication difficulties experienced by parents had far-reaching consequences, affecting their relationships with their children, their emotional well-being, and their ability to advocate for their child's needs.

Difficulty in communication also led to strained parent-child relationships, as parents may struggle to bond with their children or feel disconnected due to the lack of shared understanding. Participant 6, mentioned earlier, further elaborated on her relationship with her son:

> *"I feel like there is a wall between us. We just can't understand each other. I really want to be his mother and his friend, and just want to be someone to him. I really want him to*

> *know that I am here for him and I love him, but he will never understand this and he will never understand me. I mean, will he even know that I am his mother?"*

The emotional toll of communication barriers cannot be overstated. Parents often reported feelings of frustration, sadness, and inadequacy as they grappled with the challenges of understanding their child's needs and expressions. Participant 9 shared her emotional struggle:

> *"It breaks my heart when I see him angry, and I can see his anger in his eyes, but I don't, and I can't understand why. I feel so guilty, and I just feel so hopeless and helpless, and I just don't see this getting better at all, and it is just making me really I don't know, feel really alone, sad, angry and all of those feelings."*

Communication barriers also impeded parents' ability to effectively advocate for their child's needs in various settings, such as schools, healthcare facilities, and social situations. Participant 10 discussed her advocacy efforts:

> *"It's difficult to convey my son's needs to his teachers or therapists when he can't communicate them himself. I often worry that his needs aren't being met, and I feel responsible for that."*

Similarly, Participant 8 elaborates on her frustration from not being able to advocate for her child:

> *"I feel so helpless when it comes to helping my son. He can't talk, and it's tough to know what's bothering him when he's upset on the school bus. He uses his iPad to show me a picture of a ball and shoes, but I don't know if he got hurt or just wants to play instead of going to school. It makes me sad and guilty that I can't understand him better. I wish he could tell me what's wrong, but I'll keep trying my best to help him as much as I can."*

Communication barriers presented significant challenges for parents of children with disabilities. These barriers strain parent-child relationships, take an emotional toll on parents, and hinder their ability to advocate for their child's needs. Furthermore, caring for a child with disabilities often entails a significant additional workload, which can contribute to physical and emotional depletion. This included managing daily routines, medical appointments, therapy sessions, and navigating educational systems. Parents reported feeling physically and emotionally depleted due to the extensive demands of caring for their children with disabilities.

For example, Participant 11 detailed her daily routine:

> *"I'm constantly on the go, from the moment I wake up until I go to bed. I don't even have set hours of sleep. Every day is a struggle. Therapy sessions, doctor's appointments, school meetings, afterschool care, housework, cooking, cleaning, it feels like there's never a moment to catch my breath. I'm always exhausted, mentally and physically."*

The additional workload associated with caring for a child with disabilities often left parents with little time for self-care or self-reflection, exacerbating feelings of stress and burnout. Participant 12 shared her thoughts on the lack of personal time:

> *"I used to enjoy meeting my friends, going out and going for a movie, but now I don't have any time to do any of that, it feels like I'm always too busy or too tired, but my son needs me all the time. I don't know how long I can do this for."*

Similarly, Participant 1 explained her experience of not being able to self-care:

> *"I barely have any time for myself anymore. I'm constantly worried that I'll get a call from my son's school, or my daughter will try to escape when I'm in the shower or taking a nap. Even using a hair dryer is a luxury because my daughter gets so upset by the noise. I haven't had a chance to do anything I enjoy in what feels like forever. It's a constant juggling act to take care of my family and make sure everyone's needs are met. I know it's important to take care of myself too, but it's hard to find the time."*

The additional workload also affects parents' relationships and social lives, as they struggle to maintain friendships or find time for their partners. For instance, Participant 13 described the impact on her relationship with her husband:

> *"My hubby and I used to have date nights and spend quality time together, but now it feels like our entire lives revolve around our son's needs. We're both so tired at the end of the day that we hardly ever do anything together or have any energy left for anything.*

> *Our relationship has definitely suffered. We are more like workmates who share 24/7 roster between two of us, not a couple."*

Participant 5 also shared her experience:

> *"Our relationship just fell apart because of the constant demands of taking care of our child with a disability. We never had time for each other, and it took a toll on us. The stress just became too much, and we couldn't make it work. Sometimes I wonder if things would have been different if our child didn't have a disability. Maybe we could have had a more normal family life.*

Furthermore, parents of children with disabilities also often struggled to balance multiple roles, such as caregiver, advocate, and provider, further compounding the pressures they face. Participant 14 explained her difficulties in juggling her various roles:

> *"I feel like a mom, a nurse, a doctor, a therapist and a teacher. I can't be all, but I need to be them all, and they need me to be, but they deserve someone better than me as a nurse or teacher I worry that I'm not doing any of them well enough."*

The impact of the discussed challenges faced by parents of children with disabilities was further exacerbated by societal expectations and a lack of empathy. Many parents felt judged or misunderstood by their community, leading to feelings of isolation and despair. The interviews highlighted the experiences of participants who encountered societal insensitivity and the consequences that followed. Parents often felt judged or misunderstood by others in their community, who had little to no experience with disabilities. This lack of understanding resulted in feelings of isolation and frustration. For example, Participant 9 expressed her exasperation:

> *"People often make assumptions about my parenting skills when they see my son acting out in public. They don't realise what I have to do and how hard it is for me to even take him out. I feel scrutinized and judged, it just adds unnecessary stress that I do not need."*

Similarly, Participant 6 added that:

> *"People just don't get it. My son has a disability, and he likes to run around and scream. But people judge me and think I'm a bad mother for letting him do it. They act like they don't know about his disability, and it's frustrating. I wish they could see that he's just being himself, and I'm doing my best to support him."*

The parents interviewed frequently faced challenges in finding suitable support systems, both formal and informal, to assist them with their difficulties. They reported struggling to locate appropriate resources, services, and social networks to help manage their daily challenges and emotions. Participant 1 shared her experience:

> *"I've tried to find support groups or programmes for parents like me, but they're few and far between. I had to move to Auckland for better services and support, so I lost contact with people from my hometown. I thought I was going to find more people in Auckland but again, disability is such an isolated area, a sector and other mothers with children like mine are all busy I know this because I am busy and it's just so frustrating to feel like I'm navigating this journey alone, without guidance or understanding from others who've walked the same path."*

Parents also reported encountering a lack of empathy from healthcare and education professionals, leading to further feelings of isolation and frustration. Participate 6 recounted her experience with her child's school:

> *"I had to fight and fight to get the right support for my son at school. It is still not good enough but a little bit better than before. I feel so angry at the school and the teachers because they should be advocating for him, not ignoring him."*

Similarly, Participant 8 shared her experience:

> *"You'd think that people would help you more when you're struggling, but it seems like they see you as an easy target and don't bother to assist you. They assume you won't do anything about it because you're already struggling, and it's like bullying."*

Participants also reported dealing with misconceptions about disability and parenting, which led to feelings of isolation and frustration. Participant 3 shared her experience:

> *"Sometimes, people think that my daughter's disability is my fault or the result of my parenting choices or it is because I didn’t spend enough time with her. These misconceptions do not solve any of the problems I have, it just makes my emotional burden worse that I will carry for the rest of my life."*

Societal expectations and lack of empathy had a profound impact on the experiences of parents caring for children with disabilities. Misunderstandings, judgement, and inadequate support systems can intensify feelings of isolation, despair, and frustration. Yet, instead of acknowledging the complexities of the challenges faced by parents of children with disabilities, society and health professionals often pathologised their difficulties as symptoms of clinical anxiety or depression. This oversimplification resulted in misdiagnosis and inadequate support. Parents in the study reported instances where healthcare providers failed to consider the context of their struggles, leading to misdiagnosis and a lack of appropriate support. Participant 11 recounted her encounter with a healthcare provider:

> *"I needed help from my GP, but only came back with a prescription for antidepressants. He made no effort to understand my difficulties. I went there to get some advice or some support or some sort of letters to advocate for me and my son. But maybe my GP thought telling me that I had depression was enough for us. Maybe he thought calling me depression was going to solve all my problems.”*

The pathologisation of parents' difficulties further contributes to the stigma surrounding their experiences. These parents may feel invalidated or dismissed, compounding their feelings of isolation and despair. Participant 9 shared her perspective:

> *"I don't think people realise the weight we carry as parents of children with disabilities. When my struggles are dismissed and framed as mental health issues, it feels like my experiences are being ignored. We need empathy, understanding, and practical support, not just a label or diagnosis."*

Pathologising parents' experienced neglect the importance of understanding their everyday context, which is crucial for providing appropriate support and resources. Participant 5 expressed her frustration:

> *"Doctors seem so focused on telling me what is wrong with me and trying to tell me that I have mental health issues and I am the one with the problem, but they don't see the bigger picture. It feels like they don't even want to see it. It's the situation that I find myself in with my disabled child and the lack of support that is causing my distress, not because I am mentally unwell or ill."*

Participants highlighted the need for a more holistic approach to care, one that acknowledges and addresses the unique challenges faced by parents of children with disabilities. Participant 3 emphasised this need:

> *"I wish healthcare professionals would take the time to truly understand my experiences and understand that my struggles go beyond anxiety or depression. I need support for us, practical support, I need my children to go to school, I need someone to help me with some housework or keep my eyes on them so they don't run off so that I can get some sleep. My boys need speech therapy, they need some sort of activity classes so they don't sit around at home all day. I need some cooked meals because I can't be just cooking all day because I have to watch them all day. I need professionals to address the causes of our difficulties, not just medication to make me not depressed or anxious. And they never worked anyways."*

Participants reported that the pathologisation of parental difficulties was a fundamentally flawed approach that failed to address the challenges faced by parents of children with disabilities. They expressed that this approach only framed their experiences as a mental illness or disorder, disregarding the unique context and challenges of their lives. This narrow perspective solely focused on the parents' reactions to their challenges without acknowledging the multifaceted underlying issues that contributed to their psychological distress. This approach not only misrepresented the reality they faced but also added more distress to the parents who were already dealing with significant challenges.

The participants highlighted the urgent need to recognise and acknowledge the complex nature of underlying issues that contributed to parental psychological difficulties. Adopting a more supportive and holistic approach would provide a framework to examine their experiences and psychological difficulties to support these parents and enable identification of the challenges contributing to their psychological distress.

The pathologisation of parental difficulties was an inadequate approach that perpetuated the stigma associated with mental illness and failed to address the unique challenges faced by parents of children with disabilities and communication difficulties. Given the distressing nature of the pathologisation of parental difficulties, its adverse consequences on the well-being of parents of children with disabilities, and the high level of distress that these parents had already experienced, urgent attention was required to address this issue effectively.

Poverty trap

The findings of this research revealed six interconnected factors that contribute to the emergence of a poverty trap among these families due to ceasing employment to provide full-time care: liquidating assets to finance health care and interventions, encountering obstacles in securing appropriate education, experiencing relationship dissolution and transitioning to single parenthood, enduring persistent financial burdens, and grappling with insufficient governmental support.

