The impact of individualised funding on the wellbeing of mothers raising an autistic child in Aotearoa New Zealand

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Abstract

How best to support the wellbeing of mothers raising autistic children is an emerging issue of importance due to the growth in autism diagnosis. Meanwhile, the Aotearoa New Zealand government is reviewing systems to deliver better health and disability support services for all Aotearoa New Zealanders to achieve more equitable and efficient outcomes through individualised funding by providing personalised and self-directed support for disabled people. While such supports have been globally recognised as a viable and beneficial way to enhance quality of life among disabled people and their family, currently there is limited research examining how this funding has impacted on a mother’s perception of the challenges of caring for their autistic child, as well as improving their wellbeing. In this qualitative study, seven mothers raising an autistic child were interviewed regarding their experiences with individualised funding and its impact on their disabled child and their own wellbeing. Thematic analysis was used to analyse the data. Key findings indicated that caring for an autistic child has an ongoing negative impact on mothers’ overall wellbeing and the individualised funding did not seem to ease the stresses of caring. For these mothers, wellbeing requires the funding support to see the family as a unit of care instead of individualisation of a child’s needs, which has further perpetuated exclusion and social isolation for mothers and families. Results of this research support the need for social and healthcare professionals in the disability sector to call for the government to consider the wellbeing of parents raising an autistic child in a more flexible and holistic way to meet the unique circumstances of a family.

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To the participants who contributed to the study, from the bottom of my heart I thank you for your time and contribution to this thesis. I hope I have honoured the hard work you do, day in and day out. I also hope I have honoured your wishes for things to change and for systems to acknowledge the importance of looking after the wellbeing of mothers which gives you as mothers the ability to provide the best care for your children.

I am blessed to be surrounded by incredibly kind and generous women in my life, Anneke for your continuous support being on hand to read over my work and offer guidance, my writing improves because of you. Christine for our daily chats and check ins, you are important and appreciated. To my past and present colleagues who continue to cheer me on from the side-lines, thank you for your faith in me, some days it was what I needed to keep going.

Identity First Language

Identity first language is used throughout this thesis. Identity first language is considered an appropriate expression of a cultural shift to a neurodiversity perspective by many self-advocates and scholars, and it counteracts the risk that separating the person from the diagnosis perpetuates societal view that something is wrong about the diagnosis. Current literature has no clear consensus regarding the most preferred language from autistic people; however, there is clear consensus what is not preferred and most offensive language, which is specific person-first formulation of “person with autism” (Botha et al., 2021, Vivanti, 2019).

Language shapes our understanding of autism and the use of language influences how that understanding is shaped. Autism is both a reality and constituted from social meaning and common understanding. The use of terminology around autism, specifically language used to refer to autistic people, has a significant role in the increased risk of self-harm, suicidal ideation, post-traumatic stress disorders and death by suicide for autistic people when compared to a non-autistic population (Cassidy et al., 2014; Haruvi-Lamdan et al., 2020; Vivanti, 2019). Where possible without changing historical context or other academic literature, the term autistic has been purposely used throughout this thesis as a positive and affirming word to replace language such as autistic spectrum disorder or its acronym ASD. This use of terminology and language is also supported by Autism New Zealand (2021).

Contents

Chapter One – Introduction

1.1 Background of the study

Many countries, including Aotearoa New Zealand, have been shifting disability support from government managed to consumer or client-led approach, aligning with human right approaches, which enabled disabled people to exercise their full citizenship that have been neglected and marginalised (Foley et al., 2021; Rummery, 2006). Increasingly, more research has focused on discussing the impact of how individualised funding can impact on disabled people fostering autonomy to make decisions about services to meet their needs, and the likelihood to include disabled people as part of the co-design in developing services to challenge the traditional top-down approach (Fleming et al., 2019; Wilberforce et al., 2011; Williams & Dickinson, 2015; Yates et al., 2021). While the move to individualised funding is an international trend, which started in the 1970s and has gained momentum in Canada, the United States, the United Kingdom, Australia and Aotearoa New Zealand (Gallagher et al., 2011), much of the research is aimed from the perspectives of outcome improvement for disabled people, and how professionals and service providers developed and implemented individualised funding (Fleming et al., 2019; Foley et al., 2021), with some on families navigating appropriate information to support their disabled children (e.g., Dew et al., 2013; Tracey et al., 2017). Disabled children require a considerable level of care, support, coordination and advocacy and these responsibilities usually fall to women, which can have negative impacts on their health (Bourke-Taylor et al., 2010; Cantero-Garlito et al., 2020). So far, there is limited knowledge on the wellbeing of mothers raising disabled children, particularly autistic children. This study aimed to develop a better understand by exploring the impact of individualised funding on the wellbeing of mothers by examining the changing disability funding frameworks, the influences of neoliberalism and the impact at a societal and individualised level for those who are raising an autistic child in Aotearoa New Zealand, and to understand the implications for professionals supporting families.

Raising an autistic child can be rewarding for parents; however, it can come at the cost of negative consequences to their wellbeing. Many studies have indicated mothers of children with disabilities experience high levels of stress and poor mental health. For example, when compared to a typically developing child, mothers raising an autistic child experience higher rates of mental health issues, anxiety, and depression (Broady et al., 2015; Pertiwi & Irwanto, 2020; Reddy et al., 2019). Other research has found there is a high level of stress in the role of a mother for an autistic child (Factor et al., 2019; Green, 2003; Salomone et al., 2017), which has contributed significant disruption to supportive relationships, creating poor wellbeing outcomes (Miranda et al., 2019; Seymour et al., 2012). Mothers are often involved in the major caregiving role in the family. Unlike their neurotypical counterparts, disabled children like autistic children depend on their mothers for much longer or indefinitely, resulting in an extended period of care responsibilities on their mothers (Crowe & Michael, 2010). The long-term and additional pressure in care can compromise a mother’s ability for self-care, socialisation, and meaningful activity participation (Luijkx et al., 2017).

As stated earlier, disability funding frameworks for many countries are moving from a government managed model to a person-directed and controlled funding model, challenging the paternalistic principles, which have previously characterised disability services (Bailey et al., 2021; Laragy et al., 2015). In 2007, the New Zealand Social Services Select Committee inquiry heard that disabled people felt they had little control over the services they received, and funding was also described as inflexible (Enabling Good Lives, 2013). In response to ensuring disabled citizens have more choice and control over their lives, in 2012 some regions and some populations of the disability community of Aotearoa New Zealand began piloting a change of funding approach. The Aotearoa New Zealand Government agreed to uphold and respect seven of the nine core international human rights treaties (Ministry of Justice, 2020). One such treaty is the Convention on the Rights of Persons with Disabilities (CRPD), with article three stating the principle to demonstrate respect for the dignity, individual autonomy including the freedom to make one's own choices and independence. The intention of this new system of funding is to change what has been identified as not working for disabled people and families and to create personalisation. Personalisation is the tailoring of services according to preference and need in contrast to the traditional one-size-fits-all approach (Laragy et al., 2015; Mana Whaikaha, 2021; Ministry of Health, 2017). However, it is estimated that only 10 percent of the disabled people entitled to disability funded supports are currently being supported in a pilot of the new changed system. In late 2021, the Aotearoa New Zealand Government announced significant changes to the disability systems across government, including the establishment of the Ministry for Disabled people (Ministry of Social Development, 2021).

While there has been some research indicating individualised funding approaches may provide flexibility of care and choice for disabled children and their family, critics have argued that the notion of individualisation varies in people's ability to negotiate the system in which the distribution of choice and control across the population is not entirely inclusive and equal due to, for example, socio-economic status, ethnicity and gender (Carey et al., 2017; Malbon, 2019; Matthews & Hastings, 2012). With the growing adoption of individualised funding in the policy arena of disability service provision, understanding how individualised funding influences on freedom, choice and self-determination among mothers raising an autistic child is particularly crucial for practitioners and policymakers on how to enhance the wellbeing of these mothers. Research has indicated the importance of incorporating mothers' wellbeing when developing a new funding system for disabled people to ensure good lives are being achieved as this will create a better outcome for the disabled child or children (Giallo et al., 2011; Hogan, 2012; Miranda et al., 2019; Seymour et al., 2012).

1.2 Research objective and aims

The objective of the study was to explore the impact of the change to individualised funding on the wellbeing of mothers raising an autistic child in Aotearoa New Zealand. Specifically, it aimed to examine perspectives of mothers raising an autistic child on what is considered important to their wellbeing and identify what support or development to individualised funding would improve their long-term wellbeing. Seven mothers of autistic children participated in this study. A qualitative approach was designed for this research and semi-structured interviews were held face to face with the mothers. This allowed the researcher to collect and record the participant's experiences of individualised funding to answer the main aim of the study. It also allowed the researcher to explore their perceptions of how their wellbeing is or could be supported.

1.3 Significance of the study

With the growing adoption of individualised funding in the policy arena of disability service provision, understanding how individualised funding influences on freedom, choice and self-determination among mothers raising an autistic child is particularly crucial. This research hoped to develop a better understanding of the unique challenges faced by mothers and the contributing impacts of individualised funding on those challenges. Results of the study would provide professionals and policymakers with a deeper understanding of the current situation faced by mothers as caregivers, creating positive outcomes for mothers through changes of professional practice and changes to policy. The anticipated outcome from these changes would be a strengthened capacity for mothers to continue to provide care and support and to develop plans to ensure their children have every opportunity to reach their own developmental potential, whilst mothers also have the opportunity to live their own good life.

1.4 Positioning of the researcher

As a registered social worker my main field of practice has been within the disability sector working with children, adults, and their families. My current role as a regional disability advisor for Oranga Tamariki has positioned me supporting other social workers navigating systems to ensure that families are accessing their entitlements or developing pathways to access support if required. It was not uncommon to hear stories of people struggling for years without any support because no one had made them aware that there was additional help available, nor was it uncommon for me to hear stories of a caregiver facing emotional and physical fatigue resulting in caregiver burnout.

I am a mother raising autistic children. My motivation to become a registered social worker and pursue further academic study was due to my most valued role as a mother. Over the last 10 years, I have volunteered my time participating in support groups and leadership groups. Over the last four years, I have been a member of the local System Transformation Leadership Group, which has been part of the transformation of the disability funding system based on the principles of the enabling of good lives. I am raising four children: Sophie aged nine, Harry aged 11, Connor aged 15 and Liam aged 16. We also had a daughter, Faith, who passed away in 2009. Sophie, Harry, and Liam have a primary diagnosis of autism, with Harry and Sophie also being diagnosed with ADHD and sensory processing disorders. I am married to man who has self-identified as being autistic through the journey of raising our children; however, this year has decided to go through formal diagnosis. I have considered myself an insider researcher. My everyday life has been shaped by disability, and this has brought me both pure joy as well as pure heartbreak. I have personal stories of being supported and feeling valued by my community, to stories of me or my children being persecuted. I have been passionate about the needs of mothers and caregivers being given more priority within the disability systems. I have felt the honour and privilege to be gifted the stories of my participants mothers for this research.

However, I have also heard stories of so many other mothers feeling powerless to demand changes when those who hold the power to make things better are also the ones that have the power to take it away.

This thesis was not only an academic journey for me. When I started this research, I did not realise what a personal voyage it would be. Reflecting in the literal mirror and considering my own wellbeing and what I role modelled has resulted in significant changes to how I now live my own life. Over this period of writing this thesis, I started to make time for myself and to try and give my own wellbeing some priority whilst working fulltime, studying, and caring for all the children. Realising just how important it was to look after me while appreciating just how hard it was to "fit it in" has continued to inspire me to share this research in the hope that things would get better to ensure that the wellbeing of mothers would be given more importance and one day, I could stop fighting for mothers to be cared for because systems would be in place for that to occur naturally.

1.5 Structure of the thesis

There are six chapters in this study.

Chapter One – Introduction

This chapter was the introduction chapter, outlining the background of the study, research goals and objectives, significance of the study, and structure of the thesis.

Chapter Two – Literature Review

This chapter explores the literature and research in relation to the impact of individualised funding on the wellbeing of mothers raising an autistic child and how social workers and other health professionals can best respond to improving outcomes for families. The disability system in relation to the politics of individualisation of wellbeing and support (or lack of) for autism will also be discussed.

Chapter Three – Methods

This chapter presents the methodology and methods used for the research topic, including study design, process of recruitment, data collection, data analyses, and ethical considerations. The chapter concludes with a discussion of the process used to enhance the trustworthiness and integrity of the research.

Chapter Four – Findings

This chapter presents the findings from semi-structured interviews with the participants. Thematic analysis was used to identity two key themes: (1) overall impact of caring for an autistic child; and (2) wellbeing for mothers requires seeing the family as a unit of care.

Chapter Five – Discussion

The chapter provides a comprehensive discussion around the findings of the research, alongside existing literature focusing on three main areas: (1) individualised funding perpetuates neoliberalism and disablism; (2) wellbeing requires taking the family as a unit of care; and (3) an unwelcoming system creates despair and social exclusion.