A recurrent theme in the interviews was parents deciding to leave their jobs to become full-time caregivers for their children. This decision emerged as a response to the unique and extensive care requirements of their children with disabilities and communication difficulties. Participant 2 stated:

> *"I had to leave my job because the care my daughter needed was too much. No way I could work and look after them."*

Similarly, participant 7 added:

> *"I had to quit my job, my boys couldn't go to kindy, couldn't go to school, so I had to look after them."*

The loss of income resulting from leaving employment significantly impacted the families' financial stability. Some participants described the need to sell personal properties and businesses to generate funds for essential healthcare services and interventions for their children. The financial strain of affording these services led to a depletion of their assets, as explained by participant 1:

> *"We owned houses and a small business, but the costs of my daughter's appointments and therapy forced us to sell both. We thought we would be able to get a cheaper house, but what I didn't release was that we weren't going to be able to get a mortgage because we didn't work as much, but we couldn't work because we had to take care of our daughter. We now live in a rented apartment and spent all our money on our daughter and rent now. I don't think we would ever get a house."*

Participant 6 also shared her experience:

> *"I had to quit my job because he couldn't go to school and I had to look after him. I always thought he was going to a school for special needs kids. I never thought that he was just not going to be accepted by mainstream or special school."*

Similarly, participant 4 expressed her frustration:

> *"My husband works full time, but it barely covers our bills, and I can't work. Our son is still waiting to be enrolled in school, but the Ministry of Education says he's not severe enough for a special school, and the regular school says they can't support him. My work didn't let me stay home or take time off, and even though I'm looking for another job, I'm not sure I can make it work. We've cut down on everything we can, but one income just isn't enough. I don't know what to do."*

The interviews revealed that parents faced significant challenges in finding suitable educational placements for their children with disabilities and communication difficulties. Mainstream schools were often unable or unwilling to accommodate their children's needs, while special schools had limited capacity or accessibility. Participant 4 further elaborate on her experience:

> *"Mainstream schools were not equipped to support him, and he didn't get funding to go to a special school. He can't talk, is not toilet trained, put shit all over the place, and can't*

> *do anything by himself. So we had to homeschool him, and I had to leave my career for good."*

Several participants reported that the demands and stressors associated with caring for a child with a disability had resulted in the breakdown of their relationships, leaving them as single parents. This change further restricted their employment opportunities and financial resources. Participant 5 recounted her experience:

> *"Raising a kid with lots of needs led to the end of my marriage. He just f***ed off and is not even in the country. I am now a solo mum, I find it very challenging to do this all on my own emotionally, physically, and financially."*

Similarly, participant 8 shared her experience:

> *"I guess it was too much for him. I wanted to leave too, but I just couldn't, and yea, he left us and all of a sudden, I had no income, and the little bit of benefit money and child support just wasn't enough. We managed to survive, but I don't know what's going to happen. I know we'll struggle, but I'm not sure how we'll manage."*

The financial burdens of raising a child with a disability and communication difficulties persisted, even after parents had made significant sacrifices and liquidated their assets. Participant 7 lamented:

> *"Despite selling everything I owned, the financial strain continues. The costs associated with my son's care are for real relentless, and I constantly worry about our ability to make ends meet."*

Similarly, participant 6 shared her experience:

> *"At first, I sold my car, which gave us some relief, but the money didn't last long. We had so many important appointments for him to get into a special school, but the public line couldn't even give me a timeframe for the assessment. So, I had to sell my car, and then we sold my mom's car. We thought things would get better, and maybe I could work once he goes to a special school, but that was the case. There is no after-school or holiday program for special schools. So I just can't work, but the government won't say it. They*

> *talk about being inclusive, but the reality is that if you have a child with a disability, you just can't work, and they won't pay you or give you money to survive. So, how are we supposed to survive."*

The interviews revealed a pervasive sense of dissatisfaction with the governmental support available to families in their situation. Participants described the support they received as inadequate and unable to alleviate their financial struggles. Participant 9 voiced their frustration, stating:

> *"The level of government assistance we receive is just wrong. It barely covers anything, and it feels as if the system is designed to keep us trapped in poverty. Our family, and others like ours, urgently need more effective and comprehensive support structures."*

Similarly, participant 1 questioned the current practice and its appropriateness:

> *"So, let me get this straight - if I'm unwell and go to the hospital, the doctors and nurses take care of me and get paid for it. But if my child has a disability and needs support 24/7, and I'm the one doing it, I won't get paid? That doesn't make any sense. how am I supposed to survive? who will get the grocery? how will we pay for the power? "*

Participant 7 also added her frustration:

> *"I went to WINZ, I asked Taikura, I asked the school, I asked the Ministry of Education, I asked the Salvation Army, I asked the DHB. I even called the crisis team and helpline, but nothing worked. I needed to pay my rent, but I couldn't. Then I needed a place to stay, but there was nothing for us. They act like they care, but they say they can't help or there's nothing they can do. They tell me to call other agencies, but who can really help? It's a joke. They just want us to stay dirt poor and silenced."*

In addition, some participants provided their views of the current eligibility criteria for governmental support, as participant 5 reported:

> *"It's f***** up. You can't own anything to be qualified for support like accommodation and solo parent benefits. But I needed the help because I couldn't work because of my child and I was a solo parent, it is probably because of my child too. So I was spending the*

> *little bit of money I had. I could have used it for a down payment on a house, who knows? But no, I had to spend every single dollar, and then WINZ support finally came in. You have to wait until you're really poor to get a little bit of money. But they don't want to support you so that you can live your life. It's all f**** up. The system is f***** up. The system wants you to fail."*

Through the narratives of participants, the findings highlighted how a combination of factors perpetuates a vicious cycle of poverty for families caring for children with disabilities. The factors include the cessation of employment to provide full-time care, liquidating assets to finance health care and interventions, encountering obstacles in securing appropriate education, experiencing relationship dissolution and transitioning to single parenthood, enduring persistent financial burdens, and grappling with insufficient governmental support. These factors work together to create a safety net that entraps families in poverty. Participants expressed how parents were forced to spend everything until they had nothing left, only to become eligible for barely minimal governmental financial support.

The interplay of these factors exacerbates the financial struggles faced by families caring for children with disabilities, highlighting the urgent need for a multi-faceted approach to address the poverty trap. Policymakers, the health, education, and welfare sectors, and other relevant stakeholders develop and implement policies and programmes that provide adequate support for these families. The significant level of distress and consequences of families being trapped in poverty indicated that it would be urgently addressed, not only to alleviate their immediate financial burdens but also to break the cycle of poverty and enable them and their children to lead fulfilling and dignified lives, and that urgent action would be necessary to address this pervasive problem.

Can’t understand, can’t express

The chapter unveils three salient themes that emerged from the interviews of those with limited English proficiency. Three prominent themes emerged from the interviews: parents' struggles to comprehend their children due to restricted communication abilities, the difficulties encountered by parents in deciphering complex explanations and advice from healthcare and educational professionals, and the challenges faced by parents in articulating their concerns and advocating for their children's needs effectively.

The analysis revealed that parents with limited English proficiency encounter considerable challenges when trying to comprehend their children's communication attempts, given that these children often have limited communication skills themselves. Participant 10 poignantly articulated:

> *"It's already difficult for me to understand English, but it becomes even harder when my child tries to talk to me. I often don't know if I'm understanding what he wants or not."*

The parents reported the implications of parental limited English proficiency, as the children's restricted communication skills pose multifaceted challenges that extend beyond the immediate parent-child relationship. They reported that these challenges had significant ramifications for the quality of care, support, and educational opportunities provided to children with disabilities, as well as the overall well-being and integration of the families into the wider community. Participant 10 explained her struggle to accurately interpret her child's needs as well as to communicate the needs to others for the child:

> *"It's already hard enough to understand my child, but even then, I don't even know how to say that I struggle to understand his needs in English to his doctor or teachers. I feel completely helpless and ignored. I don't think anyone is concerned that I may not be able to understand his needs, and that I can't explain these in English. I feel like they just expect us to stay quiet."*

Participant 11 further questions the health and education professionals' practices:

> *"They can at least translate with google app, or using some sorts of apps, or dictionaries. It feels like they just don't care. They could at least send me the information in an e-mail, so I can translate them online. But they just call for a meeting, and I am just sitting there while they are talking and taking notes. I find this very unethical. It is rude. You would not invite someone who doesn't speak your language to your dinner and speak in your language to the person."*

Furthermore, the interviews disclosed that parents often grapple with understanding healthcare and educational professionals involved in their child's care due to language barriers. They also described the professionals' efforts to facilitate better communication as minimal, characterised by insufficient translator support or substandard translation services. This was significant, as the limited English proficiency may impede parents' ability to access and understand important information about their children's disabilities, available support services, and appropriate intervention strategies. Participant 12 shared their exasperation:

> *"I feel confused and lost when I go to the appointments with doctors and therapists. They use difficult words that I don't understand, and the explanations they give are not clear enough. It seems like they don't try hard enough to make things easier for us to understand."*

Similarly, Participant 11 also highlighted her perspective:

> *"no one offered any translation support or services. I didn't know what was available, and what I was supposed to do. I am sure people could easily tell when someone doesn't understand English. I mean I can't speak or write in English but sitting in an appointment or a meeting with people who only speak English. What do they expect from me? How am I supposed to even engage with them?"*

Moreover, the parents reported difficulties in expressing their concerns, opinions, and needs due to their limited English proficiency. This struggle exacerbates the challenges and stressors they already had and left them feeling invisible, helpless, and unable to advocate effectively for their children. Participant 10 lamented:

> *"I feel like I can't speak up for myself and my child. I'm not very good at speaking or writing English, so I can't explain what my child needs or tell people what I'm worried about. It's like we're invisible and powerless in the system. I feel so alone, it is hard to find meet people who are on the same journey, but when I met some parents who also had children with disabilities I couldn't even make any conversations and I felt like I don't even speak the language to connect with anyone."*

The cumulative impact of these communication challenges not only impedes parents' understanding of their children's needs but also hinders their ability to navigate complex interactions with healthcare and educational professionals. The emergent themes from the interviews highlighted the urgent necessity for more comprehensive support and resources tailored to these families, which address both linguistic and cultural barriers that hamper effective communication and collaboration between parents and professionals. This study thus underscores the need for systemic changes to ensure the inclusion and empowerment of these families in decision-making processes related to their children's care.

The study revealed the cumulative impact of communication challenges faced by parents of children with communication difficulties. These challenges not only impeded parents' understanding of their children's needs but also hindered their ability to navigate complex interactions with healthcare and educational professionals. The emergent themes from the interviews highlighted the urgent necessity for more support and resources tailored to these families to address both linguistic and cultural barriers that hampered effective communication and collaboration between parents and professionals.

The study's findings emphasised the need for systemic changes to ensure the inclusion and empowerment of these families in decision-making processes related to their children's care to address the systemic barriers faced by these families. The findings suggested that there was a lack of support services prioritising cultural sensitivity and inclusion, which was designed in partnership with diverse communities and effective communication skills from health and education professionals to ensure that these parents and their children meet their unique needs. The severity of distress and the consequential impact of these issues suggest an urgent need for them to be addressed promptly.

Solo mothers feeling incarcerated and confined

There were four salient themes of incarcerated solo mothers that emerged from the interviews. First, it was imperative for mothers to remain at home due to the dearth of suitable educational placements for their children. Second, there were financial repercussions of staying home. Third, there was prevailing uncertainty regarding their future prospects. Fourth, there was a sense of confinement within a metaphorical penitentiary.

The interviews revealed that many solo mothers felt compelled and obligated to stay at home as their children were unable to attend school and there were no suitable alternatives available. For example, Participant 3 said:

> *"I have no choice but to stay home with my children because there's nowhere else for them to go. The schools won't accept them, and I can't find anywhere anyone that will cater to their needs."*

As a result of staying home to care for their children, these solo mothers had to relinquish their jobs, careers, and educational pursuits. Consequently, they found themselves reliant on scant government benefits, such as the solo parent or supported living payments. Participant 5 elaborated on her financial struggles:

> *"I had to give up my job to care for my child, and now I'm living on a benefit that barely covers our basic needs. I rely on food parcels and community grants just to survive. I have no money, I never have any money to do anything. I can't even go get a coffee with friends. I can't even go for a walk because I have no one to help me with my kid."*

The solo mothers also expressed concerns about their future, as they were unsure when they might be able to re-enter the workforce or pursue further education. Participant 14 poignantly articulated her worries:

> *"I don't know when or if I'll ever be able to get a job, study, or get off benefits. I feel like I'm stuck in limbo, I don't see myself doing anything anytime soon at all. I know other solo mums. They go to uni, they go take their courses or work. They do well, but me, I feel so trapped."*

The solo mothers reported feeling confined in their circumstances, as if they were imprisoned by their responsibilities and the limitations imposed on them by their children's disabilities and communication difficulties. Participant 8 expressed her sense of entrapment:

> *"It feels like I'm living in a prison. I'm stuck at home, I'm not doing anything, I'm not out with my friends, I don't have any friends, I don't have any free time, and I'm barely paying my bills and WINZ treat me like I'm a criminal like I have done something wrong. They asked me to take budgeting classes, I don't even have a car to travel or time to go. Who's going to look after my kids? I just can't see a way out of this."*

Similarly, participant 13 expressed her frustration:

> *"Living like this is like a life sentence, except you actually did something wrong and will probably get paroled if you got a life sentence, but I didn't do anything wrong, and I won't get paroled."*

Although the theme of feeling "imprisoned" mostly emerged from solo parents, one married participant added a similar analogy to her experiences. This further highlights the difficulties of caring for children with disabilities and communication difficulties, which take the freedom away from the parents and make them feel like they are imprisoned. Participant 9 elaborated on her experiences:

> *"It is like if I'm wearing invisible chains, bound by my child's disabilities and the weight of my obligations, sense of guilt, with no hope for a reprieve."*

The findings highlighted the compounding challenges faced by solo mothers caring for children with disabilities with communication difficulties, including limited educational placement options for their children, financial constraints, and a lack of social support. These challenges work together, leading to feelings of entrapment and a sense of being "imprisoned".