Chapter Six – Recommendation and Conclusion

This chapter concludes the thesis. It summarises the key findings, reflects on the research processes and discusses the limitations. Implications for social work practice and recommendations for future research and policy will be discussed.

Chapter Two – Literature Review

2.1 Introduction

This chapter examines the existing research and literature in relation to the impact of individualised funding on the wellbeing of mothers raising an autistic child and how professionals and practitioners such as social workers can best respond to improving practice and outcomes for families. This chapter begins with an overview of autism, which will discuss the prevalence, diagnosis, and characteristics of autism, followed by experiences and issues illustrated from existing research and literature about the impact on mothers and families when raising an autistic child. As mothers are mostly seen as the primary caregiver to disabled children, the chapter goes on to explore what the barriers are to their wellbeing such as stigma, loss of relationships, and constant negotiation of the disability systems. The next section explores wider disability systems and influences of the individualisation of wellbeing, looking at these influences within an Aotearoa New Zealand context. The chapter then moves to consider how the role of practitioners such as social workers can support mothers' wellbeing by examining some of the key changes and development in the disability systems and how they impact on service users.

2.2 Overview of autism

Autism was first reported in 1943 and was described as extremely rare and estimated to affect 2-4 children out of 10,000 (Cath et al., 2008). In 1980, autism was officially identified as a clinical diagnosis and published in the Diagnostic Statistical Manual of Mental Disorders (DSM-III). Over the last 40 years, the understanding of autism has considerably evolved with an increase in autism genetics research and a rapidly growing number of discoveries (Thapar & Rutter, 2020). Autism is a developmental disorder characterised by deficits in social communication and restrictive, repetitive behavioural patterns emerging from a young age

(Hyman et al., 2020). The number of people diagnosed with autism appears to be rising worldwide with an estimate of 0.5–1 percent of the world population diagnosed with autism (Manohar et al., 2019; Ministry of Health, 2018) and is about 4.5 times more common among boys (Juergensen et al., 2018; Klin et al., 2015). Literature has suggested that the increase can be explained in part by changes in diagnostic criteria, improved awareness of autism by wider society and an increase in recognition by clinicians (Bishop-Fitzpatrick & Rubenstein, 2019). Changing definitions that now include autistic disorder and the broader spectrum of neurodevelopmental conditions such as Asperger’s syndrome and pervasive development disorder have also contributed to the rise of the prevalence (Bowden et al., 2020). Autism did not feature as a formal diagnosis until the Diagnostic and Statistical Manual of Mental Disorders (DSM-III). The most recent edition of the DSM-5 published in 2013 dropped the terms autistic disorder, Asperger’s syndrome and pervasive developmental disorder and not otherwise specified diagnoses and replaced all of these with one new overarching criterion known as Autism Spectrum Disorder (Hyman et al., 2020). Other research has reported that the increase in prevalence of autism is related to diagnostic substitution, indicating that the same child who was identified as having a different developmental delay, for example intellectual disability in the past is now identified as having autism (Shattuck, 2006). In addition, environmental causes, and genetic/environmental interactions such as advanced maternal and paternal age have been suggested but with a lesser role to play (Amaral, 2017). Bishop-Fitzpatrick and Rubenstein (2019) have strongly argued that there is no evidence which exists that vaccination is a postnatal risk for autism.

In Aotearoa New Zealand, there is very limited data on the estimate of prevalence of autism and other additional data such as age of diagnosis (Bowden et al., 2020). Prevalence of autism in Aotearoa New Zealand is often based on other international data and generalised to the

Aotearoa New Zealand population, suggesting autism affects one percent of people living in Aotearoa New Zealand. (Bowden et al., 2020). One of the leading sources of autism prevalence data is reports from the United States by the Centers for Disease Control and Prevention. The latest report in 2020 estimates that in children eight years of age, one in 54 are diagnosed with autism. This is roughly ten percent higher than the previous prevalence estimates from the previous report published in 2018 (Shaw et al., 2020). Autism is reported to be slightly more common in Aotearoa New Zealand European ethnicity as opposed to Māori and Pasifika populations (Bowden et al., 2020).

Autism is now known as one of the most highly heritable disorders (Thapar & Rutter, 2020). A study focused on twins in Sweden has shown that autism is a highly heritable condition, and three quarters of its genetic variance was shared with attention deficit hyperactivity disorder (ADHD) and other genetic factors, which contributed to the overlap between autism and learning disorders, motor coordination problems and tic disorders (Lichtenstein et al., 2010). Recent literature has supported the link between autism and additional co-occurring developmental conditions, which also includes mental, and physical health conditions such as intellectual disability, epilepsy, anxiety, depression, diabetes, hypertension, obesity, and cardiovascular disease (Malik-Soni et al., 2021). Professionals supporting families will need to be mindful that a child diagnosed with autism may also have other disorders or impairments beyond the diagnosis of autism (Lichtenstein et al., 2010; Malik-Soni et al., 2021). Due to the neurologically complex condition which impairs social interaction and communication (Hickey & Wilson 2017), children and people diagnosed with autism can have difficulties adjusting to new situations, have restricted behaviours, sensory sensitivity, poor cognitive skills, and emotional and behavioural difficulties (Hickey & Wilson., 2017; Oprea & Stan, 2012; Salomone et al., 2017). Early intervention is critical for the development of certain important skills such as motor and language skills and without effective intervention during childhood, this can impact a child’s ability to benefit from educational services and attain developmental milestones when compared to typically developing children (Kiami & Goodgold, 2017).

2.3 The role of mothers as primary carers

The lifelong nature of autism creates a deep impact on parents raising an autistic child resulting in a wide range of challenges for parents, particularly for mothers. In recent research literature, even when the term parent is used, it tends to be equated with mothers (Ring et al., 2018; Stace, 2013) because mothers are often the primary caregivers of children diagnosed with autism (Foody et al., 2014; Khan et al., 2016; Olsson & Hwang, 2001; Wong et al., 2016). Harvey and Long (2020) stated that these mothers’ experiences should be distinct, and not be generalised with other disabled people due to their experiences of their “suffering and exclusions” (p. 462). This is to better understand the lives of disabled children and their parents who face stigma and isolation. A study by Burrell et al. (2017) also examined why mothers as caregivers are over-represented in academic studies and they suggest that this may be due to the desire of studies to only examine the experiences of primary carers. Tuhiwai-Smith (2012) and Lalvani (2011) argued that mothers of disabled children are often being considered as “m(others)” (p. 276) as they have been marginalised by the mainstream society “within a stigma-phobic, normative world view claiming others as external and inferior” (Carroll, 2016, p. 253). Despite fathers increasingly adopting this role, mothers continue to be more likely the primary carer. Furthermore, studies have suggested that the paternal experience of raising autistic children is largely overlooked by research due to work commitments, societal perception of the parental roles and lack of involvement or opportunities for fathers in the care of their children (Ellison et al., 2009; Ring et al., 2018).

Several studies have reported that the health of mothers is negatively affected by caring for a child with a disability when compared with fathers (DePape & Lindsay, 2014; Kvarme et al., 2016; Ring et al., 2018; Tossebro & Wendelborg, 2015). In the 1960s, autism was associated with a style of parenting, describing mothers who appeared to be unavailable and cold leading to the child becoming emotionally shut down. Mothers were referred to or described as ‘refrigerator mothers’, resulting in mothers feeling blamed for their child’s condition (O’Reilly et al., 2019). There has been a move from a psychoanalytic view of the ‘refrigerator mother’ to a science-based explanatory framework, resulting in a shift of mother-blame from parenting skills to blaming her genes as the cause of the autism. In the past, the behaviours and responsibilities of mothers have been identified as potential causes of autism. It is important to recognise that the concept of ‘mother-blame’ has received criticism in health discourse (Jackson & Mannix, 2004; Maher et al., 2020) as it claims that women are individually responsible for their children’s wellbeing regardless of how social and economic constraints shape both women’s mothering and children’s wellbeing. Wendt et al. (2015) have argued that the discourses of motherhood are gendered and perpetuated inequality and oppression intersecting between mothering practices, disability and welfare of a disabled child. Present day mother blame still exists despite a deeper neurodevelopmental positioning of autism (O’Reilly et al., 2019). Mothers consistently experience isolation, a lack of support and blame through the accounts of ‘good mothering’ (Goodwin & Huppatz, 2010). However, with the austerity and ongoing reduction of welfare and social support under the influences of neoliberalism, maternal responsibility has been increasingly individualised and reinforced (Reich, 2014). For those mothers who are marginalised, seeking welfare support in neoliberal states has become harder and harsher with more systematic institutional and social barriers encountered (Maher et al., 2020). These pressures are also leading to services and supports of children being increasingly impacted by neoliberal agendas of cost-cutting (Carey et al., 2018). Neoliberalism assumes the value of individual responsibility, self-sufficiency, efficiency, and profit (Charmaz, 2019). Stace (2013) stated that one of the ways mothers have fought back is to become an expert, advocate, and activist on child development; yet this role is often a lifetime occupation for mothers with low value and status. Courcy and des Rivieres (2017) have noted a change in expectation concerning mothers of autistic children in which mothers are now expected to be involved more than ever in their disabled children's lives. This has posed an irony that while mothers were previously held accountable for their autistic children's behaviours, they are now encouraged to act as their children's co-therapists (Levy et al., 2006). This shift has indicated that mother-blaming is being repackaged to the involvement and commitment of mothers who should actively engage and participate to help or even to cure their children (Courcy & des Rivieres, 2017). Mothers raising autistic children are constantly being forced to achieve the ideal of "good" mothering, which can increase pressure and blame to the extent it can affect their mental health, and lead to sleep problems and burnout (Serrata, 2012; Zablotsky et al., 2012).

There is considerable evidence to suggest that mothers caring for a child with a disability are at greater risk of experiencing negative psychological outcomes than mothers of non-disabled children (Oprea & Stan, 2012; Ozgur et al., 2018). It has been consistently demonstrated that mothers of autistic children experience higher levels of parenting-related stress and report lower levels of wellbeing (Ekas et al., 2008; Oprea & Stan, 2012; Ozgur et al., 2018). They are also more susceptible to other forms of stress and depression and are in greater need of social support than mothers of typically developing children (Benson, 2006; Kvarme et al., 2016; Wang et al., 2010). Not every parent raising an autistic child will experience negative outcomes; however, evidence has strongly suggested that there is significantly increased risk of poorer psychological outcomes (Bromley et al., 2004; Hayes & Watson, 2012; Wang et al., 2010). The complexity of issues which contributes to parenting stress requires a comprehensive approach to understand the possible characteristics and variables of issues (Miranda et al., 2019). There is a small but growing literature examining the experience of raising an autistic child in Aotearoa New Zealand. In 2004, Bevan-Brown’s qualitative research with 23 Māori caregivers described difficulties including service and funding shortages; geographical, cultural, procedural and financial barriers to services and loss of support and discrimination. Htut et al. (2019) have reported that the current disability support services provided by Ministry of Health is complex, fragmented and difficult to navigate not just for the mainstream parents with autistic children but also for autistic Asian children and their families. A recent study in Aotearoa New Zealand states the psychological wellbeing of a parent raising an autistic child is connected to the quality of care they can offer their child; therefore, a parent suffering from poor mental health may undo benefits of interventions or create an increase in problem behaviours (Shepherd et al., 2021).

Parents of autistic children experience fatigue beyond what is normal for parents with typically developing children (Gouin et al., 2013). Recent research has stated it is likely that a child’s behavioural difficulties contribute to maternal fatigue, which in turn influences the use of ineffective coping strategies and increases stress. This cyclic pattern of unpredictable demands and changes in the child’s behaviour has been found to create a heightened awareness and concern with the mother responding appropriately and restoring the balance, resulting in physical and mental fatigue that increases stress (Miranda et al., 2019; Seymour et al., 2012).

The additional demands to care for an autistic child not only increased the level of parenting stress but studies also indicated that parents of an autistic child have less sleep and experienced poorer quality of sleep when compared to parents of typically developing children (Marsack &

Samuel, 2017; Meltzer, 2011). Mothers of autistic children have been reported to experience habitual stress and fatigue consistent with that experienced by soldiers in combat due to the responsibilities associated with caring for their autistic child (Fletcher et al., 2012; Smith et al., 2019). Autistic children tend to have more ritualistic behaviours, which can interfere with participation in daily routines, resulting in families of autistic children experiencing more difficulty orchestrating smooth functional family routines (Schaaf et al., 2011). Mothers often play a major role in orchestrating the family routines (Bagatell, 2015; Larson & Miller-Bishoff, 2014) and this kind of family management can impact on the health and wellbeing of the family. For example, families of autistic children tend to experience increased stress levels during dinner and bedtimes (Marquenie et al., 2011; Schaaf et al., 2011). Other research has reported that the substantial efforts required to maintain family routines can be a potential risk to a mother's health and wellbeing (McAuliffe et al., 2018). Furthermore, research has demonstrated that simply being a parent or caregiver of a person who is marginalised (e.g., disabled children/people) may result in being stigmatised (Ostman & Kjellin, 2002). Stigma by association has been shown to add significant stress to parents caring for autistic children (Farrugia, 2009; Gray, 2002).