The limited educational placement options for their children, combined with financial constraints, result in mothers being forced to balance the expenses related to their children's care and support. This forces mothers to prioritise expenses related to their children's care and support, leading to sacrifices in other aspects of their lives. Additionally, navigating complex healthcare and educational systems alone, without sufficient resources or support, exacerbates their sense of confinement. Furthermore, the lack of social support exacerbates the sense of being "imprisoned" experienced by solo mothers. The isolation and entrapment experienced by these parents lead to emotional difficulties, further exacerbating their sense of confinement. The absence of support services designed to address the unique needs of these families perpetuates the feeling of being "imprisoned" experienced by solo mothers.

The emergent themes from the interviews underscored the urgent need for targeted support and resources to address the systemic barriers faced by solo mothers caring for children with disabilities with communication difficulties. The study found that there was an absence of comprehensive programmes and resources to address the limited educational placement options for their children and the financial constraints that restrict their ability to provide adequate care. Additionally, there were no social support services to address the isolation and entrapment experienced by many solo parents, or reduce their sense of confinement and promote overall well-being.

The findings highlighted the systemic barriers that perpetuate the feelings of entrapment and the sense of being "imprisoned" experienced by solo mothers caring for children with disabilities with communication difficulties. These findings underscored the urgent need to remove systemic barriers that they face and to prioritise their unique needs.

Racism

There were three themes that constitute the topic of racism emerged from the interviews. They were the condescending communication style adopted by medical and health professionals, the dismissive treatment of parents based on their educational background, and the unjust assumptions and judgements made about the parents.

The interviews revealed that educated Māori and Pasifika parents, including those with bachelor's degrees or post-graduate qualifications and specialised professional jobs, often encountered condescending communication from medical and health professionals. Participant 4 shared her experience:

> *"They talked to me like I was a baby. But when I told them what I do for a living, they were surprised. Then they started speaking to my partner in a very slow and simple way.*

> *They assumed that my partner, because he is brown, yes he is Māori, thought that he doesn't understand English well and doesn't know much about medical terms. For God's sake, English is his first language and he is well educated."*

Parents without a specific educational background reported being treated dismissively by medical and health professionals. These parents felt that their opinions were disregarded, and they were urged to be appreciative of the services provided, as they would not be accessible in their "islands". Participant 8 elaborated on this experience:

> *"Doctors and nurses sometimes talk to me like I don't know anything, and they don't listen to my ideas. They said I should be happy with what I get here and joked about how things are a lot better in Samoa. I felt so angry."*

Māori and Pasifika parents in the study reported feeling judged by medical and health professionals, who made unjust assumptions about their lifestyle and parenting abilities. Participant 3 recounted her experience:

> *"The doctors and nurses asked me if I was drunk, using drugs, or hurting my child. But when I talked to parents who weren't brown, they didn't mention anything like being asked those kinds of questions."*

Participant 7 further expressed her frustration with racial discrimination she experienced from professionals, stating:

> *"They think I'm dumb. I'm not dumb. I know what I am talking about. They think they can make a better decision. Like I know what my kids need, and I ask for it, and then they will say oh we will look into it, but it never happens. But when I see other white mums, these people are all friendly and nice, and they get it without even asking for it. How is this possible? It doesn't make any sense, but it is the reality."*

The participants also identified inappropriate cultural practices during their engagement with healthcare services. They reported that certain cultural processes, such as starting with Karakia without any other considerations for their culture, held no significance for them and were perceived as a mere box-ticking exercise. The participants emphasised their desire for culturally inclusive and sensitive support. Participant 4 explained her experiences:

> *"If they wanted to be so worried about my culture, they should stop being so racist and should support me with my needs. They can't even pronounce it right but want to open up with white-washed Karakia. For whom? For what? No one is Māori in the room. My husband is Māori. I'm not even Māori. They probably think I am Māori and forgot what I was. How about making sure my kids get what they need? Basic needs. Clothes, food, schools, activities, education, therapies, income support, and housing support. They don't want to do anything to support us but just want to do a little prayer. I bet they don't even know what it means but they just say it."*

The emergent themes from the interviews highlight a pervasive issue for parents of children with disabilities from ethnic minority groups. These parents frequently report being subject to dismissive attitudes, undervalued input, and intrusive questioning. The lack of cultural sensitivity in healthcare and educational practices led to parents feeling isolated and neglected by a system that fails to appreciate their unique needs and experiences.

The absence of anti-discrimination policies and action plans that protect the rights of parents of children with disabilities who were from ethnic minority groups was evident from the parental experiences, which highlighted the lack of cultural sensitivity among healthcare, educational and disability-related services providers. Moreover, there were no specialised support services available to parents who had suffered from racial maltreatment, such as counselling or other resources to help them cope with the trauma of discrimination.

These findings indicated an urgent need for an appropriate framework that recognises and respects the diversity of cultural backgrounds and needs to provide effective support for parents of children with disabilities. Such a framework should prioritise cultural sensitivity and inclusion and be designed in partnership with diverse communities to ensure that it meets their unique needs.

Housing insecurity

The discussion of housing insecurity was broken down into five distinct thematic categories. These categories consisted of financial constraints and affordability issues, discrimination faced during the housing search, obstacles encountered while seeking appropriate and accessible housing, difficulties experienced in accessing housing modification services, and a shortage of available social housing options that are accessible to those with disabilities.

One of the main concerns raised by the participants was the financial constraints associated with raising a child with a disability and communication difficulties. Many parents mentioned struggling to afford appropriate housing due to high costs, limited income, and the additional expenses related to their child's specific needs. Participant 2 said about their struggle:

> *"It's just so hard to make ends meet. Between appointment bills, therapy, and special equipment, there's not much left for housing. We've had to cut corners and make sacrifices just to keep a roof over our heads."*

In addition to financial constraints, parents also reported encountering discriminatory attitudes from rental agencies and homeowners, who often refused them housing due to their child's additional needs. Parents expressed feeling unwelcome, with concerns that their family would not be seen as an ideal tenant. Participant 11 shared her experience:

> *"I'm very lucky to live where we live now. But it was a real struggle. No one wanted us. When they found out that my child has a disability, they asked many questions, like, would he ruin the walls, make noises, set a house on fire. After all the questions, they would always say no. I tried so many houses, but no one would accept us."*

Participants expressed frustration in finding suitable and accessible housing that could accommodate their child's specific needs. Many reported that the available housing options were not designed to support individuals with disabilities, which presented challenges related to accessibility and safety. Participant 4 described their experience:

> *"We've looked at so many houses, but none of them seems to have what we need. Wide doorways, ramps, a safe bathroom. It's like trying to find a needle in a haystack. And*

> *when we do find something, it's always way out of our price range. Where are we supposed to live?"*

Another theme that emerged from the data was the difficulties parents faced in accessing housing modification services. These services, which provide support for adapting existing homes to better suit the needs of people with disabilities, were described by participants as having long waiting lists, inadequately trained professionals, and inconsistent regulations. Participant 7 expressed their frustration:

> *"We've been waiting for more than two years to get our home modified, and it's very frustrating. When the hospital people came to assess our situation, they didn't seem to understand our child's needs very well. They said they could only fence off the area I can see from my window, not the whole area. They asked if I still wanted it, but what's the point? My child could still run off if the other areas are not fenced. I didn't know what to do and still haven't made any decisions but of course, they did not follow up."*

The final theme identified was the limited availability of accessible social housing for families with a child with a disability and communication difficulties. Parents described the social housing options as being inadequate in terms of accessibility features, with many units lacking essential adaptations to accommodate their child's needs. Participant 7 shared her experience:

> *"We've been waiting for years to get a house that's accessible for us, but it seems like we're not getting anywhere. We moved into this house temporarily while we wait, but now we have to move out next month because Housing New Zealand is changing the house into something else. They don't have any other houses that are safe for our children. It's really frustrating, because all we want is a place we can call home."*

The findings indicate that these parents faced substantial financial constraints, experienced difficulties in finding appropriate housing, encountered challenges in accessing housing modification services, and faced a scarcity of accessible social housing options. These issues were interrelated, contributing to a heightened sense of housing insecurity among parents, which negatively impacted their well-being and that of their children. Financial constraints were a significant barrier for parents, as they often had to balance the expenses related to their children's care and support against the cost of housing. Limited income and restricted access to financial resources made it challenging for many parents to secure suitable and accessible housing. Parents were often forced to prioritise expenses related to their children's care and support, leading to sacrifices in other areas, such as housing.

Finding appropriate housing was also a significant challenge for parents of children with disabilities. The physical layout of housing and the availability of accessible features were critical considerations for these families. Housing providers often lacked the knowledge and expertise to understand the unique needs of these families, resulting in a limited supply of suitable housing options. Accessing housing modification services was also challenging for parents. The process of obtaining modifications to existing housing could be lengthy and complicated, resulting in delays that exacerbated the housing insecurity of families.

The scarcity of accessible social housing options further exacerbated these challenges, particularly for families who needed social housing as their primary housing option. Ironically, social housing options were not designed to meet the needs of families with children with disabilities, leading to inadequate and unsuitable housing options. The lack of accessible social housing options meant that families were forced to either live in unsuitable housing or remain on waiting lists for extended periods, exacerbating their housing insecurity. The findings suggests that the interrelated challenges faced by parents of children with disabilities and communication difficulties in securing suitable and accessible housing were significant and urgently needed to be addressed.

Relinquishment

The notion of "relinquishment" emerged as a salient theme from the interviews, illustrating the various dimensions in which parents felt compelled to abandon their efforts in supporting their children with five predominant sub-themes, which have been discussed earlier, of stigmatisation as mentally unwell, financial constraints, domestic confinement, racial and ethnic discrimination, and housing predicaments.

As previously discussed, a recurrent issue encountered by participants was the stigmatisation and discrediting by others, who frequently attributed the parents' challenges to mental health issues rather than recognising the inherent complexities of caring for a child with a disability. Participant 6 expressed her vexation:

> *"Even though I try so hard to help my child, people think I'm crazy. It makes me feel really bad, and sometimes I feel like giving up trying."*

The financial ramifications of providing for a child with a disability and communication difficulties became apparent throughout the interviews. Parents delineated the exhaustion of their financial resources on therapies, equipment, and other essential provisions, resulting in a pervasive sense of helplessness and a lack of alternatives. Participant 1 articulated his despondency:

> *"We have used up all our money and can't afford to support our child's needs anymore."*

Numerous participants alluded to the fact that their endeavours to care for their children often culminated in a sense of entrapment within their homes. This seclusion generated a pervasive sentiment of despair that contributed to the inclination to relinquish their efforts. Participant 4 asserted:

> *"We've tried really hard to make our home work for our child, but now we feel like we can't leave the house. It makes us feel really sad and hopeless, and sometimes we want to give up trying."*

Some parents reported experiencing discrimination predicated on their racial or ethnic background, which further exacerbated their feelings of helplessness. They perceived differential treatment compared to European parents, who seemingly received more comprehensive support and resources. Participant 9 delineated her experience:

> *"I feel like I'm being treated unfairly because of my skin colour. White parents seem to get more help and resources for their children, even though my child's needs are more severe. It makes me feel really sad and sometimes I feel like giving up trying."*

Securing suitable housing that accommodated the specific requirements of their children emerged as another formidable challenge faced by the parents. This issue frequently compelled them to contemplate relinquishing their efforts to create a stable environment for their children. Participant 7 conveyed her desperation:

> *"We've tried really hard to find a good place to live, but we keep running into problems that we can't fix. It feels like we have no choices left, and we might have to give up trying."*

The concept of relinquishment played a significant role in the experiences of parents raising children with disabilities and communication difficulties. The various factors contributed to the decision-making process and emotional journey parents undergo as they grappled with the idea of relinquishing their efforts to provide the necessary care and support for their children.