Previous studies have compared outcomes of parents raising a child with a range of disabilities and they have found that parents of autistic children are more at risk of experiencing difficulties compared to parents of typically developing children or children with other developmental disabilities (Bouma & Schweitzer, 1990; Hall & Graff, 2011). An autistic person requires a higher level of physiological, educational, and social care and support. Research has also established that there is likely to be a variance in maternal wellbeing due to how these physical and behavioural challenges of parenting an autistic child are faced by the mother (Bonis 2016; Carter, 2007; Lai et al., 2015). In autism literature, many studies have explored the challenges faced by parents of autistic children, the emotion that it brings, along with coping strategies parents have used. Some of the research has highlighted that those parents of autistic children use both adaptive and maladaptive coping styles. Adaptive support such as cognitive reframing and seeking social support has been linked to positive mental health outcomes (Benson & Karlof, 2008; Taylor & Stanton, 2007). However, a longitudinal study conducted over a sevenyear period examining maternal coping styles and adjustment among mothers of raising an autistic child found that increased use of maladaptive coping styles was related to increased stress and distress and decreased parental efficacy (Benson & Karlof, 2008; McAuliffe et al., 2017). On the whole, research to date has suggested that aside from dealing with the child’s challenging issues and behaviours, primary caregivers have been shown to experience stress, isolation, financial barriers, grief and loss, relationship dissatisfaction, affecting their overall wellbeing.

2.4 Barriers and unmet wellbeing needs among mothers of autistic children

Parenting autistic children is more stressful and challenging than parenting children with typical development, which can lead to higher risk of parenting stress and poor psychological wellbeing (Hickey et al., 2019). The mother of an autistic child often faces substantial challenges due to the child’s disability that can be manifested in many ways, causing tension for the mother as well as the family (Smith et al., 2007). These common stressors experienced by the mother and her family include financial strains, job loss, insufficient support services, demands for ongoing child advocacy and uncertainty about their child’s future (Kiami & Goodgold, 2017). After the child’s diagnosis, mothers may feel confused, sad, and even a deep sense of loss as they are forced to give up their dreams and expectations for the child’s future. Therefore, when it came to engaging with some personal time, they would feel guilty about it (Gahagan et al., 2007; McAuliffe et al., 2018). This shows the paradox of the role of mothers, where they need to provide support for their children and families over and beyond, but they also need to stay healthy in order to fulfil this role. Research has indicated the importance of promoting 'me-time' among mothers of autistic children to enable them in fulfilling their mothering role in striking a balance in their everyday life (Larson & Miller-Bishoff, 2014).

Various studies have identified challenges faced by mothers raising an autistic child are directly related to accessing disability support. These challenges include obtaining a diagnosis, finding appropriate treatment, costly medical treatments and therapies and managing problematic behaviours whilst learning how to navigate support service systems (Ekas et al., 2010; Minnes et al., 2014; Ratima & Ratima, 2007; Weiss et al., 2013). On average in the United Kingdom, it takes three and a half years for autism to be diagnosed (Crane et al., 2015) and at least half of the parents were dissatisfied with the process (Crane et al., 2015; Gobrial 2018). The negative impact of a drawn-out diagnostic process for mothers resulted in an increase in anxiety and depression levels (Gobrial, 2018). Research has shown mothers who perceive social support as more accessible have reported fewer stress-related problems and lower depressive symptoms (Dunn et al., 2001; French & Swain, 2012).

Some studies have suggested that couples raising an autistic child may experience lower levels of relationship satisfaction when compared to couples raising a typically developing child or a child with a disability other than autism (Gau et al., 2012; Sim et al., 2016; Stuart & McGrew, 2009). Mothers have reported feeling less satisfied in couple relationships with increased conflict and a greater risk of separation/divorce (Hickey et al., 2019). Literature has suggested that there are many factors which impact relationship satisfaction for couples raising an autistic child, one such factor is couples raising an autistic children who presents with challenging behaviour (Sim et al., 2016). Such findings seemed to suggest that the need to manage challenging behaviours may be a more salient predictor of relationship outcomes than autism severity (McAuliffe et al., 2018). The demands of caregiving associated with raising an autistic child have also been linked to generating stress in parents, resulting in lower relationship satisfaction in parents of an autistic child (Sim et al., 2016; Stuart & McGrew, 2009). Support within the marital relationship was found to be related to better personal marital life satisfaction amongst parents of autistic children (Schopler & Mesibov, 2013). While spousal support has been shown to be associated with better physical and mental health functioning in mothers of sick and disabled children (Rini et al., 2008), the extent of support that is expressed is very important in determining parental quality. Boyd (2002) argued that although mothers may turn to their spouse first for support, their spouse may not provide effective support as they themselves may be equally distressed and unable to provide constructive assistance (Boyd, 2002; Ekas et al., 2010). Some studies have suggested that fathers may be involved less with the care of disabled children than neurotypical children and this is particularly important for mothers of autistic children from social and culturally diverse backgrounds where heteronormative patriarchy still focuses on child rearing as the mother's domain (Jose et al., 2021).

Autistic children often encounter stigma due to their characteristics and behaviours by mainstream society. Stigma not only impacts autistic children, but also extends to parents, siblings, and extended families (Liao et al., 2019). A study examining the association between stigma and raising an autistic child reported that over 40 percent of parents stated that they have isolated themselves from family and friends within the last 6 months because of the autistic behaviours of their child (Kinnear et al., 2015). The study went on further to state that over 30 percent of parents felt that they were excluded from events and activities by others. Other studies also emphasised parents felt blamed or judged for their autistic child's behaviour, which further isolated and excluded them from family and friends (Ryan & Runswick-Cole, 2008; Woodgate et al., 2008). Due to social stigma, parents were reported to isolate themselves and their families from social contacts as they found social encounters burdensome because of their child’s disruptive, antisocial behaviours coupled with a need to provide a normal appearance (Kinnear et al., 2015). A substantial amount of research has shown that social contact is critical to the wellbeing of parents raising an autistic child (George et al., 2020; Marsack & Samuel, 2017; Savage & Bailey, 2004), highlighting that the loss of social connection or feeling socially excluded by family and friends will create ongoing detrimental wellbeing impacts.

2.5 Disability systems – The politics of individualisation of wellbeing

The World Health Organisation (2013) estimates that 15 percent of the world’s population live with a disability and that this number is likely to continue to grow into the future (WHO, 2013). Until the 1960s, the medical model was the dominant approach towards people with a disability. Deinstitutionalisation saw a move to people with disabilities living a more independent life; however, much of the literature has consistently criticised the top-down support structure delivered by organisations and professionals, which has left disabled people with little influence or power (Bennie & Georgeson, 2019; DeCarlo et al., 2019; Laragy, 2001). The 1970s saw the development of individualised planning which made the shift of care from ‘planning for’ to ‘planning with’ and is described as the beginning of global changes aiming to increase the involvement and self-determination of people with disabilities (Laragy, 2001).

Premodern societies were based on communal structures in which people within those communities formed relationships. Modern societies have moved to collective structures where individuals created relationships based on shared needs, interests and wants (Beck, 2002). Academics have argued there are two contrasting views of individualism. Literature has suggested that the first consequence of individualism can have a positive impact on society, creating a diversity of lifestyle choice and freedom (Ray, 2005). Individualisation has allowed people to be released from the confines of societal expectation that dictated the path that an individual life should take and how a family should be defined. Ray (2005) suggested that individualisation has been credited for enabling flexibility; however, this could come with the risk associated to that freedom of choice, which is the personal responsibility for that freedom. Ray (2005) went on to state that the previous obligations due to shared interests have now been replaced by accountability and responsibility. The second consequence of individualisation, described by Bauman (2003), was the changing nature of social responsibility and obligations that has led to a breakdown of families due to social isolation and separation in order to manage the risks created by modernisation and individualism.

Two paradigm shifts in public policy since the 1980s have driven the international trend towards individualised funding. The first was neoliberal public sector reforms creating privatisation and marketisation of social services. The second was a greater attention to human rights (Purcal et al., 2014), such as the disability policy of the United Nations Convention on the Rights of Persons with Disabilities, which recognised the importance for a disabled person to have individual autonomy and independence, including the freedom to make their own choices (UN, 2020). Choice is a central driver in both paradigms in which neoliberalism emphasises choice in a free market, and human rights advocates choice of the person with a disability (Purcal et al., 2014; Stevens et al., 2021).

The neoliberal influence has not only created sector reforms, but it has also redefined parenting in the 21st century. Neoliberalism has dichotomised good mothers as those who can cope and are raising an independent and economic producer (Tabatabai, 2019) versus bad mothers who struggle and are a burden to society (Charmaz, 2019). According to Runswick-Cole and Goldey (2017), parenting is an individualised task, which also defined "good parenting" or a "good mother" through the assumption that is socially constructed imposing upon women who choose to become mothers to behave a certain way and to align with social expectations (Goodwin & Huppatz, 2010). This societal expectation is described by Goodley (2016) as disabled people being devalued, discounted, and cast as disposable in an age of 'neoliberal-ableism'. According to Thomas (2020), Neoliberal-ableism is described as disabled people and their families having their rights eroded under neoliberal regimes leaving parents to deal with the 'system' which provides an ecosystem for the privatisation of ableism.

Individualised funding or personalisation policies vary widely internationally regarding their degree of choice, flexibility, access, and entitlements to funding. Basically, the mechanisms that underpin individualisation or personalisation are about greater choice and control for public service users through personal budgets or voucher systems (Meagher & Goodwin, 2015).
Canada, for example, introduced individual funding in the 1970s in response to pressure from the independent living movement. Similarly, the United Kingdom responded to those pressures leading to individual funding implementation in 1988. The United States of America introduced individual funding programmes from the 1970s to give people more choice (Purcal et al., 2014). In Sweden, the 1993 disability legislation supported people to choose supports and services from the open market (Laragy, 2001), whilst in Europe individual funding policies reflected a recognition of traditionally strong informal family and community supports.
The Australian National Disability Insurance Scheme (NDIS) is an example of individualised funding and supports approximately 460,000 individuals of which 56 percent are children since its inception. The National Disability Insurance Scheme Bill (NDIS Bill) was introduced in November 2012 and has been rolling out across Australia since July 2016 (NDIS, 2021). The

common principles of individualisation or personalisation are that participants are considered as consumer agents in care services and these individualised schemes are seen as a tool to provide choice and control to participants (Carey et al., 2019). Whether these schemes have improved disabled peoples' lives is still an ongoing debate but the NDIS system in the early stages had been criticised for being inflexible and unable to accommodate changes to plans for example using funds for different types of therapies (Carey et al., 2019). Late in 2019, the Australian government announced a series of changes to address these concerns and further changes as the COVID-19 pandemic began such as assessment processes by phone rather than in person, pushing priority access to shopping and access to funds to purchase technology to assist in telehealth appointments (Fleming et al., 2019). While the changes to the Aotearoa New Zealand system are not replicating the Australian system, it has led change to disability systems and is being closely watched to guide and support system changes in Aotearoa New Zealand.

2.6 Disability support for autism in Aotearoa New Zealand

Diagnosis and management of autism in Aotearoa New Zealand is guided by the New Zealand Autism Spectrum Disorder (ASD) Guideline. The guideline is used to guide the delivery of services and supports for autistic individuals and their families. Although not a policy document, the ASD guidelines written by the Ministry of Health (MOH) and Ministry of Education (MOE) used international best practice evidence to provide guidance and recommendations for decision-making on health and education issues (Ministries of Health and Education, 2008) despite no formal outcome measures currently available to evaluate this (Searing, 2014). The ASD guideline acknowledges stress experienced by families raising an autistic child and recommends that parents be provided with coordinated and well-organised support that meets each family's individual needs, including their cultural preferences. A recent study examining the adherence to these guidelines in Aotearoa New Zealand found that there were discrepancies between recommendations and practice, indicating that parents were dissatisfied with the assessment process and there was a large variance of services offered throughout the country (Taylor et al., 2021).

The supports which can be accessed by families of autistic children living in Aotearoa New Zealand are highly dependent on the socio-political factor (Searing, 2014). The Aotearoa New Zealand health system is governed by the MOH, and the Needs Assessment Service Coordination (NASC) is contracted by the MOH and has two roles. The Needs Assessment aspect is to assess the disability support needs of people with disabilities and allocate MOH funding to meet these needs. The service coordination aspect is to identify supports and services that could meet those needs (Ministry of Health, 2021). Fourteen percent of the Aotearoa New Zealand population lives in remote or rural areas (Stats NZ, 2014), and it has been reported that there are differences in service utilisation and health outcomes for people living in rural areas compared to those living in an urban area (Triggs et al., 2007). These differences in provision of health services for families raising an autistic child who are living rurally have been attributed to difficulty in recruiting and retaining skilled professionals, long travelling distances for services, longer wait times for service providers and a perceived lower quality of service due to a lack of staff (Searing, 2014).

The need for change to the current disability system has been demonstrated through multiple strategies and reports, such as the 2001 Disability Strategy (Office for Disability issues, 2001), the 2008 report on the Inquiry into the Quality for Care and Service Provision for People with Disabilities (Social Service Select Committee, 2008) and the obligation to adhere to the signed United Nations Convention of the Rights of Persons with Disabilities (Social Services Select Committee, 2008). These strategies and reports have created a strong pathway and background to the current initiative of transforming the Aotearoa New Zealand disability funded system. The service provision for diagnosis and post-diagnostic support for autistic children and their families has been criticised as complex and often in high demand and with a long waitlist (Htut et al., 2020). To address those challenges, the initiative called “Enabling Good Lives” (EGL) was a cross-government approach to bring funding from the MOE and MOH and the initiative is based on eight principles proposed in the Enabling Good Lives report. The eight principles are described are: self-determination, beginning early, person-centred, ordinary life outcomes, mainstream first, mana enhancing, easy to use and relationship building (Enabling Good Lives, 2021).

The first steps in developing a more individualised, facilitation-based support plan for disabled people living in Canterbury was the Canterbury Plan which was released in June 2012. The Canterbury Plan recommended a full system change, and this aligned with the original Enabling Good Lives report, and it was described as a truly bottom-up approach (Enabling Good Lives, 2021). In July 2013, the Hon Tariana Turia, Minister for Disability Issues and Associate Minister of Health, announced that cabinet had approved a three-year demonstration of the EGL approach in Christchurch. The reason Christchurch was selected was due to the 2011 Governments Disability Action Plan which had stated a priority to include disabled people during the Canterbury earthquake recovery (Office for Disability Issues, 2016). Parallel to this process, several providers in the Waikato area contacted the facilitators of the Canterbury demonstration to see if the EGL approach could be applied in the Waikato. In 2013, a small budget was allocated to the newly established Waikato leadership group to build capacity and strengthen local networks. In 2014, a larger investment of $3.82 million was announced to be used over three years to roll out the EGL approach in Waikato. In October of 2018, Mana Whaikaha was launched. It was described as a prototype for the disability funding system and described as taking a try, learn and adjust approach for implementation (Office for Disability Issues, 2017). Mana Whaikaha is the only disability system where geographically everyone in one area is included in a changed system, the Waikato and Christchurch changes are limited by eligibility.

The criteria to be eligible to receive disability funding is that the disability is physical, intellectual, sensory or autism, that it is likely to last six months, and the disability limits your ability to function independently, and ongoing support is required (Lifelinks, 2019; Mana Whaikaha, 2021). A diagnosis of autism made people eligible for disability supports only within the last eight years, coming into effect in April 2014 (Ministry of Health, 2018). Prior to this date families supporting children with a primary diagnosis of autism were typically denied funded support. The Ministry of Health's (2017) current figures show approximately 34,000 people are receiving funded disability support, which is less than one percent of the total Aotearoa New Zealand population. Of this 34,000, it is estimated that about 10 percent of people eligible for disability support are currently being supported by an Enabling Good Lives approach model (Office for Disability Issues, 2017), which inadvertently has created a "have and have not system" of further inequality. This means that families who are not eligible for one of the pilots or demonstrations watch and hear how well it is working for the fortunate families who are included. Several Aotearoa New Zealand studies have sought to identify correlations between parental wellbeing and raising an autistic child through studies focused on parental coping styles and parental stress, including individual characteristics of the child and parent, such as age (Goedeke et al., 2019; Landon et al., 2017; Shepherd et al., 2020). These Aotearoa New Zealand-based research findings aligned with international research that raising an autistic child is challenging and caregiving tasks are demanding, often resulting in a degree of dissatisfaction with their lives (Landon et al., 2017; Sim et al., 2016), and a decline of personal health and wellbeing, (Malbon et al., 2019; Shepherd et al., 2018). The connection between individualised funding of a disabled individual and the impact of the child's disability on caregivers' wellbeing is not currently well understood within the Aotearoa New Zealand context. While the new and more self-directed model of care such as EGL may bring more collective support to the disability sector and community, the complexity of autism support and needs is likely to remain problematic, especially for those who are already struggling or marginalised by the current system (Htut et al., 2020).

2.7 The role of practitioners to support mothers and their autistic children

Mothers of autistic children in Courcy and des Rivieres's (2017) study revealed that they were reluctant to share their child's diagnosis for fear of discrimination and talk to their relatives and friends about their children due to the stigma attached to 'mother-blaming' or not meeting the ideal of 'good mothering'. Many parents raising autistic children have also reported that they did not tend to perceive friendships as a significant source of support (Brock, 2015; Knight, 2013) although research has acknowledged that support from professionals may help to reduce care-related stress (Goedeke et al., 2019). Bennie and Georgeson (2019) argued that currently those in social work roles are mainly practitioners who do not have lived experience or have a limited knowledge of disability, which means that the future direction of social work in the field of disability will require these social workers to negotiate their way through a system somewhat unprepared that increasingly features services by and for disabled people. The paradigm shift in practice of disabled people having more power and control over their lives has been seen in the wider Aotearoa New Zealand context over the past two decades with Kaupapa Māori services, by Māori for Māori (Tupou et al., 2021) and Whānau Ora which is based on the understanding that whānau (family) should be resourced in order to make critical decisions about supports and services (Bennie, & Georgeson, 2019). In their study, Hogan et al. (2019)

conducted focus groups with disabled people, and they emphasised that ‘nothing about us without us’ could not engage with transformative changes in the disability field. Social work training programmes need to prepare practitioners for disability practice and to ensure that courses and qualifications are accessible to disabled people and family members to establish qualified social work practitioners with lived experience (Bennie & Georgeson, 2019). Academic literature highlights the importance of raising awareness about disability issues and awareness through inclusion in professional education, (Hogan et al., 2019; Sarmiento et al., 2016) and through education of support people such as relatives and friends to avoid further judgment on mothers (Kattari et al., 2018).

Disability studies continue to evaluate what is working and what is still considered an unmet need. Households with a disabled child are more likely to be in income poverty than families with non-disabled children (Murray, 2018). According to Oldman and Beresford (2000), 29 percent of disabled children live in poverty and three quarters of families reported their housing was inadequate (Hartley and Schultz, 2014; Jarvis, 2008). The need most commonly reported to be both important and unmet need across studies was financial support. Financial support was described as important as it reduced fears about the child’s future, enabled access to therapies that could improve their futures and provided continuity of care as well as information about special programmes (Bishop-Fitzpatrick & Rubenstein, 2019). Other studies have shown that lower family income and reduced access to financial support were predicative of lower health wellbeing measures of parents of autistic children (Bones et al., 2019; Hu, 2011).

The “terrible toll” on marriages has been conveyed in popular media sources and academic literature, with as high as an 85 percent divorce rate among parents of autistic children (Lashewicz et al., 2018; Walmark, 2020) and most of time it was the mothers who became the primary caregivers and experts of autism. In Aotearoa New Zealand, disabled children are more likely to live in a one-parent household than non-disabled children, and these one-parent households have higher rates of unemployment than other one-parent households (Murray, 2018). It is critical to gain a deeper understanding of how financial funding impacts both the social and family function of caring for an autistic child. Creating a greater understanding of optimal funding support could lead to better development of funding options when considering the support needs of the child, creating strategies for families to promote more positive outcomes for both the mother and child (Bishop-Fitzpatrick & Rubenstein, 2019). This could be achieved through specialist roles such as disability advisors which are established in some Aotearoa New Zealand government organisations including Oranga Tamariki and Ministry of Social development or seeking advice through established organisations with a disability focus.

Another reported unmet need is access to trusted information in a format that is easy to understand. Laragy (2001) stated that parents raising an autistic child will need different types of information, requiring strategies to disseminate that information at different points within the funding process. Laragy also stated that families will always have different requirements in terms of the information content and finally that this diversity of needs will present challenges for that information provision. Further research has reported that information needs to come from a trusted source (Lord & Hutchinson, 2003). Trust is associated with a strong relationship to the providers of the information, and perception of competence, expertise, and experience. Paid workers, other families using services, family and friends are often described as sources of highly trusted information (Laragy & Ottmann, 2011). Laragy et al. (2015) stated that people only take up information when the persons providing the information are professional, an advocate or peers, and that this information often needed to be translated into an easier to understand format by one of these trusted relationships. The enabling good lives principle of relationships, which is based on building and strengthening relationships between disabled people, their whānau and community, is likely to be key in changing this narrative of mistrust and lack of information. through building connections and channels of communication (Care Matters, 2021).

There is clear evidence that early identification and treatment are the two most important factors for improving lifetime learning of independence skills and language (Kelley et al., 2010). Early behavioural intervention implemented during key developmental stages means an autistic child is more likely to learn essential social skills and improve outcomes significantly (Hu, 2011; Juergensen et al., 2018) as well as improving wellbeing (Minnes et al., 2014; Ratima & Ratima, 2007). International research has demonstrated that early identification is also cost beneficial, with several studies claiming that early intervention is cost-effective with savings to both direct costs, such as health care use, and indirect costs, such as parental time spent on care. Doyle et al. (2009) stated that every dollar spent on early intervention would save US$8 on education and other social costs (Executive Office of the United States Government, 2014). Finance and funding are issues that affect disabled children and their families in terms of services available to them and services they can afford to use. Dowling and Dolan (2001) stated that on average caring for a disabled child costs three times more than a non-disabled child. In the United States, it is estimated that the lifetime societal cost of autism per person is between US$1.4 and US$3.6 million, depending on the person's level of disability, while in the UK this lifetime cost is approximately £2.2 million (Buescher et al., 2014; Klin et al., 2015). Autism Action New Zealand (2014) announced that investment in early intervention could provide significant cost savings in Aotearoa New Zealand. Cost-effectiveness of early intervention is also described by Snow and Donnelly (2017) and to ensure best practices of early intervention in Australia, an increase of between 14 and 34 hours of support is required by families in addition to what they are on average receiving. This additional funding could be used to resource supports that have been identified in research to improve wellbeing and social skills to promote independence (Hu, 2011; Juergensen et al., 2018; Minnes et al., 2014; Ratima & Ratima, 2007).

Literature has highlighted the need for culturally appropriate services which meet the needs of ethnic minorities and indigenous communities when supporting families accessing individualised funding (Laragy & Fisher, 2020). Studies have demonstrated a need for professionals delivering information to be sensitive to the cultural and social preferences (Tupou et al., 2021) and aware of how cultures conceptualise disability and disability services (Baxter et al., 2000; Htut et al., 2020; Laragy et al., 2015). This may be especially true for indigenous populations who have a well-documented history of health disparities across a broad range of outcomes, including access to healthcare (Rolleston et al., 2020). A recent scoping review has found that there may be broad differences between Māori and Western understandings of autism which can impact the way in which autism is defined and assessed for needs and services for autistic Māori and their family (Tupou et al., 2021). The review has highlighted the importance of ensuring autism diagnostic and support services are both effective and culturally appropriate for Māori, including a preference of Māori models of health which tend to be holistic including a focus on spiritual and emotional development and often contrast with Western models and views of health. The concept of holistic health and wellbeing are not new and have been explored in a range of research where it was agreed that health cannot be separated out from other dimensions of people and their world (Anae et al., 2002; Predescu et al., 2018). However, professionals are not always responsive to the need for information when there are cultural differences and this was more evident when professionals were inexperienced and had not received adequate training (Laragy et al., 2015). This, coupled with the fact that the largest unmet need is accessing information for parents raising an autistic child (Tracey et al., 2017), has created more barriers for families as they navigate systems whilst maintaining a healthy level of wellbeing. Culturally inappropriate services would further reinforce disadvantage and inequity for these groups. It is also suggested that autistic individuals from minority groups are less likely to access evidence-based treatments (Tupou et al., 2021) and more research has started to examine the lack of diversity of research on treatments related to autism, and the potential barriers to access to evidence-based practices (Smith et al., 2020).

Disabled people in Aotearoa New Zealand and internationally have often reported experiencing worse health outcomes, poorer quality health care, discrimination, and more difficulties accessing social and health care services (Officer et al., 2022; Perry et al., 2021). COVID-19 has exacerbated pre-existing difficulties and inequity disabled children, adults and their families face due to the loss of services and supports, lack of access to education and therapeutic services, loss of caregiver support, and disruption of daily routines (Perry et al., 2021). These adverse effects are likely to affect the wellbeing of autistic children and their families, and heightened fears about increased infection rates. Autistic children may have difficulty adhering to basic preventive measures such as mask wearing, hand hygiene and social distancing (Parenteau et al., 2020; Spain et al., 2021). This context places parents for experiencing greater psychological distress. In their early study of the pandemic effects in the United States, Manning et al. (2020) reported that COVID-19 has increased substantial psychological distress (48%) among parents raising an autistic child when compared to the rest of the population (25%). Higher stress was reported for individuals who have typically received services such as respite and school which needed to be placed on hold during lockdowns due to COVID-19. This is understandable since these interventions have been previously shown to reduce caregiver stress and increase a caregiver’s ability to cope (Lounds et al., 2007). In Australia, families with disabled children and other disabled family members experienced significant disruption to their lives during the early stages of the pandemic, resulting in suspending and changing services and this had contributed detrimental impacts on their wellbeing (Yates et al., 2020). A recent review on the impact of COVID-19 on the mental health and wellbeing of caregivers of autistic children and youth indicated that while families are exercising their resilience and resources to cope with the sudden and ongoing changes, there is also a reduction in existing services, which impacts on their ability to balance the new challenges (Lee at al., 2021). This evidence has suggested that clinicians, researchers, and policymakers need to consider the mental health of parents raising autistic children to allow flexibility of funding to meet the unique circumstances of every family as the pandemic unfolds.