Society's limited comprehension and misconceptions about the struggles faced by parents raising children with disabilities, coupled with the propensity to frame these challenges as mental health issues, left parents feeling overwhelmed and unsupported. The pressure to conform to societal norms and expectations further intensified their emotional distress. Parents also felt compelled to relinquish their responsibilities due to financial constraints, which limited their ability to provide adequate medical and educational support for their children. As parents adapted their lives and schedules to accommodate their children's needs, they often experienced social isolation and loss of personal freedom, resulting in emotional exhaustion and helplessness.

In addition, ethnic minority parents encountered additional obstacles in accessing resources and support, which were attributable to language barriers, cultural differences, and prejudices. This complexity exacerbated the already challenging task of navigating disability care. Additionally, securing suitable, accessible, and affordable housing for families with disabled children presented a daunting challenge. Unstable living situations heightened stress and strain on the family unit, in addition to the above-mentioned issues fostering feelings of hopelessness and prompting the consideration of relinquishment.

These findings highlighted the multifaceted and emotionally charged journey toward relinquishment for parents raising children with disabilities and communication difficulties, and the factors were significantly influenced by various environmental factors. This highlighted the urgency of addressing these issues, necessitating increased societal empathy, support, and resources to assist families in navigating the intricate obstacles associated with raising a child with disabilities and communication difficulties.

And repeat

In this final subchapter of the findings section, this subchapter examined the intricate cyclical process characterising the experiences faced by parents of children with disabilities and communication difficulties. The analysis builds on previously discussed findings to elucidate the "Repeat" cycle, a construct encompassing seven interconnected elements: pathologising difficulties, the poverty trap, loss and isolation, racial discrimination, housing insecurity, the inclination to capitulate, and the perpetuation of the cycle. By emphasising the interrelationships among these findings, the study demonstrates that these elements form a continuous, self-reinforcing process, thereby exacerbating the dehumanising and untenable circumstances confronting these parents and illuminating the complex dynamics underlying this cycle. The interconnectivity of the findings reveals that the parents' experiences embody a cyclical process. The "Repeat" cycle underscores the manner in which one aspect of their experience can give rise to another, culminating in a self-sustaining cycle that perpetuates and intensifies the challenges faced by these parents.

The pathologisation of parents' difficulties by society and mental health professionals serves as a catalyst that initiates a cascade of events contributing to the "Repeat" cycle, which masks the origins of the challenges. As parents grapple with the challenge of accessing essential support and resources due to their difficulties being erroneously reduced to mere symptoms, they become increasingly vulnerable to the poverty trap.

The poverty trap constitutes a critical nexus in the cycle and operates as a pivotal component in the cycle, which precipitates a series of interconnected adversities and ensnares parents in a web of interconnected adversities. Financial hardships are found to be associated with the loss of employment, housing, partners, friends, and financial resources, consequently amplifying feelings of isolation and despair, further fuelling the cycle. Moreover, the poverty trap exerts influence on other facets of the cycle, such as housing insecurity and the inclination to capitulate.

The psychological burden of adopting their lives to accommodate their children's needs engenders a profound sense of loss and isolation. This psychological burden had a multifaceted nature of this loss, highlighting the impacts on social connections, loss of personal freedom, and emotional exhaustion. Furthermore, the psychological burden of isolation reinforced the cycle, as parents become more susceptible to despair and the inclination to capitulate.

Racial discrimination serves as an exacerbating factor within the "Repeat" cycle. Discriminatory attitudes and practices heighten feelings of alienation and isolation, further impeding parents' efforts to extricate themselves from the cycle. Additionally, racial discrimination contributes to housing insecurity, thereby destabilising the living conditions of affected parents.

Housing insecurity, a critical aspect of the cycle, heightens feelings of despair, feeding into the inclination to capitulate. The arduous task of securing stable and suitable housing for their families, while concurrently managing a plethora of other challenges, frequently drives parents to the brink of hopelessness. This inclination to capitulate also reinforces the "Repeat" cycle, rendering parents progressively less capable of addressing and surmounting the obstacles they encounter.

The confluence of these factors impels parents to contemplate relinquishing their responsibilities, as the emotional and practical challenges become insurmountable. The factoring contributing to this inclination to capitulate and how this mindset can further perpetuate the “Repeat” cycle, entrenching parents in a continuous loop of adversities.

The interconnected nature of these elements perpetuates the cycle, engendering a self-reinforcing process that intensifies the dehumanising and untenable circumstances encountered by parents raising children with disabilities and communication difficulties.

Each factor reinforces and magnifies the others, creating an ongoing and seemingly insurmountable series of challenges for the parents.

In summary, the findings presented in this study shed light on the intricate dynamics of the "Repeat" cycle and the numerous interconnected factors that shape the experiences of parents raising children with disabilities and communication difficulties. The cyclical nature of the challenges faced by these families emphasises the crucial need for a comprehensive and multifaceted approach to support them and address the dehumanising and untenable circumstances they confront. These findings provide a valuable contribution to the field of disability studies and can inform the development of policies and programmes that better serve and support these families. Further research is necessary to deepen our understanding of these issues and to identify more effective ways to address the needs of parents and children in similar situations.

Love, joy, and hope

In order to provide a comprehensive understanding of the experiences of parents raising children with disabilities and communication difficulties, I have included an addition section in this chapter. This section is dedicated to showcasing the quotes of hope, love, and joy expressed by all the participants. The significance of this was rooted in the need to acknowledge the coexistence of both positive and negative emotions and experiences within the lives of these families. Given the significant levels of distress and consequences that arise from their situations, it was imperative to provide space for the participants to express their gratitude and positive emotions. The inclusion of this additional section enhances the readers' appreciation of the multifaceted experiences of these families and highlights the need to inform policies and practices that better support their well-being.

> "*The love and connection we share as a family are what keeps us going*." – Participant 1
>
> "*My child is a gift."* – Participant 2
>
> "*It's not always easy, but seeing my child himself in his own way brings me so much joy and pride."* – Participant 3

"*Life with a child with difficulties is not what I expected, but the love and laughter we share as a family are more than enough*." – Participant 4

"*Sometimes it feels like the world, everything is against us, but the love I have for my child is unbreakable. He's my reason for living."* – Participant 5

"*Raising a child with disabilities is a challenge, but the love and happiness my child brings to my life make it all worthwhile."* – Participant 6

"Communication difficulties can be frustrating, but seeing my child's progress and seeing him smile makes me think that he is saying 'I love you mummy' and makes it all worth it." – Participant 7

"*But my child has taught me so much about resilience and unconditional love. I am grateful for him every day."* – Participant 8

"*My life is full of ups and downs, but I am so grateful for the love and happiness he brings to my life."* – Participant 9

"Having a child with communication difficulties is a challenge, but watching her grow and overcome obstacles has brought an uncountable and unexplainable amount of joy and happiness in my life." – Participant 10

"It's definitely not easy, but I wouldn't trade my child for anything in the world. Seeing him smile and just being next to him makes me so happy, he is my happiness." – Participant 11

"*Life is tough, especially when you have kids with special needs. But my child has brought me more love and happiness than I ever thought possible."* – Participant 12

"Raising a child with disabilities can be exhausting, but seeing my child thrive and being able to support him makes me really happy and proud." – Participant 13

"The love and laughter he brings to our family are worth every challenge." – Participant 14

Chapter 4 Discussion

In this study, I explored the misconceptions about mental health and the oversimplification of parental experiences with children with disabilities in the New Zealand context. By utlising CRT the findings were explored within the context of the participants. The findings clearly highlight the intersectional nature of challenge and highlighted an intricate cyclical process reflecting the experiences faced by parents of children with disabilities and communication difficulties. This was captured in the ‘Repeat’ cycle, a construct encompassing seven interconnected elements: pathologising difficulties, the poverty trap, loss and isolation, racial discrimination, housing insecurity, the inclination to capitulate, and the perpetuation of the cycle. The interconnectivity of the parents' experiences embody a cyclical process and the ‘repeat’ cycle underscores the manner in which one aspect of their experience can give rise to another, culminating in a self-sustaining cycle that perpetuates and intensifies the challenges faced by these parents.

Depathologising experienced difficulties

The findings revealed that pathologising parents’ difficulties as mental health issues such as depression and anxiety may lead to a narrow understanding of the parents' experiences while overlooking the broader context of the parents’ lives (Frunel & Lorr, 2022; Hansen et al., 2014). This approach oversimplifies the parental experiences by overlooking the broader context of these psychological experiences, failing to consider the unique social, economic, and cultural challenges faced by the parents, which may result in inadequate support. Furthermore, it stigmatises the parental experiences as individual mental health, potentially causing parents to hesitate in sharing their difficulties or seeking support due to fear of judgment or discrimination (Ntinda & Hianze, 2015; Saunders et al., 2015). Pathologising also further marginalises parents from diverse backgrounds, as framing the difficulties that are associated with systemic barriers and discrimination may be overlooked through the lens of individualised and Eurocentric mental health aspects that scale the difficulties of individuals to meet the criteria of diagnostic criteria of a disorder (Adjei, 2018; Hansen et al., 2014).

The findings of this research underscore the necessity for a comprehensive and multi-faceted understanding of the challenges encountered by parents of children with disabilities, as well as the importance of de-pathologising the difficulties associated with raising children with disabilities and communication issues as mental health concerns (Taylor et al., 2021). A starting point for fostering this understanding can be derived from a thorough examination of their experiences and struggles through their narratives, which are often misconstrued as mental illnesses (Carel, 2023; Kidd et al., 2022). Acknowledging the distinct and specific challenges faced by these parents as highlighted by CRT, identifying appropriate support and resources, and promoting collaborative approaches among parents, healthcare professionals, academia, and the healthcare system can provide valuable insights into the process of de-pathologizing their difficulties. This process necessitates a consideration of the intricate interplay between social, economic, and cultural factors that contribute to these challenges, as well as an acknowledgment of the systemic barriers and inequalities faced by these families (Hirano et al., 2018; Skaar et al., 2021).

By de-pathologising parental difficulties, healthcare and mental health systems and settings in Aotearoa can facilitate pragmatic and meaningful changes that respect individuals' lived experiences, amplify their voices, and embrace their diverse cultural perspectives. This approach also serves to challenge colonial frameworks and foster a more inclusive and supportive environment for families with children with disabilities and communication difficulties (Dei & Asgharzadeh, 2001; Joseph, 2019). The implications of de-pathologizing parental difficulties are significant for fostering a more inclusive and culturally sensitive approach to mental health care in (Aotearoa). In addressing these concerns, this process may also contribute to decolonising mental health practices (Lewis et al., 2018; Linklater, 2020).

These changes and strategies for de-pathologizing parental difficulties potentially contribute to the decolonisation of mental health practices by incorporating parents' experiences from various backgrounds, including Māori, Pasifika, and other minority communities (Clarke, 2022; Cullen et al., 2022). The approach ensures cultural inclusivity and relevance. This acknowledgment of diverse perspectives challenges the traditionally Eurocentric models of mental health care, allowing for a more nuanced understanding of the unique challenges faced by families from different cultural backgrounds (Horton, 2022; Shepherd & Phillips, 2016). Integrating culturally therapeutic approaches also involves considering collective worldviews and cultural aspects of disability and mental health (Meekosha, 2011; Puszka, 2022). This shift from an individualistic to a more collectivist approach can help address the historical marginalisation of indigenous and minority cultures in mental health care by acknowledging and valuing their beliefs, customs, and worldviews and incorporating them into practice (Bramesfeld et al., 2019; Kiyimba & Anderson, 2022). In addition, encouraging collaboration among pertinent sectors, such as mental health, social work, and education, can guarantee a comprehensive comprehension of the challenges identified from parental experiences and the provision of culturally suitable support through appropriate service delivery. This interdisciplinary approach recognises the significance of a holistic understanding that encompasses various factors and dimensions in facilitating support for individuals confronting challenges, thereby deviating from the exclusivity of a medical model (Hogan, 2019; Thompson, 2018).

Furthermore, Governmental input can facilitate the creation of more community spaces for parents of children with disabilities and communication difficulties, as well as culturally appropriate spaces that support the development and delivery of culturally relevant mental health services, policies, and programs (Berman-Bieler et al., 2023; Cullen et al., 2023). By emphasising culturally sensitive practices, the mental health care system can address the unique needs of diverse communities, ensuring more equitable and effective support for all families facing the challenges associated with raising children with disabilities and communication difficulties (Handtke et al., 2019; Shepherd, 2019).