2.9 Summary

In summary, the complexity of raising an autistic child within a complex funding system is creating additional stresses and negative impacts on the wellbeing of mothers. This chapter has drawn on extensive research, illustrating the wide-ranging impacts of wellbeing on mothers. Evidence has also shown that reduced parent and family wellbeing creates a bidirectional, negative cycle which can exacerbate the child's behaviour which is problematic and challenging. However, the link between funding support and the impact that this has on mothers remains unclear, particularly in the Aotearoa New Zealand context. A better understanding of the impact of raising an autistic child on the mother and how systems of support can improve her quality of life will have long-lasting positive impacts on both the child, her family and within her community. The next chapter will discuss methodology and methods adopted in this study.

Chapter Three – Methods

3.1 Introduction

The aim of this study was to explore how individualised funding has impacted on the wellbeing of mothers caring for autistic children. A qualitative approach was employed to guide this research on how to explore the mothers' own experiences. This chapter begins with an overview of the study design, followed by a description of the process of participant recruitment, data collection, data analysis, and ethical considerations. Finally, the chapter will conclude with a discussion of the process used to enhance trustworthiness and data integrity of the research.

3.2 Study design

The current research employed a descriptive and an interpretive qualitative approach, combining semi-structured interviews and the theoretical underpinning of social constructionism to examine the aims of the research. The constructivist perspective is useful in qualitative research as it assumes that all knowledge is context specific and influenced by the perspective of the perceiver (Ritchie et al., 2013); in the context of this research the perceiver was the mother and her experiences. This research adopted a qualitative approach using a descriptive and interpretive lens derived from a constructivist perspective. A qualitative approach was essential to gain the narratives of the lived experiences of mothers raising autistic children in Aotearoa New Zealand as it was the basis of the data. The goal of using a qualitative approach is to be broad enough to represent a population, large enough to conduct the analysis and small enough to be manageable (O'Leary, 2017). By using an interpretive approach to address the research aim, this has allowed the researcher to understand and describe the experiences of mothers while also acknowledging the differences of each family situation. Interpretive description is described by Thorne (2016) as a strategy to examine and disseminate knowledge that sits somewhere between fact and conjecture. It is more useful to understand interpretive approach as socially constructed through the perspective of the person who experiences it. The principles of considering the perspective of others while accounting for the social forces that have shaped that perspective aligned with this research. In this research, having an idea or generalising the mothers' experiences of caring for their autistic children was not enough to understand the many facets of their lives. My interactions with these mothers and sharing and reliving significant moments of their personal stories, alongside with my insider view, provided a broader and more in-depth insight on their perspectives and subjective experiences of being a mother raising an autistic child. These were the important components of a descriptive and interpretive inquiry adopted by the current research.

3.3 Study participants

The recruitment process was commenced upon receiving ethics approval from the Massey University Human Ethics Committee (Appendix A). To be eligible to participate in this research, the three selection criteria were: (1) a mother of a child (aged 21 years or under) diagnosed with autism and receiving individualised funding; (2) currently residing in the greater Christchurch area; and (3) able to participate in an interview conducted in English. The reason this study specified the age limits of a child being under 21 was because for some disabled children, it was possible to remain at school until this age while remaining in the care of parents at home.

A recruitment flyer was developed (Appendix B) for circulation. Through informal conversations with friends and work colleagues and with my consent, my email address was shared with mothers who met the research criteria. The six mothers who contacted me via email were then sent an information sheet (Appendix C) and all six mothers went on to accept the invitation to participate in the research. During the fifth interview, a technical glitch was found in the digital recorder, and this meant the first 20 minutes of the 60 minutes of the interview were gone. While every effort was made to document the missing 20 minutes as soon as the interview finished, it was deemed important to try to recruit one more participant to ensure information-rich data would be collected to enhance the research's credibility.

Previously, one of the research participants mentioned she knew of someone who would also like to participate in the research. Contact was made with this participant to ask her to circulate the information sheet to this potential mother participant. Within 24 hours this person made contact and agreed to participate in the research. A face-to-face interview date and time was organised as quickly as possible with the Aotearoa New Zealand government in discussion to resume another lockdown phase due to the second wave of COVID-19. The face-to-face interview was able to be completed with the seventh participant before the rest of the country went back to Level 2. All mothers were given a gift voucher, approved by the School of Social Work's Graduate Research Fund, as a token of appreciation of their time and effort to share their stories.

3.4 Data collection

Upon receiving an email from each participant confirming that they had read the information sheet and agreed to participate in the research, a mutually agreed time and venue was arranged. One participant chose to come to my home office (which had a separate entrance from my house); five participants choose to hold the interview in their home and one interview was conducted in a bookable meeting space in Christchurch. Before the commencement of each of the interviews, participants were reminded about the purpose of the research, their rights, and responsibilities before signing the consent forms (Appendix D). Each of the interviews lasted between 50 and 110 minutes. The primary method of data collection was the use of semi-structured interviews (Appendix F), which was described by Carey (2017) as the best format for social work research as they provide freedom to ask additional questions if necessary. The interviews were conducted face-to-face using open-ended questions and carried out in a conversational style to engage deeply with the participants. The use of a semi-structured interview also allowed the participants to provide answers that did not conform to the researcher's expectations, even if these expectations were not known (Ackerly & True, 2010), nor did the questions anticipate the participants' answers (Hardwick & Worsley, 2010). Tolich and Davidson (2019) stated that by getting people to talk on a topic and keeping it broad enough so that their own story can fit within it, the participants will not only answer the questions but also supply additional valuable information. Research has also identified non-verbal communication, empathic listening, and the use of open questions are key skills for working with and understanding the parental view (Forrester et al., 2012), which aligned not only with my own professional lens as a qualified and registered social worker but also as a mother of autistic children. This insight is described by Hardwick and Worsley (2010) as a strength to be able to use inductive knowledge that is specific to the situation and context. The insider researcher's lens has enabled me to develop an established understanding of the culture and being able to know how to best approach people, which could take a long time for an outsider to acquire (Unluer, 2015). This trusted position also helped promote the ability to both judge and express the truth more readily (Taylor, 2011). Statements made by several participants compared their experiences with others. For example, one participant stated, "people with neurotypical children don't understand".

Once the interview was completed, they were transcribed verbatim by the researcher herself. A copy of the interview transcripts was emailed to the participants for review, provide a response and complete the transcription release authority form (Appendix E) within a set period of time.

All participants read, agreed, and signed the transcript release document without amendments to the transcript.

3.5 Data analysis

Using an interpretive descriptive approach, a thematic analysis of the interviews was carried out. Thematic analysis is used in qualitative research to identify, analyse and interpret patterns within the qualitative data (Ritchie et al., 2013; Seale, 2017). Interpretive description considers the social, political, and ideological complexities, thus challenging the researcher to look below the obvious within the issue, to document patterns and themes among the more self-evident issues (Seale, 2017). Thematic analysis was considered a good fit as it has a focus on the lived experience of the research participants, such as the mothers' experiences in the current research (Seale, 2017). This approach was used for its strengths in helping to identify, analyse, and report patterns or themes in the collected data (Cartwright, 2020). The original development of thematic analysis is described by Seale (2017) as a way for qualitative researchers to legitimise and validate the methods of research. The legitimising of the research, which linked to the theory of trustworthiness of the research and in particular the concept of dependability and confirmability will be discussed further in this chapter. Preparing for thematic coding, Seale (2017) believed it is important to consider theoretical sensitivity.

Theoretical sensitivity refers to researchers making links with existing theory which may further develop the emerging theories (Ritchie et al., 2013). Seale (2017) and Thistoll et al. (2015) agreed that while it is important to read for ideas to acquire theoretical sensitivity, there is debate as to how much literature needs to be analysed. It is also agreed that a researcher needs to develop and acquire their theoretical sensitivity to a point where they are capable of assigning and interpreting meaning to data. The researcher must also guard against trying to develop hypotheses prematurely that the data collection then seeks to verify, set aside preconceptions, and look at the data anew (Urquhar & Fernandez, 2016).

Analysis of the data began during the data collection process as themes became more evident during the interview process and on reflection of each interview. These early learnings also helped to guide the subsequent interviews. During the process of transcription and rereading the transcriptions, I was able to reflect more and make note of some emerging patterns and themes and began to highlight some of the statements that captured these themes in the mother's own words. The research aim was examined against these emerging themes and patterns. New literature reviews were also undertaken at this time to examine the research aim against the emerging themes and patterns to audit the analysis.

3.6 Trustworthiness

Trustworthiness is described by many scholars (Grinnell & Unrau, 2010; Hardwick & Worsley, 2010; Seale, 2017; Thorne 2016), based on the original work of Lincoln and Cuba in 1985, as having four interrelated concepts that needed to work together to achieve trustworthiness. The first concept of trustworthiness is credibility in which the findings of a study represent the genuine feelings of the research participants (Grinnell & Unrau, 2010). Credibility was considered by reducing and reflecting on my bias as the researcher, triangulation of data sources and theories. The second concept is transferability, and this was linked to how the research finding was useful to social work theory, policy, and professional development (Grinnell & Unrau, 2010). The final two concepts are dependability and confirmability. Dependability is described by Seale (2017) as something that can be achieved through investigating the competency of an audit trail and this was achieved through the documentation during the project as well as the end product. Auditing is also useful in establishing confirmability to demonstrate that the research findings were not imagined or made up, but firmly linked to the data (Padgett, 2017). Competency and confirmability were demonstrated in this research through good record keeping of the fieldwork notes and transcripts, allowing the researcher to describe the participants mothers' stories which guided the research.

An interview schedule (Appendix F) was developed based on existing literature review and research evidence, combining my knowledge as a social worker practising in the field of disability and as a mother raising autistic children. An example of using social work theory and experience to build trust was using semi-structured interview questions, such as initially using short, less targeted questions and by discussing a shared interest which has shown to help build trust (Ackerly & True, 2010; Grinnell & Unrau, 2010). The advantage of building this trust and rapport quickly allows for more challenging questions to be asked later in the interview (Grinnell & Unrau, 2010).

Regular supervision with my research supervisors provided opportunities to have ongoing reflexivity within the discussions about initial perceptions and then on the more concrete emerging themes. Undertaking ethical considerations and applying for ethics by drawing on the Massey University (2017) Code of Ethical Conduct for Research, Teaching and Evaluations Involving Human Participants Revised Code 2017, alongside consulting with the Aotearoa New Zealand Association of Social Workers Code of Ethics (ANZASW, 2013) was essential in the research process to ensure ethically sound judgements in my research practice.

3.7 Ethical considerations

Ethics approval was obtained from the Massey University Human Ethics Committee (Appendix A). Ethical principles concerned in this research, such as respect for persons, minimise harm to participants, researchers, institutions, and groups, were guided by the Massey University (2017)

Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants. The code of ethics also informed the process for voluntary and informed consent, respect for privacy and confidentiality, cultural and social sensitivity to gender, religion, age, and social class. As a professional and a student researcher, I was aware of the potential vulnerability of this group of participants. For some of the participants, there may have been a power imbalance due to the education and research positioning that I potentially had, unintentionally making people feel I was the expert, when in fact the mothers are the experts of their own lives. Due to this position of power and the sensitive nature of the research, consideration was given to the emotional wellbeing of the research participants. Several participants did become emotional during the interviews; on every occasion I offered to stop the interview to give the participants a break. One participant stated that although reflecting on the past was sad, it was nice to talk about it with someone that understood and also to remind herself how far they had come. The following day after each of the interviews, participants were contacted by email to check in on them and thank them again for their time and sharing.

As part of the research process, all participants were offered to have their audio file returned to them. Although no one requested a copy of the audio recording, a copy of the transcribed interviews was sent to each participant. During the transcription process, I was the only person who listened to the recording, and they have been stored securely on a password-protected file folder on my personal computer. A brief summary of the outcomes of the research will be sent to all seven participants at the completion of my thesis.

3.8 Summary

This chapter has examined the methodology and methods for the research, with the aim of exploring how individualised funding impacts on the wellbeing of mothers caring for an autistic child in Aotearoa New Zealand. A qualitative interpretive approach, combining semi-structured interviews and the theoretical underpinning of social constructionism were used to examine the purpose of the study. By using an interpretive approach, it allowed the researcher to understand and describe the experiences of mothers, whilst also acknowledging the differences of each family situation. Identifying patterns and themes was conducted through the use of thematic analysis of the interviews. Finally, this chapter discussed the trustworthiness and ethical issues relating to the research. The following chapter presents the results from the seven mothers with autistic children who participated in the research.

Chapter Four – Findings

4.1 Introduction

This research set out to explore and explain the impact of individualised funding on the wellbeing of mothers raising autistic children through the voices and stories of seven mothers who were successfully recruited and completed the interviews. This chapter will first commence with background information of these participants. To protect the privacy of each mother, a pseudonym has been given to each participant and not every quote was attached to the participant's name to avoid identities being revealed unintentionally. Two major themes have been identified as: (1) the overall impact of caring for an autistic child, and (2) the disability system does not support mothers' wellbeing adequately. Each of the themes will be discussed in detail with support from several subthemes, using direct quotes from the study participants to help with interpreting the phenomenon. Autism impacts families in multifaceted ways which weaves through all parts of daily life. The author has tried to maintain an order for the reader; however, some subthemes do imitate real life resulting in themes needing to weave in and out across the subthemes.

> *It has embraced our entire lives. Like I never would have thought possible. It impacts your marriage, your children, your work life, your social life, your everything.*

4.2 Brief profile of the participants

At the time of the study, the seven mothers were reported to be aged between 30 and 50 years of age. Most of the mothers have been raising one autistic child, with one mother raising three autistic children. The autistic children ages ranged from nine to 20, with their siblings ranging from primary school aged living at home, to school leavers no longer living at home. Of the seven participants, four reported to have separated from the fathers of the children. Three of these separated families had limited or no contact arrangements with the children's father with the remaining mother having an equal care arrangement in place between herself and the child's father. Table 1 provides a brief description of the profiles of the mothers.

Table 1. Brief descriptions of the seven mothers who participated in the study

Name	Relationship to children's father	No. of children	No. of autistic children	Children's education level	Other impairments	Employment status
Nadia	Separated	3	3	primary, intermediate and high school	ADHD	not employed
Maggie	Separated	2	1	intermediate and high school	ADHD and Dyspraxia	employed part-time
Heather	Separated	2	1	high School and school leaver	--	self-employed
Julie	Married	3	1	primary	ADHD	employed part-time
Alice	Married	3	1	high School and university	--	Full time
Anne	Married	2	1	high School and university	Rare disorders	full time
Kim	Separated	2	1	primary school	--	not employed

Theme one: The overall impact of caring for an autistic child

The emotional and physical strains of raising and caring for an autistic child were acknowledged by all participants. This first theme looks at how the overall wellbeing of mothers was impacted by raising an autistic child, through the subthemes of relationships, societal stigma and the perception of challenges faced by mothers.

The importance of emotional support to wellbeing

Kim was a single mother of two children and both her parents have passed away. Her only sister and family living in Christchurch were unwilling to provide support to Kim or her children. The reality for Kim was that she had no biological family either through circumstance or choice to help her emotionally and practically. This has proven to be significantly difficult for Kim because her sister's choice to not be part of her life mirrored the emotional pain of being a single parent. Kim was happily married for over two decades, but her marriage ended abruptly very soon after the diagnosis of their child's autism. As such, Kim has associated the loss of both significant relationships to having an autistic child. Kim revealed that this has become difficult not only for the day-to-day coping, but also as emotional fatigue takes a toll on her own wellbeing.

> *We were together for 27 years … we were happy … I always saw it as being a life partnership and I'm pretty sure he did as well. And I think it was just the stress got worse and worse and of course neither of us knew what to do to alleviate it, because it doesn't alleviate and… it is always stressful even when things are going well because you never know when things are going to blow up.*

Kim described what would help improve her wellbeing was "to just be" and not feel guilty about it. The feeling of being the only person raising the children, with no emotional relief in sight was exhausting. This sense of needing time "*to just be*" was also described by some of the other mothers.

> *The definition of wellbeing for me is about having time each week to be able to not worry about the kids. Just having ... time and space to actually be me. I guess feeling rested and feeling healthy and happy.*

> *Everybody feeling sort of safe would be the primary thing, you know just sort of emotionally safe as well as physically safe. It's actually the mental space and emotional space to actually even think.*

Many of the mothers mentioned that wellbeing was also about having adequate support. Adequate support was described as including support from their wider local communities. Nadia stated she would love to go back to work but was not able to due to the demands of raising three autistic children. She described what she considered to be important for her wellbeing was *more funding, more support whether that is community, family, friends or school*. Nadia expanded on this statement stating how financial and community support would help her to reach her goal of being able to return to work because with little support from her family or wider community it was an impossible task.

> *I could have a job, I had to give up my studies. I managed my first year of study, it was very stressful. It was just something that I had to choose between, the few marbles of sanity I had left, or pushing on with a degree that at the end of it I would be burnt out anyway.*

Further questioning during the interview was to better understand what was currently in place to take care of a mother's wellbeing and if that current support was adequate to meet their wellbeing needs. Most of the participants stated that they had a good relationship with their family doctor and that their family doctor understood the situation and the demands that placed on the mother raising an autistic child. Some of the participants also shared they have been on antidepressant medication due to the stress of caring for an autistic child. Nadia disclosed that her family doctor suggested she added more exercise into her routine to look after her mental wellbeing. Nadia stated she laughed at the doctor’s suggestion as *she barely had time to take the antidepressant medication let alone go for a walk*. Other mothers expressed similar statements as while family doctors understood the situation, they did not truly understand the full picture of the emotional toll on their wellbeing. Many mothers felt very little could be offered to them from the family doctor to help improve their personal wellbeing.

> *Unless you actually have a child with special needs, you can't understand somebody coming to you and saying that they're struggling. I have a child with special needs and I'm struggling.*

Dealing with grief and loss in relationships

The complexity of relationships for mothers raising an autistic child often result in missed opportunities to develop positive relationships, including friendships. Participants reported a significant decrease in the quantity and quality of their social ties and relationships. The loss of quality relationships is also linked strongly to the previous subtheme, the demand of raising an autistic child often puts strain on a range of relationships resulting in connections prematurely ending. Most of the women interviewed felt they missed out on typical relationships such as close female friendships, due to the repercussions of raising an autistic child. Many of the mothers said they often had to deal with a fear of stigmatisation by others in which they could no longer relate to their old friends. They also found it hard to build or maintain quality friendships with mothers raising typically developing children mostly because they felt judged and misunderstood. Nearly all the women reported they did enjoy the company of other mothers who were also raising disabled children, because these mothers mutually understood and appreciated the demands placed on them.

> *We can all go yup, I can see how that could happen, and another person might say I've got this big bruise because he threw this book at my face. And you know, I mean these are things that don't happen in normal families.*

Alice reported that one of the major factors in friendships was being able to take her child to the persons home and feel accepted. Alice stated *she avoided taking [child's name] to people's homes in the end because it became too much for her*. One of the downfalls of only having a network of friendships with those who are also raising a disabled child was that when you meet up, you would mostly talk about the child. This resulted in the mothers feeling you do not get that quality time away from the challenges faced day to day.

The importance of trying to provide support and care for the autistic child and the family has meant losing opportunities to have a much-needed break. This was further complicated by the compounded feelings of grief and loss having been denied the opportunity to have a more typical friendship with others that was restful and fulfilling.

> *This has actually been a huge factor for me … where can I go with him? Where we can be accepted because a lot of the time has behaviour is so unacceptable.*

> *I think deep down, I think I feel slightly resentful towards people who don't have a child like this, you know the ones that say, Owe are going away skiing next week. I do feel resentful if I am honest.*

> *You have to have certain types of friends. I feel like you know, there's the ones that don't understand at all, so I can't have them. There are the friends that try to understand and they mean well and then there is the ones that just get you.*

Raising an autistic child has also caused a change in family life as the whole familial ecology had to adapt to a new reality. Marriages of parents raising children with disabilities have often been portrayed as dysfunctional, challenging and particularly likely to end in divorce or separation. Over half of the mothers interviewed had separated from the father of the child. All mothers who separated from the child's father indicated this was due to the challenges and difficulties of raising an autistic child. This was a negative change that affected their relationship and communication, which has made them experience a sense of loss. The mothers who were still in a relationship nearly all reported that their marriages were strained due to the challenges and stress of raising an autistic child. One mother stating *they lived like flatmates*, although hopeful that one day potentially they could find their love for each other, maybe when their child leaves home. Other mothers also commented on the challenges in marriages and partner relationships.

> *You know we consider a marriage to be forever and then it doesn't, you know, everyone has problems and it's not about the problems that you have is about what you do to fix them and get out the other side.*
>
> *To help families cope because a lot of families, husbands and wives split up when there's a child with a disability. That's huge.*

The negative impact from losing relationships, which in turn has impacted the wellbeing of mothers, was reported to be associated with a lack of support and funding. Under the current disability funding framework, there is no mechanism to use funding for families to access relationship or personal counselling. Counselling could provide essential help to strengthen the family while enhancing wellbeing for both the mother and the greater family systems. Due to the barriers of cost and time, only one participant mother received some regular counselling. This one mother stated that her counselling was only made accessible due to the generosity of the counsellor offering a reduced rate and providing it online. Another participant, Maggie, talked about her daily challenges and ongoing issues could have been relieved with some counselling support. Kim also talked about how counselling would have been useful for her to deal with her marriage ending, the lack of family support and the loss of her job.

> *I feel that we are in survival mode so much that your're always in survival mode anyway, so anything really dreadful that comes along it's like just another battle in the war.*

Respite breaks were seen as important, and the participants understood the value of these breaks. Often mothers were encouraged to have respite breaks and the wording of funding frameworks imply this is achieved by having the autistic child leaving the family home. Practically this would look like the child leaving the home to stay with another caregiver or respite provider overnight. In theory, this may help mothers enhance their relationship building with their families and their own wellbeing. However, many mothers reported they would enjoy having a supported break that included their autistic child, like how other families raising typically developing children get to experience a break.

> *We could use the funding to give us all, I mean, even if it's together … more inclusively for the whole family so that we can use it to pay for something that we wouldn't normally do…I'm not wording it very well. An outing that we could do where she needs extra support, and somebody could come and support her, but we can still all do it together*.

Participants certainly wanted more respite support, but they wanted more flexible support, allowing them to tailor-make to suit their needs, not just for the mothers but for the whole family. Having quality time as a family would allow the autistic child to feel a valued part of the family rather than constantly being sent away. Some of the mothers felt that sending a child away to make provision for a break only added to the message that the autistic child was the cause of any family issues, but in fact these issues may have already been brewing for a long time. Instead of bringing the family together, the fragmented support from existing services was likely to magnify issues that were already happening within the home environment.

Social stigma and burden

There has been a strong societal belief that mothers should take care of themselves allowing them to provide the best care for the children. However, in contrast to this wider societal belief, the reality for mothers raising autistic children was different in which they were often negatively judged in social situations and there was little financial support offered to make that self-care possible.

Many of the mothers stated that the behaviours of their autistic child were not understood. They felt society was very quick to judge them as poorly skilled parents raising "naughty" children. Mothers talked about not being welcome in the homes of families raising typically developing children and feeling judged in public settings. They also commented on school environments as being particularly challenging. This lack of understanding from others identified by interviewed mothers has a significant negative impact on wellbeing.

> *So, when my son started school there was a group of mothers who sat outside waiting for their children. [Child's name removed] at that stage was six months old, as time went on and she didn't do the normal things I mean she would never sit in a pram, she would climb out of it and then she would run, they just started to drift away ... Sometimes it would be nice to have someone that actually understood.*

The second part of the interview explored how mothers felt their wellbeing may differ for mothers raising typically developing children. Questions were designed to promote deeper thinking of these perceived differences and to consider how the definition of wellbeing may change depending on the support needs of the child. Most of the narratives from the mothers revolved around how their experiences were shaped by societal expectations of mothering. One mother summed up the participants' shared view of the differences between mothers raising an autistic child to those raising a child who is developing typically as *I guess there isn't as big of a significance for them to stay alive.* This sense to stay alive was not just because of the strong maternal relationship a mother and child have got. These feeling came from an internal belief that no one would choose to raise your autistic child because it could bring additional stress, work and take a negative toll on your life.

All the mothers had strongly linked the impact of wellbeing to raising autistic children. They assumed this might not be the case for other families raising typically developing children because mothers of typically developing children would not be all consumed 24/7 by the responsibilities of parenting a child. The participants felt mothers raising typically developing children would reduce the need to worry about the financial, social and health wellbeing costs that come with raising an autistic child and they would be more likely to have more ‘me time’ in their days to look after themselves and make time for what they enjoy and to have a better sense of wellbeing.