As discussed above, the practical changes stemming from de-pathologising, such as incorporating parents' experiences, developing assessment tools tailored to their needs, implementing culturally responsive support models, creating community spaces and networks, addressing systemic barriers, and ensuring the adoption and evaluation of these changes, further encourage health professionals to integrate culturally therapeutic approaches (Cohen et al., 2014; Shepherd, 2019). The process of depathologising the difficulties faced by parents who have a child with a disability requires implementation of policy aimed at alleviating obstacles to accessing supportive services for parents, emphasise the responsibility of the state and society to ensure equal opportunities, access to resources, and social inclusion for families with children with disabilities rather than empathising the perceived difficulties as parental mental health issues (Sung & Dries, 2023; World Health Organization, 2021). The implementation of policy revisions, as informed by the principles of CRT, must also encompass a multifaceted approach, as ascertained by this study, which includes improving the accessibility of interpreter services, providing educational opportunities that are attuned to the needs of families, and augmenting financial support for disability-related expenses (Goodley et al., 2017). As outlined, it is vital to extend aid in addressing the challenges faced by individuals in accessing existing services, such as childcare, financial aid, and transportation, which have been identified as critical areas requiring attention in this study (WHO, 2022). Additionally, an increase in funding for disability support programs targeted at underprivileged groups, including individuals with communication impairments, ethnic minority communities, and single parents of children with disabilities, is a necessary step toward promoting more equitable access to support and services (Williams et al., 2023).

The findings from this study, as elucidated by the parental narratives regarding the insufficiency of accessibilities and resources within the current support system, underscore the criticality of ensuring that any changes implemented to support parents of children with disabilities are effectively adopted, evaluated, and refined. This process may involve various methods, such as soliciting feedback through surveys, conducting focus groups to assess the efficacy of services, and implementing ongoing evaluations for continuous improvement (Lopez-Gavira et al., 2021). The overarching objective is to optimise service delivery in a manner that better serves marginalised populations. Moreover, fostering collaboration between government agencies, non-government organisations, community groups, and academic institutions is imperative for developing evidence-based strategies and programs tailored to the diverse needs of parents with children with disabilities. Such collaborative efforts can facilitate the successful implementation, adoption, and evaluation of these strategies and programs, thereby promoting more comprehensive and equitable support for these families (Kaehne, 2015; Wee et al., 2021).

However, notwithstanding the potential challenges and resource requirements, the benefits of de-pathologizing parental difficulties related to raising children with disabilities and communication difficulties and promoting culturally sensitive practices in Aotearoa far outweigh the drawbacks. This approach can lead to better mental health outcomes, empower parents, and promote social justice, resulting in a more equitable society for all. The long-term positive impact on parents and their children, as well as on marginalised communities, justifies the investment of resources and the effort required to implement these changes. Aotearoa can play a significant role in the development of more effective support systems that uphold human rights and social justice that addresses the issues for the intersections between race, disabilities, and ethnicities for parents with children with disabilities in New Zealand (Goodley et al., 2017).

Towards eradicating poverty for families with children with disabilities

In this discussion, I aim to elucidate the intricate dynamics of the poverty trap for families with children with disabilities and communication difficulties, exploring the poverty trap with systemic barriers usitlising CRT (Goodley et al., 2017). A multifaceted approach is crucial for dismantling the poverty trap and fostering a more inclusive and equitable society for all, including families with children with disabilities. The poverty trap is a complex, self-reinforcing cycle wherein individuals and families experience cumulative disadvantages that hinder their ability to escape poverty (Stapleton et al., 2006). For families with children with disabilities, the trap is particularly pernicious due to the presence of multiple interrelated factors that exacerbate their vulnerability to poverty (Hughes, 2013; Stapleton et al., 2006). A thorough understanding of these factors and their interactions is vital to design targeted interventions capable of dismantling the poverty trap's components.

Access to quality education is a crucial determinant of future socioeconomic mobility, especially for people with disabilities (Abidi & Sharma, 2014; Ruhindwa et al., 2016). However, as expressed by the participants in the study, children with disabilities and communication difficulties often face significant challenges in accessing appropriate educational services (Booth, 2018). Insufficient accommodations, absence of appropriate educational facilities or programs, a lack of specialised programs, and inadequate support from trained professionals in the educational settings contribute to disparities in educational attainment and, consequently, both parental and children’s employment prospects and earning potential (Ainscow, 2020; Blustein et al., 2016; Saunders et el., 2015; Walton, 2018). Parents face challenges in going to work when their children with disabilities or communication difficulties cannot attend school due to the lack of appropriate educational services (Blustein et al., 2016; Saunders et el., 2015). This situation also hinders the children's development and reduces their opportunities to learn skills and explore employment prospects (Koller et al., 2018; Shields & Shynnot, 2016). As a result, children with disabilities are less likely to secure employment in the future, leading to limited socioeconomic mobility.

To address this systemic barrier, it is imperative to create an inclusive education system that caters to the diverse needs of all children, including those with disabilities (Ainscow, 2020; Booth, 2018; Walton, 2018). This entails reviewing the longstanding issues of lack of special educational input from the government and the ministry of education, implementing humane and suitable strategies- for example, increasing the special education resources and capacity to cater for all children with needs, reviewing the education strategies for children with disabilities that are working well for other countries, investing in teacher training and suitable and accessible felicities, and developing and implementing evidence-based interventions to support the learning and development of children with disabilities (Ainscow, 2020; Hardy & Woodcock, 2015; Mitchell & Sutherland, 2020; WHO, 2015).

In addition, the financial burden associated with raising a child with disabilities also has been identified as a strain on a family's resources, exacerbating the poverty trap (Saunders et al., 2015; Stabile & Allin, 2012). High healthcare costs, including medical treatments, therapies, interventions, and assistive devices, may force families to make difficult choices between essential needs and their child's well-being, further entrenching them in poverty (Groce et al., 2011; Mitra et al., 2017). To mitigate this barrier, governments must develop robust social safety nets that encompass accessible healthcare and financial support for families with children with disabilities (Mitra et al., 2017). This requires a comprehensive, multi-sectoral approach that integrates healthcare services, financial assistance, and social support to address the unique needs of these families (Baldwin, 2015; Moffitt, 2015; WHO, 2015).

Parents of children with disabilities also encounter discrimination in the workplace due to their caregiving responsibilities (Williams et al., 2012). Employers may perceive them as less committed or reliable, limiting their opportunities for career advancement and income growth (Henle et al., 2020; Williams et al., 2012). To dismantle this aspect of the poverty trap, it is crucial to develop and implement workplaces and policies that promote inclusivity and support parents in balancing their caregiving responsibilities and economic stability (Brennan et al., 2013; Resch et al., 2010). This may include enacting flexible work arrangements, parental leave policies for parents with children with disabilities, and anti-discrimination measures that protect parents from prejudiced practices in the workplace.

The insufficiency of social services and government support for families with children with disabilities further exacerbates the poverty trap. Limited funding, the absence of targeted support programs, and bureaucratic barriers for the parents to access the available support also hinder access to essential services, further entrenching these families in poverty (Saunders et al., 2015; Stabile & Allin, 2012). To address these issues, governments must allocate resources to support these families, including financial assistance, healthcare services, and tailored educational support by enhancing social safety nets as discussed, streamlining access to crucial services, and adopting a holistic approach to policy design and implementation (Henle et al., 2020; Saunders et al., 2015).

Dismantling the poverty trap necessitates collaboration and coordination among multiple stakeholders, including government agencies, non-governmental organisations, health, legal, social welfare and education sector, academia, members of the society and many more (MoH, 2016; Keforlwe & Smit, 2021; Mclntyre & Brown, 2018; Thompson, 2006). Whilst the scope of this research has not been focused on identifying how to break the poverty cycle, it is acknowledged that to effectively implement the proposed solutions, a coordinated effort to share knowledge, expertise and expertise of people from their own lives and additional resources is crucial. Developing cross-sector partnerships, including the parents, can facilitate the sharing of best practices to support the families with the identified issues and will enhance the overall effectiveness of interventions designed to support families with children with disabilities (Groce et al., 2011; MoH, 2016; Wynd, 2015). By involving them and enabling them in the design, implementation, and evaluation of policies and programs, interventions can be tailored to the specific needs of these families, enhancing their effectiveness and fostering a sense of ownership and agency among the affected communities (Fisher et al., 2019; Shogren & Turnbull, 2014). This approach can contribute to breaking the cycle of poverty and empowering families with disabled children to lead more fulfilling and self-determined lives.

Dismantling the poverty trap for parents with children with disabilities and communication difficulties demands exploration of the systemic barriers and potential solutions (Groce et al., 2011; Mitra et al., 2017; WHO, 2015). These challenges bring to light the intricate interplay between disability and race, revealing the multifaceted and interconnected nature of poverty and other pressing issues that require urgent attention (Goodley et al., 2018; Hosking, 2008). By employing a multifaceted approach that involves addressing educational barriers, healthcare costs, workplace discrimination, inadequate social services and government support, societal attitudes, cross-sector collaboration, monitoring and evaluation, and community engagement, we can promote social justice and human rights while contributing to a more inclusive and equitable society for all as discussed in the previous section (Saunders et al., 2015; Stabile & Allin, 2012). While challenges persist, the potential positive outcomes, such as improved quality of life for families, greater economic participation and social inclusion, reduced reliance on social services, and the advancement of social justice and human rights, justify the investment and commitment needed to create a more inclusive and equitable society (Berman-Bieler et al., 2023; Needham & Dicknson, 2018).

Inclusive practices

Parents with communication difficulties often face myriad challenges, particularly when caring for children with communication disabilities (Alsharaydeh et al., 2019; Miranda et al., 2019; Searls, 2019). These parents experience numerous barriers in accessing information, resources, and support due to their own communication difficulties, which are further compounded by inadequate professional practices and a lack of understanding and accommodations for their needs (Alsharaydeh et al., 2019; Miranda et al., 2019). This article aims to discuss these additional challenges in an academic context, the implications of their exclusion and silencing, and the urgent need for research and innovative frameworks to accommodate them.

Prevailing methodologies concerning the approaches to children with disabilities and communication difficulties in research, practice, intervention, and policy contexts continue to frequently presuppose that parents can communicate without communication difficulties (Bruce, 2020; Lindsay & Fuentes, 2022). This supposition originates from an ableist perspective and is not universally applicable. Recognising the existence of parents with communication difficulties and the development of more inclusive research and support systems is crucial. Consequently, parents with communication difficulties are habitually excluded from conversations and decision-making processes concerning their children's care, education, and healthcare. This systemic exclusion and marginalisation are amplified when these parents are responsible for children with communication disabilities. The voices of these parents have been predominantly disregarded and silenced due to systemic academic exclusion, resulting in limited representation in existing research.

The consequences of excluding and silencing parents with communication difficulties, especially those from marginalized racial and ethnic backgrounds, are profound and far reaching, as CRT highlights the intersections of race, power, and social inequity (Goodley et al., 2017). When these parents are unable to access resources or participate in decisions, their children's health, education, and overall well-being are compromised (Kubicki et al., 2019; Waltz & Schippers, 2021). Failure to address these disparities, which are deeply rooted in systemic barriers creates a cycle of marginalisation, resulting in greater social issues, increased costs, and inhumane living conditions for both the parents and their children. When these parents cannot access resources or participate in decisions, their children's health, education, and general well-being suffer. Neglecting to address these disparities through the lense of CRT perpetuates a cycle of marginalisation, culminating in exacerbated societal problems, increased expenses, and untenable living conditions for both parents and children (Goodley et al., 2017).

To dismantle these systemic barriers, it is vital to ensure that public services and resources are accessible to all, encompassing parents with communication difficulties (Ainscow, 2020; Mithcell & Sutherland, 2020). This may necessitate providing information in alternative formats, such as sign language, simplified materials, or augmentative and alternative communication (AAC) tools. Additionally, healthcare, education, and social service professionals should undergo pertinent training to enhance their understanding and support for parents with communication difficulties, accommodating their requirements and offering resources for both them and their children (Alsharadeh et al., 2019; Shakespeare et al., 2009). Implementing legislative measures, including policies and practices that promote the inclusion of parents with communication difficulties caring for children with disabilities, is essential to address these concerns (Callow et al., 2011; Mepham, 2010). In order to address the needs of parents with communication difficulties, the development of an extensive and innovative framework is imperative (Cohen et al., 2014; Meadan et al., 2020). This framework should prioritise the inclusion of parents with more severe communication challenges and accommodate their needs in accessing resources, support, and decision-making processes. By doing so, we can help bridge the chasm between marginalised individuals and the mainstream population, ensuring that these parents and their children have the opportunity for an improved future.