> *Wellbeing for people without children on the autism scale, they will say things like we had a fantastic weekend we went bike riding… whereas for me, I can say we had an awesome weekend, [child’s name] didn't have a meltdown, that is the scale as weighted heavily from one to the other. I will say to people you learn to live in a world where you enjoy the simple things in life and life.*

> *I think they would* [be different], *but I think they may be more… possibly they'd have higher aspirations for their neurotypical children.*

> *I have probably lowered my expectations of what I think is achievable. It is actually the mental space and emotional space to actually even think that I can go and start birdwatching or take up jogging, or whatever, it all just feels too hard.*

Cultural norms and societal motherhood beliefs have been strongly linked to the expectation of the ‘good mother’ discourse, which was definitely woven throughout the discussions of the participants’ interviews. Many mothers talked about the need to appear to be in control and managing well. They expressed the constant need to keep up appearances rather than be able to reach out for support from the community, which has made them feel anxious and eventually avoid situations where they felt they would be judged. Having people that could offer support in common settings, such as, schools or workplaces, without judgement would create a positive difference for mothers who are faced with so many other challenges when parenting an autistic child.

> *Sometimes it would be nice to have someone that actually understood you… If you just had a friend that you could say, for god's sake these people are idiots.*

Theme two: The disability funding system does not support a mother's wellbeing

Theme two examined how mothers have found their experiences with the disability funding system involving the assessment process and the tangible support that would help them have more opportunities to address their wellbeing needs. All the participants expressed their strong views of the complexity of the funding systems. This made them feel anxious, stressed, and disenfranchised. Kim described the process to get individualised funding as *one of the most stressful times of her life.*

Assessment process – Unwelcoming, oppressive and complicated

The needs assessment process was often the first step and first introduction to the disability funding systems and based on the experiences from many of the mothers, this process was considered as oppressive. They felt that the assessment often focused on what the child was not able to do and what challenges the child would bring to the home, community, and school. While mothers expressed concerns of the deficit-based assessment nature, they were often advised by other mothers who have already been through the assessment process to not to say anything positive about their child to maximise the entitlement and get closer to what would be needed for the family to support the child. These assessment meetings often left mothers feeling sad and challenged about the situation they found themselves in and with little hope that things would get better.

> *Having to prove how much of a challenge it is to people… especially when it comes to getting support and the sad thing is, I don't want to say autism is a deficit, but it has aspects of positive … but it's very hard when every time you need to get support. You actually just had to lay on how much of a deficit it is, and the celebration of the child is absolutely lost.*

> *When the shit hits the fan and you have nowhere to turn, when you're at your breaking point. There is the day that NASC need to know about.*

> *The process is hard. The needs assessment is long and negative.*

They said that the current system of needs assessment involved one person who was employed by a NASC service to meet with the family and complete an assessment of the child's needs. This assessment was typically completed in the family home with the child and parent(s) also in attendance for the meeting. The completed assessment was then allocated to another employee within the NASC who was ultimately responsible to make the funding decision and allocation. The mother's perception of this process was that it was disjointed and complicated. Most felt that to fully appreciate the situation, the assessor would need to meet the family in person. Without that, this has led to strong feelings for the mothers that the allocated funding for their child would not truly reflect what was needed in the home. The lack of confidence in the process has also led to a very strong sense that the child would never be fully understood, meaning they were never fully supported. Never feeling truly understood or truly supported was a significant deficit to wellbeing for many of the mothers expressed in the current study.

Nearly all the mothers felt that their confidence in the assessment process would increase if the person who made the decisions regarding funding allocation was also the same person that has met with the family, meaning that they would have been able to see first-hand what the family were struggling with.

> *These guys haven't even met [child's name removed] … and they already determined that he wasn't going to get …. That to me is shocking… I have never met the woman that makes all the decisions. In fact, I didn't even get a phone call this time.*
>
> *You haven't actually stepped into the household. You haven't met the family or for many families, the wider family, to see what are the issues...like in this house? You know, if you look on paper there's a mum and dad ... Okay, perfect …., oh look they will be fine. They'll tick along. Well, how do you know?*

In contrast to all other mothers, Alice felt the assessment process was robust and would give a clear and accurate picture of support needs. It seemed Alice's view came from her own work experience in a corporate environment where one person sought the information and others made decisions based on that collected information. This has given Alice confidence that this system would produce accurate reflections of need. This certainty in the process also created positive feelings for Alice and unlike the other six participants, she did not have a lingering sense that she was being unfairly evaluated. This may demonstrate that it could be possible for the process of assessment to meet the needs of some mothers while not negatively impacting the mother's wellbeing.

> *I’ve worked in corporate... so I'm kind of used to that bureaucracy of people making decisions on other people, you know, because I've worked in banking and lending and things for a long time. I haven't really dwelled on that because like I said, I feel comfortable enough.*

The final step in the process was the notifying families of the outcome of the assessment. Alice was the only person to be interviewed that expressed a simplistic statement that if she did not agree with the outcome, she would have been happy to challenge the decision. This may again reflect her confidence of the system processes and that she felt at ease to be included as part of that process.

> *I feel comfortable enough that if I didn't agree with what the outcome was that I would challenge it… I've got the ability to convey, say I was a mum who was on the spectrum herself, you know or had some mental health issues that you know, they could make it quite hard to convey exactly… I guess I am quite a direct person. So, if we were struggling, I would just say we are struggling whereas some of the people can’t do that.*

Most of the mothers talked about feeling powerless to take any action if they disagreed with funding assessments. Feelings of frustration and powerlessness relating to the assessment process not only came from a lack of confidence in the assessment process, but also from a belief that the funding offered to support the child did not meet the actual projected costs that the family had. But for Nadia, the outcome of the assessment process and the supports that were put in place were strongly linked to her wellbeing. She stated *that wellbeing is about adequate funding, more community supporters, and the right home supports.* For Nadia, who has been on her own raising three autistic children, the quality of her life seemed to have been controlled by the amount of funding she received. She explained that adequate funding has allowed her to arrange the children to have opportunities in the community to attend classes like other typically developing children. The funding has also allowed for therapeutic and activity-based classes tailored around the child's disability needs, such as music therapy, social skills classes, and classes to keep the child safe, such as swimming lessons. Nadia also required another person supporting in the family home most days to be able to manage the complexity of three autistic children in her sole care. This additional home support provided Nadia opportunities to take children to classes, medical appointments or attend events such as school meetings. Without funding to cover these critical supports, life would be incredibly difficult for her.

Heather became emotional when discussing the outcome of her child's last assessment. She had tried to advocate for additional funding to support them both since their living situation had changed with her partner recently leaving and her son in need of having additional behavioural support needs. Heather described the last six months as being a real challenge due to her not having enough funding to live a *good life*. Even after seeking additional support from senior advocates and talking to the leadership team within the NASC, she ended up with less funding than the previous year for her child. In the end, Heather gave up the fight to be treated fairly as it was too emotionally draining.

> *It's just been an absolute challenge and, in this day and age you can't just call someone out and say hey you need to do the job properly. Sometimes it takes time and energy to do a polite email.*

Funding is to be individually focused

Feedback from the mothers felt that individualised funding of a disabled child has not considered the wider and more holistic needs of that child, including caring for the wellbeing of a mother. What appeared to be missing with individualised funding was being able to support the unique circumstances around that child and respond appropriately. This subtheme was to honour the stories and voices of the mothers and to consider what would be needed to make the system work better by acknowledging that mothers were often the experts in the solutions that would work best for their family. When Julie, a mother of three children, was asked "what would have helped you in the process?", she responded that it would reduce her stress to have someone that could get to know the family, to understand them and what they were entitled too. Someone that did not only understand them but had the time and skills to understand the system. This would make it a more transparent and fairer system to respond quicker and more promptly to a change in need. As mentioned in the previous subtheme, the lack of confidence in the current system has led to feelings that mothers raising autistic children were never truly understood, meaning they are never feeling fully supported. Julie stated *people are on the verge of breakdowns… and all they need is a bit of support but because [the funding system] it's also secretive and complex it is very hard to get straight answers.*

The concept of being able to access support early or as needed was also linked to personal wellbeing by many other mothers. In Maggie's words, *wellbeing would be earlier interventions, feeling safe and supported and listened to and access to help when you need it, rather [than] when someone else decides that you need it.* This sense of empowerment for the families to be able to manage how and when support could be accessed was also described by Heather, *it shouldn't need to be a battle, why does it have to be a battle? There is enough stress in your life*. If families had a process that enabled them to work in partnership with the NASC to better understand what the families were trying to achieve, this may reduce those feelings of frustration, powerless and hopelessness that funding issues were simply a battle and barrier.

Anne was one of the first families to be allocated individualised funding in Canterbury and has seen many changes over the years, such as the change from a paper-based system to an online system. Initially, when the funding was allocated, Anne was parenting two children at home. Anne said she would often remind other mothers raising autistic children to take care of themselves and in her words said *if you don't look after yourself, you know, who is going to look after the child*. Anne went on to elaborate.

> *Actually, the government... If you don't look after the caregivers who is going to look after these children. We know that all the research shows that these children will live a lot happier productive lives, but also that it costs the country a lot less money.*

Many mothers felt the needs assessment should focus on a child's strength. A strength and goal-based conversation may give mothers hope of things improving. *If you're supported, you're going to feel like you can get through*. All the mothers stated that if there was more empathy and sensitivity and collective consultation within the assessment process concerning and supporting their wellbeing, they may alleviate the feelings of being undervalued and unappreciated. Some mothers stated they just had to keep going until a crisis occurred, which would result in additional support finally being offered, such as an increase in respite hours.

The mothers agreed that currently there was no provision within the individualised funding system to make the mental health, physical health and overall wellbeing of mothers caring for an autistic child a priority.

> *I strongly think sort of holistic support for the family is really important. I've said it often as the sort of band-aid on a train wreck. There is a train wreck and somebody comes and puts a band-aid on, but there is still a train wreck left behind and [the specialist] goes there that's better and … goes off again and the train wreck is there, but it has a band-aid on it.*

> *Just think that there has to be acknowledgment that it is hard work, and we love our kids and we're giving them the best that we possibly can but takes a toll physically, emotionally, mentally… What a good life looks like to every one of our children is different, the same as what wellbeing looks like.*

All mothers commented that if there was some small provision of flexible funding to provide additional support to look after their wellbeing, they would use it. Most of the mothers felt they would benefit from some form of regular counselling; however, all of them remarked that the funding would need to be flexible. For them, wellbeing was an individual perspective within a collective unit in a family; therefore, it would require a collective solution to support wellbeing for mothers and their family as a whole.

> *I think I would need a fund, not a counselling fund because I wouldn't want to do that. But a fund where you could choose what to do for you. If you wanted to have a weekly deep pressure massage, even if they paid the place directly so that you're not misusing it to buy wine. I would appreciate if they had something like that… Just so you can feel like you're not just existing, but you have like a sense of purpose or… something to look forward to.*

> *If there was a small pocket of money that you're allowed to spend once a month on yourself, even if it was something like go and get a massage too actually. To relieve your stress, something like that…. An acknowledgement that actually this is really hard work. I know my body is really knackered from years of lifting… But, you know, just something small, it wouldn't have to be a lot if there is a small discretionary amount within your assessment for the main caregiver of that child.*

More barriers and stress from confusing system

While many of the mothers had been using individualised funding for several years, including two mothers who have been part of the individualised funding system for longer than 10 years, there was still significant confusion around the funding guidelines as reported by all of them. Alice, who has been using individualised funding for over eight years, was university educated and worked in a corporate workforce, also agreed that *I don't feel that it's very easy to work out what you can and can't spend it on.* The funding guidelines were meant to inform parents of the rules around using individualised funding and how to work within those rules, enabling the family to use the funding well and support their child to reach their developmental potential; yet the reality was just another barrier to cause more stress.

> *Guidelines just like a piece of paper that doesn't give you a list of what you are or not allowed.*

> *It's all very well getting this funding but it's sometimes hard to actually work out what you can use it for.*

> *Maybe I'm not proactive enough with asking the right questions but I don't feel that it's very easy to work out.*

Most mothers felt it was their responsibility to find out if there had been changes to the funding guidelines and to seek clarification. When interviewing Maggie, it became apparent she was still working on information which was presented to her at the initial set up meeting. Maggie was surprised to hear changes had been made to the system over those six years; yet, she had not received any information regarding these changes. Working from outdated information meant Maggie had been using the family income to pay for support she could have been accessing through funding for many years. It seemed this was a common experience for families as reported by the mothers. Finding information out years later ended up creating feelings of anger and grief for these mothers knowing that they had been financially stretched, using the family income for years to pay for something that could have been supported through individualised funding. Many of these families have got other typically developing children in their care, using the family income to pay for disability-related costs that could have come from the child's funding also made families feel they have denied opportunities that the money could have provided to the other children within the family unit.

Having the responsibility to constantly try to navigate the complex system to seek information about the autistic child's funding has made mothers feel that they were being put in a vulnerable position. This vulnerability stemmed from having to explain how they have been using the funding and making justification to the authority to ensure they were working within the rules. Furthermore, this sense of vulnerability was often increased due to misinformation and stories of parents being reprimanded for making innocent errors.