As discussed in this section, parents who experience communication difficulties and care for children with communication disabilities encounter unique challenges that often remain overlooked and insufficiently explored within academic settings (Gonzales et al., 2021; Millstein et al., 2020). The lack of attention given to their unique circumstances and obstacles hinders our understanding of their situation and exacerbates the marginalization resulting from the intersection of race and disability (Goodley et al., 2018; Hosking, 2008). Consequently, it is of paramount importance to initially address these disparities by carrying out inclusive research and formulating innovative frameworks tailored to the needs of these marginalised populations (Gonzales et al., 2021; Meadan et al., 2020). By empowering these parents with a voice and facilitating their access to resources, Aotearoa can promote the establishment of a more equitable and inclusive society for everyone.

Abolishing the punitive approach to disability for solo parents

The intersectionality of single parenthood and caregiving for a child with a disability generates a distinctive array of challenges that may lead to a sense of confinement or feeling "trapped" within the domestic sphere. A more comprehensive understanding of this phenomenon can be achieved by examining the cumulative impact of these intertwined factors rather than merely assessing them as separate issues (Goodley et al., 2017).The idea that the difficulties faced and challenges encountered by solo parents of children with disabilities, particularly those from marginalized race and ethnic backgrounds, are a mere addition to the challenges of solo parenting and the challenges of caring for a child with a disability is a misconception. In reality, as discovered in this study, the interaction of these two factors, along with racial and ethnic disparities, often results in a multiplication of difficulties and an amplification of hardships, creating distinct and intricate obstacles for these families (Goodley, et al., 2017). A more profound understanding of this phenomenon can be achieved by exploring specific instances that exemplify these complex interactions.

Solo parents face a constant struggle to balance multiple roles, such as providing care, managing the household, and securing or earning an income (Djap et al ., 2021; Mackenzie, 2023). When they are also responsible for a child with a disability, the time and efforts required to provide and care for the child increase exponentially due to the additional care and support required for the child's special needs (Djap et al., 2021; Mackenzie, 2023). This can create an overwhelming sense of pressure, leaving little time for self-care, personal interests, or social activities. As a result, solo parents may feel trapped in their situation and experience heightened stress, leading to a perpetual feeling of being overwhelmed.

Solo parents who care for a child with a disability face even greater financial challenges (Lu et al., 2020). The additional expenses for specialised care, equipment, and therapies can create a significant strain on the family budget, making it challenging to afford essential external support, such as respite care or additional therapies (Kim et al., 2023). This financial burden can lead to a sense of isolation and confinement, as solo parents may feel compelled to remain at home to provide care for their child and themselves (Dyches et al., 2016). This lack of resources can further exacerbate the already difficult task of solo parenting, making it more challenging to balance multiple responsibilities while also providing for the family's basic needs (Djap et al., 2021; Kim et al., 2023).

Solo parents who care for children with disabilities often feel socially isolated due to the unique demands and challenges of their situation (Dyches et al., 2016). Time constraints can limit their ability to participate in social activities, and traditional support networks may not fully understand the difficulties they face or be able to provide the necessary support. This can leave solo parents feeling further isolated, with little opportunity for meaningful social interaction outside of their homes (Currie & Szabo, 2020; Kim et al., 2023). Furthermore, the societal stigma surrounding disability can create additional barriers to social inclusion for both parents (Gray, 2022; Lalvani, 2015).

Solo parents who care for children with disabilities often experience a compounding emotional burden that can lead to heightened feelings of anxiety, depression, and stress (Dyches et al., 2016). The constant demands on their time and energy, combined with the emotional weight of their child's struggles, can leave them feeling emotionally depleted. This mental and emotional exhaustion can contribute to a sense of being trapped, as solo parents may not have the resources or energy to seek help or engage in activities outside of their caregiving role (Currie & Szabo, 2020; Kim et al., 2023). As a result, they may feel isolated and unable to access the support they need to manage their emotional well-being, further exacerbating their sense of burden and overwhelm.

Addressing the challenges faced by solo parents of children with disabilities, especially those from marginalized racial and ethnic backgrounds- requires targeted interventions and support systems that take into account the complex and unique nature of their experiences, as well as the systemic racial inequities (Goodley et al., 2017). Interventions and support systems should be designed to provide targeted assistance and resources that address the specific needs of solo parents caring for children with disabilities, including financial and emotional support, access to specialised services and equipment, and opportunities for social engagement and respite (Djap et al., 2021; Dyches et al., 2016) . By addressing these challenges as highlighted by the lens of CRT, we can help to improve the well-being of both solo parents and their children and promote a more inclusive, equitable, and supportive society that acknowledges and confronts systemic marginalization and disparities (Goodley et al., 2017).

The current social support system for families with children who have disabilities often treats solo parenting and caregiving as separate issues, failing to recognise the unique challenges that arise when these two factors intersect (Djpa, et al., 2021; Kim et al., 2023). When disability and solo parenting are treated as separate issues, support services may not fully recognise or address the unique challenges that arise from the intersection of these factors. This can result in a "one-size-fits-all" approach that fails to meet the specific needs and challenges faced by solo parents of children with disabilities (Levine, 2008). For example, a service intended to assist solo parents may not have the necessary skills or resources or to address the distinct needs of caring for a child with a disability, especially for those who are from racial and ethnic backgrounds. Conversely, a program focused on helping families of children with disabilities may overlook the extra challenges that solo parents face, such as the difficulties described in the previous chapter in the context of CRT (Goodley et al., 2017).

By providing targeted assistance specifically tailored to meet the requirements of single parents caring for children with disabilities, and actively working to confront and alleviate the additional burdens posed by systemic inequities, we can create more inclusive and effective support system (Goodley et al., 2017; Park et al., 2016). By offering individualised and specialised support that directly addresses these complex challenges, it is possible to alleviate the sense of entrapment often experienced by single parents, ultimately fostering improved outcomes and enhanced well-being for both parent and child (Aunos et al., 2008; Wolstencroft et al., 2021). Ensuring that families receive the necessary support to manage the dual responsibilities of single parenthood and caring for a child with a disability not only highlights the importance of a comprehensive and empathetic approach but also underscores the need for evidence-based interventions that prioritise the well-being of these families (Kim et al., 2023; Weiss, 2002). Moreover, it is crucial to recognise and address the varying needs of single parents of children with disabilities by considering factors such as socioeconomic background, race, ethnicity, sexuality and language (Goodley et al., 2017). This ensures that support services are accessible and pertinent to all families, irrespective of their circumstances. The framework should be anchored in evidence-based practices and be regularly updated to reflect the latest research and understanding of the distinct challenges faced by single parents of children with disabilities (Djpa et al., 2021; Dyches et al., 2016) . This approach guarantees that support services remain effective, responsive, and aligned with the evolving needs of these families.

Towards anti-racism

In Aotearoa New Zealand, indigenous ethnic groups such as Māori and Pasifika parents caring for children with disabilities and communication difficulties face multifaceted challenges due to the intersection of racism, racial disparities, and systemic barriers (Ingham et al., 2022; Neuwelt-Kearns et al., 2020; Topou et al., 2021). Racism experienced by the parents is not a standalone factor but rather one that intertwines with all other aspects of the parental experiences of caring for children with disabilities, creating compounded difficulties.

The intersectional approach to understanding the experiences of Māori and Pasifika parents reveals the complexity of the barriers they face, highlighting the urgent need for a more comprehensive and nuanced understanding of the ways in which racism and other factors intersect and mutually reinforce each other, resulting in a compounding effect on the challenges experienced by these families (Harwood, 2010; Ingham et al., 2022). This makes it crucial to adopt an intersectional lens, recognising the interconnected nature of the various factors that contribute to the difficulties these families encounter, acknowledging that racism, cultural differences, language barriers, and systemic barriers do not operate independently but instead converge, amplifying the challenges faced by these parents and their children (Goodley et al., 2017; Hosking, 2008).

As discovered in this study, racism exacerbates the challenges faced by Māori and Pasifika parents caring for children with disabilities and communication difficulties, such as accessing services, information, and unfair treatment from others, including professionals involved in the care of the children (Harris et al., 2013; Selak et al., 2020). Furthermore, the historical and ongoing impacts of colonisation, systemic oppression, and racism contribute to the disparities in access to resources, support, and opportunities experienced by Māori and

Pasifika parents (Ingham et al., 2022; Neuwelt-Kearns et al., 2021; Tupou et al., 2021). These factors create a compounding effect that further impedes their ability to provide adequate care and support for their children.

Effectively addressing the compounded difficulties faced by Māori and Pasifika parents caring for children with disabilities and communication difficulties necessitates a comprehensive understanding of the historical and ongoing impacts of colonisation and systemic oppression (Manuel et al., 2021). These factors, as highlighted in CRT, contribute to the considerable challenges these families encounter due to the intersectionality of race and disability (Goodley et al., 2017, Hosking, 2008). By promoting equity and inclusivity, we can work towards mitigating these disparities and ultimately improve the quality of care for their children.

To achieve this, a series of targeted interventions must be introduced to cater to the unique needs of Māori and Pasifika families. First and foremost, increasing the allocation of resources for these communities is essential (Brown & Bryder, 2023; Humpage, 2017; Palmer et al., 2019). By providing additional resources, we can enhance access to essential services, support, and opportunities for these families, further addressing the disparities they face. Following the allocation of resources, it is imperative to design and execute culturally appropriate services that address the distinct needs of Māori and Pasifika families (Mhurchu et al., 2019; Topou et al., 2021). Achieving this necessitates enhancing cultural competency among professionals in healthcare, education, and social services (Ingham et al., 2022; Topou et al., 2021). Simultaneously, it is vital to support the growth of Māori and Pasifika professionals within these sectors, as their presence can significantly improve cultural understanding and sensitivity (Koia, 2022; Masters-Awatere & Graham, 2019). As a result, the provision of more effective and tailored services becomes feasible for these communities.

In parallel with these efforts, empowering Māori and Pasifika individuals to participate actively and establishing mechanisms that enable them to engage in the decision-making process is vital (Came et al., 2019; Enghali & Azizi, 2022). This can be achieved by creating platforms for dialogue, consultation, and collaboration with community leaders. Additionally, removing barriers that hinder their participation is essential. This may include providing the necessary resources, offering practical support such as compensating for their time, ensuring transportation if needed, and establishing facilities that meet their families' needs while centring their collective views (Cram, 2014; Jatrana et al., 2011; King, 2001). This approach fosters Māori and Pasifika-led decision-making, which enables culturally appropriate and sensitive practices that effectively address ongoing disparities and racism within their communities.

This equitable provision of resources and support for Māori and Pasifika families caring for children with disabilities is imperative in addressing the socioeconomic disparities experienced by these communities (Maoate & Frizelle, 2013; Roy et al., 2021). Some may argue that targeted interventions constitute differential treatment, but it is essential to recognise that such measures are necessary to address historical and ongoing issues experienced by these communities, such as colonisation, land dispossession, loss of cultural identity, and systemic discrimination (Bahamondes et al., 2022 ; Fraser & Kick, 2000). These historical and systemic injustices resulted in the loss of their values, customs, languages and traditions and the deconstruction of their social structure, all of which have further marginalised them (Brittain & Tuffin, 2017; Moewaka Barnes & McCreanor, 2019). This marginalisation has contributed to significant disparities in health, education, and economic outcomes for Māori and Pasifika populations (Barber & Naepi, 2020; Came et al., 2019). Specifically, the loss of cultural identity and values has resulted in poorer health outcomes, including higher rates of chronic diseases and poorer overall health (Maree Kopua, 2020; Wilson et al., 2021). The dismantling of traditional social structures has led to disengagement from education and lower academic achievement (Ka'ai-Mahuta , 2011; Pihama, 2019; Smith, 2000). Economic outcomes are similarly impacted, with Māori and Pasifika communities experiencing higher rates of poverty and unemployment (Brown & Bryder, 2023; Mutu, 2019; Zambas & Wright, 2016).

Recognising and addressing the impact of these historical and systemic injustices ,as highlighted by CTR in this study, is crucial in promoting social justice and ensuring that Māori and Pasifika families caring for children with disabilities have equitable access to resources and support (Bowden et al., 2015; Goodly et al., 2017). By acknowledging the underlying factors contributing to socioeconomic disparities, we can work towards creating a more just and equitable society for all (Goodley et al., 2017), ensuring that all families have equal access to resources and support, irrespective of cultural background or the challenges faced (Chin et al., 2018; Maydell et al., 2022).

To effectively address the multifaceted challenges faced by Māori and Pasifika parents, interventions must be grounded in an intersectional framework that takes into account the interconnected nature of racism, systemic barriers, and other factors (Chin et al., 2018; Goodley et al., 2017). Such a framework will guide the development of culturally appropriate and context-specific strategies that address the diverse needs of these families while also dismantling the systemic barriers that perpetuate racial disparities and inequalities (Ravichandra et al., 2022; Roy et al., 2021).

Accessible and affordable housing

The relationship between housing security and parenting children with disabilities is both interconnected and interrelated, with implications that affect both aspects of life (Jordan & Prendella, 2019; Schwartz et al., 2019). Housing insecurity can significantly impact the lives of parents with disabled children, while the challenges of raising such children can, in turn, exacerbate housing insecurity (Devine et al., 2020; Lee & Evans, 2020). The various factors contributing to this interrelated issue and potential solutions to address the difficulties will be discussed utilizing CRT, including the implications of housing insecurity for the parents of children with disabilities, the impact of parenting children with disabilities on housing insecurity and potential solutions to address these interconnected challenges (Goodley et al., 2017; Mclntosh & Leah, 2017).

For parents of children with disabilities, there are four key ways in which housing insecurity influences their lives. Firstly, it can restrict access to suitable housing that meets the specific needs of disabled children, such as proximity to specialised services, schools, and public transportation (Semeah et al., 2019; Soria et al., 2023). Securing affordable housing that accommodates these criteria can be difficult, especially in areas with limited housing options (Aitken et al., 2019). Secondly, housing insecurity can lead to frequent relocation, which disrupts the continuity of care for disabled children (Hirdes et al., 2020). Constant changes in healthcare providers, therapists, and schools can impede the child's progress while also increasing the burden on parents to adapt to new support systems (Esser et al., 2022; Hirdes et al., 2020). Thirdly, the stress and anxiety associated with housing insecurity can negatively affect parents' mental health, making it harder for them to effectively care for their children (Rose-Jacobs et al., 2019). This additional psychological burden can further strain their coping abilities in managing the challenges of raising a disabled child (Parish et al., 2008; Rose-Jacobs et al., 2019). Lastly, housing insecurity can result in social isolation, as families may be forced to move away from their support networks, making it more difficult for parents to access emotional and practical assistance (Hulse & Saugeres, 20088; Loock et al., 2020). Caregiving demands can also hinder the establishment of new connections, exacerbating feelings of isolation (Alsharaydeh et al., 2019; Walker et al., 2016).

Conversely, parenting children with disabilities can have several significant impacts on housing insecurity. First, raising a disabled child often involves additional costs, such as medical treatments, therapies, and specialised equipment (Stabile, 2012; Shahat & Greco, 2021). These financial strains can make it challenging for families to afford stable housing, potentially leading them to prioritise their child's needs over housing quality or stability. Second, parents of disabled children may struggle to maintain full-time employment due to caregiving demands (Stabile, 2012). Reduced income resulting from limited work hours or unstable employment can worsen housing insecurity. Third, the need for specialised services or educational settings for disabled children may force families to relocate to access these resources, further undermining their housing stability (Rose-Jacobs et al., 2019). Finally, parents of disabled children may face discrimination in the housing market, as landlords may be reluctant to rent to families with special needs due to concerns about potential property damage, increased maintenance, or insurance issues (Fazil et al., 2002; Heylen et al., 2016).

The relationship between housing security and parenting children with disabilities is a complex, reciprocal one (Devine et al., 2020; Lee & Evans, 2020). Housing insecurity can hinder parents' ability to provide suitable care for their disabled children, while the challenges and financial demands of raising these children can exacerbate housing insecurity (Rose-Jacobs et al., 2019). Understanding and addressing these interconnected issues is crucial to supporting the well-being of both parents and children in these families.

Several potential solutions could be employed to address the complex, interconnected challenges faced by families with disabled children in relation to housing insecurity and caregiving demands (Stabile, 2012). Developing affordable, accessible housing involves increasing the availability of housing options tailored to the specific needs of families with disabled children (Hulse & Saugeres, 2008; Lathrop, 2020). Ensuring that these families have access to suitable living environments is crucial for their overall well-being. Targeting housing subsidies for families with disabled children can also help alleviate financial strain and support housing stability. Providing these subsidies allows families to prioritise their child's needs without compromising the quality or stability of their housing situation.

In addition, implementing employment support for parents of disabled children can be achieved through the introduction of work policies and vocational training programs tailored to their needs (Cidav et al., 2012). This enables parents to maintain employment and generate a stable income, further contributing to housing security. Strengthening anti-discrimination laws and regulations is essential to protect families with disabled children from housing discrimination and ensure equal access to suitable housing options (Boxall et al., 2018). By enforcing these laws, society can foster a more inclusive environment for these families (Boxall et al., 2018; Lawson, 2016). Furthermore, improving the coordination of service delivery between housing, healthcare, and social service providers ensures that families receive comprehensive support and have access to the resources they need to maintain stable housing. This coordinated approach addresses the various aspects of their lives that impact housing security and caregiving. By addressing the interconnected challenges of housing insecurity and parenting children with disabilities, a more stable and supportive environment for these families can be created, ultimately improving their quality of life and reducing the sense of entrapment they may experience (Mmako et al., 2019; Peng et al., 2020).

In addition to housing insecurity and parenting children with disability, the discussion of social housing is crucial as this is often the last stage of where people end up when they face housing insecurity. People often result in a need for social housing, which is a crucial point of discussion when examining the challenges faced by parents of children with disabilities. While social housing is designed to provide affordable and stable housing for vulnerable populations, the lack of a comprehensive legislative framework and protection for accessible housing can result in the unmet needs of these families, perpetuating their difficulties (McCormick et al., 2023; Peng et al., 2020).

One issue is the limited availability of accessible social housing. In many cases as discussed in this study, social housing may not be constructed or adapted to meet the unique accessibility needs of families with disabled children (Goldsmith, 2012; Shakespeare, 2017). This lack of suitable social housing options further complicates the search for stable housing and contributes to ongoing housing insecurity. Another challenge is the inadequate legislative framework. While some laws and regulations may exist to protect the rights of people with disabilities, the current legislative framework often fails to adequately address specific needs for accessible and affordable housing (Boxall et al., 2018; Lawson, 2016). This lack of comprehensive legal protection leaves many families with limited options and unmet needs. Furthermore, families in need of accessible social housing may face lengthy waitlists and delays. These obstacles can exacerbate housing insecurity and increase the stress and uncertainty associated with their living situations. Lastly, the lack of enforcement and oversight is a significant concern. Even when legislation and regulations exist to promote accessible housing, insufficient enforcement and oversight can result in non-compliance by policymakers, government and non-government departments and agencies, landlords, developers, and housing agencies. This lack of accountability further restricts the availability of suitable housing options for families with disabled children.

A robust and comprehensive approach is necessary to address the challenges faced by families with disabled children in terms of accessible social housing. This approach should encompass the development of appropriate social housing, the establishment of a more inclusive legislative framework, and the improvement of enforcement and oversight mechanisms. By tackling these issues, the housing needs of families with disabled children can be better met, contributing to a more supportive and inclusive society.

By addressing the challenges faced by parents of children with disabilities in accessing appropriate social housing, the ongoing cycle of housing insecurity that many of these families face can be reduced. This comprehensive approach will help create a more inclusive and equitable society that supports the well-being of all families, regardless of their unique circumstances. However, it is vital to recognise that expecting families with disabled children to rely exclusively on social housing is neither an acceptable nor sustainable solution (Devine et al., 2020; McCormick et al., 2023; Mmako et al., 2019). Instead, a targeted approach is required to address the unique challenges these families face in terms of housing insecurity.

The issue of housing insecurity and parenting children with disabilities presents a multifaceted and interrelated challenge, further compounded by systemic inequalities perpetuated, as illuminated by CRT (Goodly et al., 2017). A nuanced understanding of the unique challenges that families encounter in addressing these issues is essential, and a comprehensive approach that acknowledges their interconnectedness is necessary. By adopting such an approach, it is possible to establish a more supportive environment that enhances the quality of life for these families and alleviates the sense of housing insecurity that they may experience. Early intervention, customised support, and a paradigm shift towards more inclusive and equitable housing accessibility, guided by CRT principles, are all critical measures to achieving this goal. It is imperative to prioritise the needs of these families and engage in cross-sectoral collaboration to devise and implement effective solutions that promote their well-being and advance social equity (Goodly et al., 2017; Jordan & Prendella, 2019; Schwartz et al., 2019).

Relinquishment

This section provides a comprehensive and in-depth discussion of the implications arising from the findings related to the phenomenon of parental relinquishment and the complex factors contributing to the extreme difficulties faced by parents raising children with disabilities and communication difficulties. The findings of this study revealed that parents raising children with disabilities and communication difficulties often experienced a profound sense of helplessness and despair, which precipitated thoughts of relinquishment. The emotional burden they faced was largely attributable to the paucity of adequate support, resources, and understanding from society and government institutions. These findings underscore the exigency for targeted intervention and the provision of comprehensive support and services tailored to the unique needs of these families. The antecedents of parental relinquishment were found to be multifarious, with a confluence of environmental, societal, and personal factors contributing to this outcome. Pathologised difficulties, such as depression and anxiety, were frequently misdiagnosed or misconstrued, leaving parents bereft of appropriate support. The poverty trap further aggravated the situation, circumscribing access to indispensable resources and services. Additionally, societal factors such as racial discrimination and housing insecurity magnified the challenges confronting these parents.

Recommendations

In order to address the intersectional cycle that is contributing to parents' experiences of distress, marginalization, poverty, and feelings that the only answer is relinquishment of the child, there are a number of recommendations. These recommendations are based on the findings and designed to delineate a comprehensive and systemic approach to supporting families with disabilities.

Firstly, there is a need to enhance mental health service provision to accurately diagnose and treat parents experiencing pathologised difficulties. This requires specialised training and augmented funding for mental health services designed to cater to the unique needs of parents raising children with disabilities and communication difficulties.

Secondly, alleviating financial burdens through policies and programs that tackle the poverty trap can empower parents to access essential resources and services without succumbing to financial constraints. Measures such as financial assistance, job training, and subsidised childcare services can help to mitigate financial barriers and improve the economic stability of families.

Thirdly, targeted educational and communicative support programs should be developed for both parents and their children. These programs should exhibit cultural sensitivity and linguistic accessibility to ensure equitable access for parents hailing from diverse backgrounds.

Fourthly, policies and interventions aimed at attenuating racial discrimination and fostering social inclusion are crucial. These may include anti-discrimination legislation, cultural competency training for service providers, and public awareness campaigns.

Fifthly, ensuring stable housing conditions is essential. Formulating housing policies and programs that cater to the unique needs of families with disabled children can include affordable and accessible housing options, housing subsidies, and support services.

Finally, facilitating support networks for parents through peer support groups, community-based organisations, and social services is crucial. These networks can furnish emotional, practical, and informational support, enabling parents to navigate the multifarious challenges associated with raising a child with disabilities and communication difficulties.

Limitations of the Study

Although the sample size was deemed appropriate for this study, it remains relatively small in comparison to the larger population of parents with children facing disabilities and communication challenges (Hertzog, 2008). The participants therefore may not represent the broader population, leading to findings that cannot be extrapolated to other parents of children with disabilities and communication challenges so more research is needed.

The study's focus was on a specific population of parents with children experiencing disabilities and communication difficulties within the Aotearoa context, potentially limiting the generalizability of the findings to other populations and settings (Simundic, 2013). This is due to cultural, social, economic, and political factors that may vary across different contexts, influencing parents' experiences and the support systems available to them. To enhance the generalizability of the findings, future research should investigate the experiences of parents across various settings, cultures, and socio-economic backgrounds. Such investigations can offer valuable insights into the extent to which the current findings apply to different populations and help identify additional factors that may be relevant in other contexts.

As most participants were recruited through disability communities, this study may not have captured populations who are not part of the community or have no access to online and local communities. Furthermore, my insider status does give a particular view to the findings, while not necessarily a limitation it should be acknowledged (Chenail, 2011). This awareness can help guide and offer recommendations for future research.

Future Research Directions

One area that requires further exploration is the long-term effects of challenges faced by parents of children with disabilities, chronic illness, and mental distress. While many studies have focused on the immediate effects of challenges such as postpartum depression, research on the long-term impact of parenting challenges is relatively limited. Longitudinal studies that follow parents over time could shed light on the ways in which these challenges affect parental well-being, child outcomes, and the parent-child relationship. Such studies could also help to identify factors that mitigate the negative effects of these challenges, such as social support or access to mental health services. Moreover, there is a conspicuous dearth of research investigating the experiences of parents with communication difficulties who care for children with communication disabilities (Gonzales et al., 2021; Millstein et al., 2020). The limited studies conducted often concentrate on matters of English proficiency and possess inadequate representation from the broader disability community (Krnjacki et al., 2018; Meadan et al., 2020). This underscores the necessity for more inclusive research that delves into the lived experiences of these parents and their distinct challenges.

Another area that requires further research is the effectiveness and adaptability of interventions and support strategies for parents of children with disability. While there are many interventions and support programs available for parents, relatively few have been rigorously evaluated, and little is known about which strategies work best for which types of challenges. Future research could investigate the effectiveness of various interventions, such as group therapy or parent coaching, and explore factors that contribute to the successful implementation and uptake of these programs. Additionally, the researchers could examine the adaptability of interventions across diverse populations and contexts, as well as the feasibility of delivering these interventions through digital or remote channels.

There exists a pressing need to establish a distinct research framework and area of comprehension that concentrates on single parents raising children with disabilities (Djpa, et al., 2021; Kim et al., 2023). Identifying this demographic as a separate group possessing unique requirements will facilitate the development of more targeted and efficient support systems (Aunos et al., 2008; Wolstencroft et al., 2021). The novel framework should perceive the challenges experienced by single parents of children with disabilities as resulting from the interaction between disability and single parenthood rather than a mere aggregation of these factors. This perspective enables the creation of support services that tackle the cumulative difficulties encountered by these families.

Research on the intersectionality of various challenges faced by parents is another area that requires attention. Many parents face multiple challenges simultaneously, such as racism, poverty, and disability. However, few studies have examined how these challenges intersect to shape parenting experiences and outcomes. Future research could explore the unique challenges and strengths associated with different intersections of challenges, as well as the ways in which social identities and contexts interact to shape parenting experiences. Additionally, the research could investigate the effectiveness of interventions and support strategies that are tailored to the needs of parents who face multiple challenges.

Lastly, addressing issues related to sample size and selection bias will be critical for advancing our understanding of parental experiences and ensuring that interventions and support strategies are tailored to the needs of diverse populations of parents. Future research could aim to recruit larger, more diverse samples of parents, using stratified or random sampling techniques to ensure that the sample is representative of the population of interest. Additionally, researchers could employ rigorous methods to minimise selection bias, such as using standardised recruitment procedures, offering incentives for participation, and accounting for missing data.

By addressing these critical research questions, a deeper and better understanding of the challenges that parents face can be expected, which could lead to the development of more effective strategies to support them.

Conclusion and final thoughts

This research has made a salient contribution to the scholarly understanding of the complex challenges encountered by parents of children with disabilities and communication difficulties. By examining the New Zealand context, the study enriches the international corpus of literature, highlighting the necessity of accounting for the unique experiences of parents from diverse cultural and regional backgrounds. The explication of the "Repeat" cycle serves as a critical theoretical advancement, illustrating the interconnected nature of the challenges faced by these parents and underscoring the imperative for adopting a comprehensive and holistic approach when addressing their concerns. The application of an intersectionality framework in this research elucidates the intricate interplay of factors that shape the experiences of parents, accentuating the need for tailored support strategies that consider the distinct challenges faced by different subgroups. In recognising and addressing the intersection of race, socio-economic status, and disability, stakeholders, including policymakers, practitioners, and researchers, can more effectively devise interventions and support systems that empower parents and enhance outcomes for their children. The insights generated by this study have the potential to not only inform future research and policy development but also to improve the lived experiences of parents and children navigating these complex challenges.

In closing, it is of paramount importance to emphasise the ongoing need for research and support for families grappling with these challenges. As our understanding of the distinctive experiences of parents of children with disabilities and communication difficulties expands, so too must our dedication to providing them with the requisite resources and services. By acknowledging and addressing the multifaceted and interconnected challenges they face, we can facilitate the disruption of the "Repeat" cycle and promote a more equitable and inclusive society for all. The findings of this study serve as a clarion call for researchers, practitioners, policymakers, and communities to collaborate in addressing the myriad challenges faced by these parents. In doing so, we can cultivate an inclusive and supportive environment that fosters resilience and well-being among parents and their children, ultimately enriching our society as a whole, and ensuring that we build a brighter future for everyone.

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Appendices – ethics document

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

The experiences of parents with a child a disability: Exploring communication difficulties

INFORMATION SHEET

Researchers Introduction

My name is Yeseul Kim, and I am a student at Massey University in psychology. I am interested in the experiences of people facing challenging event(s) and adversity, particularly parents and caregivers living in New Zealand who have a child or children with disability.

Project Summary and Invitation

I would like to talk with you about your experiences of raising a child with a disability in Aotearoa New Zealand focusing on the challenges and rewards of parenting a child with a disability. I am particularly interested in talking with you if your child requires assistance to communicate (e.g. sign language, use of devices). I hope the findings of this research will contribute to a better understanding of the challenges you face so I can suggest better and more appropriate services and support.

Inclusion Criteria

- You must be a caregiver or a parent of at least one child with a disability
- Your child(ren) must have an official diagnosis of a disability
- Your child(ren)'s disability impacts on communication
- You must reside in New Zealand.

Participating in this study

If you wish to participate in this research, you will be interviewed at a time and place of your preference but within current COVID-19 protection frameworks. Currently, this means the interview may take place online. The interview will last about an hour. The interview will be recorded and transcribed by the researcher for analysis with your permission. You will be offered the chance to review your interview transcript, and this should take no more than 30 minutes. There is the chance the interview will discuss topics that will be distressing but you do not have to discuss anything you do not want to. I have included some information about free counselling support on this information sheet. As an acknowledgement of your time you will offered a $30 grocery voucher.

Confidentiality

The confidentiality and anonymity of you and your family will be ensured. A code name will be given to you and for any other information such as name, and locations such as schools or other services. We will send you a copy of your interview transcript to confirm whether the information is correct and anonymous. After this confirmation, the recorded interview files will be disposed of.

Your rights

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

1. decline to answer any particular question;
2. withdraw from the study up until two weeks after your interview;
3. ask any questions about the study at any time during participation;
4. provide information on the understanding that your name will not be used;
5. be given access to a summary of the project findings when it is concluded.
6. ask for the recorder to be turned off at any time during the interview.

Thank you for taking the time to enquire about this project, and to read this information sheet. If you have any questions about the project, please do not hesitate to reach out to Yeseul Kim, at the details below.

Yeseul Kim:
Email: Yeseul.Kim.1@uni.massey.ac.nz
Supervisor: *Dr Kathryn McGuigan*
Email: K.Mcguigan@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 22/17. If you have any concerns about the conduct of this research, please contact A/Prof Fiona Te Momo, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800, x 43347, email humanethicsnorth@massey.ac.nz

Support Services

- 1737, need to talk? If you're feeling anxious, down, overwhelmed or that you need to talk with someone, you can call or text the helpline for free, anytime (24 hours, 7 days a week) 0800 1737 1737 – free call
- The Depression Helpline (0800 111 757) or text 4202
- Healthline (0800 611 116)
- Lifeline (0800 543 354)

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The experiences of parents with a child a disability: Exploring communication difficulties

PARTICIPANT CONSENT FORM - INDIVIDUAL

I have read, or have had read to me, and I understand the Information Sheet provided. I have had the details of the study explained to me, any questions I had have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study at any time.

1. I understand my right to decline any questions, or to withdraw from the study at any time.
2. I agree to the interview being sound recorded.
3. I understand my right to ask for the recorder to be turned off at any time during the interview
4. I agree to parts of the interview being used in the researcher's study, and articles based on the study, and public seminar, provided I am not to be identified by these
5. I agree to participate in this study under the conditions set out in the Information Sheet.

Declaration by Participant:

I ___________ [print full name]__________ hereby consent to take part in this study.

Signature: _______________________ Date: ________________

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RESEARCH INFORMATION SHEET

To whom it may concern,

REQUESTING PERMISSION TO ACCESS YOUR FACEBOOK GROUP FOR RESEARCH PURPOSES

My name is Yeseul Kim and I am a student at Massey University in Psychology. I am hoping to do some on the experiences of having a child or children with a disability with communication difficulties. This research would occur during the months of July 2022 and October 2022.

I would like the opportunity to advertise on your Facebook page for this purpose. If you agree a small advertisement (pasted below) would invite your members to contact us for more information.

Thank you for taking the time to read this request. If you have any questions about the project, please do not hesitate to reach out to either Yeseul or Dr. Kathryn McGuigan at the details below.

Email : Yeseul.kim.1@uni.massey.ac.nz

Supervisor: Dr Kathryn McGuigan

Email: K.Mcguigan@massey.ac.nz

> This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application 22/17 If you have any concerns about the conduct of this research, please contact Dr Fiona Te Momo, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 43347, email humanethicsnorth@massey.ac.nz.

The experiences of parents with a child a disability: Exploring communication difficulties

My name is Yeseul Kim. I am the researcher of this research project supervised by Dr Kathryn McGuigan. I aim to investigate the experiences of migrant families with a child with disabilities. I would like to talk with parents/caregivers where the child's disability makes communication difficult (e.g. the child is non-verbal, has limited English, developmental or other disability impacting on speech, or deaf)

I invite you to participate in our study if you are (1) a parent or caregiver with a child(ren) with a disability, (2) live in Aotearoa New Zealand and (3) your child's disability impacts on communication.

I hope the findings of this research contribute to understanding the experiences of parents and caregivers of a child(ren) with a disability and helping to develop, deliver and apply more appropriate services and support for them in the future.

Koha of 30$ vouchers will be gifted to participants for their time.

If you want to know more about this study, have any questions or want to participate, please contact Yeseul Kim, email: Yeseul.kim.1@uni.massey.ac.nz

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Interview topics

1. General background information on parents
    a. ethnicity, culture or nationality of origin
    b. age/gender/sexual orientation
    c. brief personal perception of socio-economic status of self
    d. whether they have any communication difficulties
2. information about your child (ren) (diagnosis, place of birth, age)
    a. diagnosis process
    b. diagnosis labels and how the disability presents
    c. required additional needs of the child
    d. communication difficulties
3. experiences of caring for a child with a disability with communication difficulties in Aotearoa New Zealand (financial differences, struggles, cultural differences, stigmatisation, attitudes, personal difficulties etc)
    a. Barriers to care – what are they? e.g. finances, language, cultural differences, attitudes and understandings of the child's disability,
    b. Changes to the day-to-day life – what are they? e.g., transportation, relationships within the family and others, other commitments, living arrangements, daily routines, holiday plans, activities,
    c. Changes in the personal life – what are they? e.g., career, relationship with others, changes in your thoughts on disabilities, goals,
4. Communication
    a. your experience of communicating or having attempted to communicate with your child
    b. do you also have communication difficulties?
    c. your experience of communicating for your child
5. Experiences of facing challenges as a caregiver of a child with a disability with communication difficulties
    a. Major challenges as a parent for the parent
    b. major challenges for the child in their life
6. Experiences of dealing with challenges as a caregiver of a child with a disability with communication difficulties
    a. What is helpful and useful in your day to day life
    b. what support do you have
    c. what support would you like to have in an ideal world for you and your child
7. Any experiences that you would like to share and/or highlight
8. What could have made the difficulties mentioned above better or can make the challenging experiences better
9. Current reflections or thoughts of the interview today

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The experiences of parents with a child a disability: Exploring communication difficulties

CONFIDENTIALITY AGREEMENT

I .... (Full Name - printed)

agree to keep confidential all information concerning the project
....
....
....
.... (Title of Project).

I will not retain or copy any information involving the project.

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