> *Life is complicated and difficult for people [and] parents with children on the spectrum and we don't know what we don't know, and we also often don't have either the time or the energy to go looking for what we don't know.*

> *There is enough stress in your life and then you think oh great I have to spend three weeks doing this. The guidelines could be clearer.*

The vulnerability and additional stresses were highlighted in the experiences of the study participants. There had been times Kim thought she would be better off without individualised funding because she felt that those who hold power about her funding were judging her decisions on how she would use it. Kim became tearful explaining the emotional impact on her when she was denied funding to purchase a bike during the COVID-19 lock down and then shortly after being denied the cost of swimming lessons for her daughter. Kim said *it is terrible as a mother to be judged as someone that doesn't know what is best for their child, as her mother I know what she needs and that should be trusted.* She also expressed her deep hurt about not being able to provide things like a bike or swimming lessons, especially when she heard that many other families were able to purchase these exact items.

Lack of information coming from the NASC or fundholder regarding the funding guidelines and the stress of having to seek information meant most mothers were sourcing information from social media platforms. Most mothers mentioned Facebook groups as the most common source of the information. As this was not a credible source of information, it could cause unnecessary anxiety due to the uncertainty of the information that was being presented.

> *I quite often see on Facebook online you know like Autism New Zealand Facebook page people say, can I use it for this, or can I use it for that, and then people coming* back *and say things that actually I think, no that's not right. I think the information is confusing.*

> *It wasn't fully explained to me, now that we've had it for a while and I joined a Facebook group and people talk about what you can and cannot purchase and all that kind of stuff.*

> *I call it the Chinese Whispers. I mean you even see it on Facebook and then like stuff and the social networking groups and even on the Manawanui site, when they do their live sessions, there has been a few that I have hopped on and sometimes there is a heap of people saying but I thought you could use this and no we only did that, and especially over COVID-19 there was so much confusion about what you could and couldn't use it for.*

> *The NASC, they tell you one thing. Ministry of Health will tell you another, in all the needs assessment places who they are with, there are different things. It is not like one rule, this is it. So, I think it needs a good shake up because it's a bit antiquated.*

All the mothers felt it was important that improvements ought to be made to how funding changes should be communicated to families to create equity of access. More clarity around funding rules to ensure that people would not depend on social media to avoid second-guessing the reliability of the information. While there are many agencies in Aotearoa New Zealand receiving government funding to ensure disability information is reaching the community, not one participant mother mentioned receiving help and support from other organisations to help them understand or navigate the funding process. This gap identified by the participant mothers has provided an important platform to encourage a more open conversation between NASCs and other community services to ensure there would be more appropriate access to accurate information to provide to the mothers, families and parents raising autistic children.

4.3 Summary

This chapter illustrated the mothers' perspectives on the impact on how their autistic child's allocated individualised funding can be used to achieve a good life for their family and the impact to the mothers' wellbeing. A range of concepts that would improve wellbeing for mothers were raised by the mothers, such as, reducing social judgement and stigma for a mother raising an autistic child. Having better support and understanding from health professionals including a range of accessible counselling options was also discussed as a solution to improve wellbeing. A link to relationship stress and negative impact on a mother's wellbeing was weaved through the chapter, which needs to be considered when thinking about change that could improve a mother's wellbeing. Most mothers expressed that they would feel better supported if there was one person from the NASC who would develop a strong relationship with the family. Using a strengths-based lens could contribute to better understanding of what was needed and be able to respond appropriately to urgent and changing needs. Having a stronger partnership with the NASC could also remove the barriers of the system being challenging to navigate and credible information difficult to obtain. The following chapter will offer a synthesis of the results in relation to current literature and research.

Chapter Five – Discussion

5.1 Introduction

Results of the study have shown that mothers raising an autistic child have faced a multitude of challenges that negatively impacted on wellbeing, such as loss of meaningful relationships, and negative societal stigma and judgements towards mothers due to the discourses of mother-blaming and ‘good mother’. Even though Aotearoa New Zealand has moved its disability funding system to a more individualised context to promote more freedom and choice for disabled people and their families, individualisation and personalisation of funding have not been able to respond to the unique circumstances of families, especially for mothers raising autistic children to help them achieving their wellbeing adequately and holistically. Based on the results from the current study, this chapter will present the discussion, which is conceptualised into three main areas: (1) individualised funding perpetuates neoliberalism and disablism; (2) increasing choice and control for mothers to pursue better quality of life and wellbeing requires taking the family as a unit of care; and (3) an unwelcoming system creates further despair and social exclusion.

5.2 Individualised funding perpetuates neoliberalism and disablism

The rationale behind individualised funding has emphasised the development of a person-centred approach to support services for people with a disability (Carey et al., 2017; Galpin et al., 2017). Individualised funding is an umbrella term used for many funding mechanisms in Aotearoa New Zealand and overseas, which aims to provide personalised and individual supports. Individualised funding places the service user at the centre of the decision-making process and is seen to be giving the disabled person and their family more choices and control over directing their care (Fleming et al., 2019). However, the findings from this study have shown that while the mothers desired to pursue individual tasks to meet their own aspirations of enhancing their wellbeing, the process and outcomes derived from the individualised funding were mostly peripheral for their lives. This has further perpetuated the notion of individualised funding as being exclusionary to meeting the needs of mothers of autistic children as the perception of achieving wellbeing still rests with the value of individual responsibility, rather than collective good. The pervasive effects of neoliberal influences of funding and allocation of resources, whether implicit or explicit, somehow accelerate and deepen the stigmatised injustice process to dichotomise ‘good’ mothers as those who can cope versus those who struggle as ‘bad’ mothers (Charmaz, 2019). This view of being stigmatised and exclusionary is supported by Thomas’s (2020) research, indicating that the welfare system’s failing has remained intact for disabled children and their families as they equally felt both marginalised and undermined by the neoliberal driven system that has designed a system to make help-seeking a desperate and shameful task.

In the area of disability studies, we have seen an extensive range of literature focusing on parenting disabled children and mothers with disabilities. However, it is only in recent years that a more specific focus is seen on mothers, their quality of life and their identity and relationships in caring for a child with a disability from a socio-political context. Scholars such as Weeks (2001) and Giddens (1991) have noted that the individualisation that underpins disability support payments through individualised funding has allowed space for choice to increase greater diversity of family forms and lifestyle choices. However, the possibility of self-agency to make their own decisions also means being responsible for their own choices. Results from the current study indicated that mothers did not enjoy or exercise fully the freedom of choice to pursue their own wellbeing. Instead, their decisions were socially patterned as their roles were assumed to be that of their child’s primary caregiver, expected to become the ‘experts’ in their child’s conditions, and conditioned to use the funding wisely to enhance their own wellbeing in an individualised context. For these reasons, motherhood has certain consequences in a way a woman thinks about herself and her identity and explains the strong link to societal judgement, which negatively impacts relationships for mothers raising disabled children (Brock, 2015; Cridland et al., 2013). This is evidenced from research on disability studies exploring the wellbeing of mothers of disabled children, which often refer to mothers as taking a liminal position because they are often not disabled but can experience forms of disablism (Ryan & Runswick-Cole, 2008). It is argued that this disablism occurs through discrimination directed at the child both in actions and attitudes of wider society (Broady et al., 2015; George et al., 2020; Ryan & Runswich-Cole, 2008). Literature would further suggest that they are experiencing a form of disablism, which emerges from a medical model of disability, creating an emphasis of the burden of having a child with a disability (Broady et al., 2015; Green, 2003; McKeever & Miller, 2004; Ryan & Runswick-Cole, 2008). Various researchers have recognised that the experience of mothering a child with a disability is complex, which is partly due to how disability as a concept is experienced by the mothers, but also due to how systems of support and access to resources are delivered (Brock, 2015; Ryan & Runswick-Cole, 2008; Trani et al., 2011). All the participant mothers expressed a similar sentiment of frustration, with one particular mother stating this was the most stressful time of her life in reference to how complex the health and social welfare system was to navigate for her autistic child and how she felt disenfranchised because of it.

The notion of ‘good parenting’ has been used widely as a key to the analysis of public policy and is considered central to constructing good outcomes for children (Jensen, 2012). In the United Kingdom, good parenting has been portrayed and taken on a wider social significance with the government stating it is the route through which “Broken Britain” will be mended, thus connecting it to the neoliberal discourse of cost-effective investment into children, which will save the country money in the future (Runswick-Cole & Goodley, 2017). The problematic nature of the concept of 'good parenting' and the 'good mother' is interlaced throughout the mothers' experiences of raising their child with a disability. The dominant discourse of mothering and parenting carries particular assumptions and expectations that are socially constructed to impose on women who become mothers and what attributes and characteristics they have to acquire to behave in certain ways to align with societal expectations (Arendell, 2000; Goodwin & Huppatz, 2010). For the mothers in the current study, they were portrayed to be the primary caregivers as this was the internalised norm for mothers raising children with disabilities; hence, they were 'expected' to provide care to their disabled child and anything that sat outside of this construct was seen as deviant or unacceptable (Brock, 2015). While individualised funding is supposed to provide the autonomy and choices for mothers raising a child with a disability to take respite, the interpretation of individualisation subsequently marginalises their experiences due to the demand of being a good mother because a child should be their first priority above all else. These mothers did not necessarily enjoy the freedom of choice that individualisation was supposed to purport but instead they faced greater constraint in their choices due to the 'good mother' theory.

Runswick-Cole and Goldey (2017) further stated that 'good parenting' and neoliberal influence have redefined parenting in the 21st Century as an individualised task filled with responsibilities and obligations. In a recent article, Tabatabai (2019) stated that the rationale of neoliberal efficiency expects parents to provide care and cover costs of the child's disability to absolve the state of any responsibility. Jensen (2012) further argued that the current austerity agenda positions the reduction of public support and services as a solution to this burden which countries can no longer afford. Findings from this study have shown that the mothers all experienced this austerity agenda through services being withdrawn because the Aotearoa New

Zealand government appears to be unable and unwilling to support them. A current example of this was the ‘iChoose’ system which was supposed to be implemented in Aotearoa New Zealand in 2020 to provide flexibility in respite costs. However, when the Aotearoa New Zealand Government calculated the cost of the ‘iChoose’ system, it was put on hold indefinitely (Compston, 2020). A recent Aotearoa New Zealand study has reported that the challenges faced by parents caring for an autistic child can amplify parenting stress although these challenges can be alleviated by social support (Shepherd et al., 2020). Having adequate social support was strongly emphasised by the mothers. However, it appears additional support can only occur when governments accept raising a child with a disability creates social stigma, isolation, and economic disadvantage. (Kinnear et al., 2015; Liao et al., 2019; Ryan & Runswick-Cole, 2008).

The ideologies of motherhood that validate some as good moral mothers, while vilifying the others through mother-blame and holds mothers responsible for the outcomes of their children has been criticised by feminist sociologists (Blum, 2007). Cultural norms define a collective standard, despite what an individual parent would consider to be good parenting. Through this filter of individualised narratives, mothers, particularly those caring for a disabled child, are often forced to shape their own practices within a given socio-political frame. Under neoliberalism, a good parent is one who raises an independent and economic producer child with little help (Tabatabai, 2019). However, when it applies to disability, studies have reported that mothers raising children with hidden disabilities such as autism have a higher rate of self-blame which is reinforced by ideal norms of parents (Blum, 2007, Zuurmond et al., 2020). There are similarities in other research, which has also shown that mother-blaming emanating from bureaucratic and helping professionals is attributed to one of the most distressing aspects of mothering (Blum, 2007; Jackson & Mannix, 2004). Results from previous research have substantiated the mothers feeling of being judged and labelled a poorly skilled parent, which was a significant contributor to the reduction or loss of social support through friendships and community support. Knight's (2013) research into the changes of perspective on social attitudes towards good mothers suggested that undue importance is being placed on the characteristics of families (particularly mothers) to manage the pressures of raising a child with a disability. Mothers are expected to remain positive about their own lives to negotiate around the normative framework of the 'good mother' whilst also being unrealistically expected to address systemic problems at a socio-political level due to services being fragmented, underfunded and difficult to access. As discussed by Brock (2015), mothers of children with disabilities are often put in a very challenging position not only to be expected to perform duties as the primary caregivers but also experts in their child's disability to make particular choices about their child's care with limited institutional, social, and monetary support such as individualised funding. This is reflected in Ray's (2005) discussion around how choice operates in individualisation. It is not entirely free to make choices in many constrained situations, but more about being compelled to do so because of the lack of existing choices and support, which is just another form of burden mothers of children with disabilities have to endure.

Participant mothers in the current study expressed their desire to enhance their wellbeing, but also reported this could not be realised without their children. Policies and decision-making need to consider the entire family unit, as well as the impact on the person being supported so that parents and caregivers are recognised for their contribution to society (Hickey & Wilson, 2017; Ministry of Social Development, 2019; Ryan & Runswick-Cole, 2008). During the development of future government policies, it is critical to understand that policies have the potential to expand and entrench inequities (Laragy & Fisher, 2020). There is a growing concern that the responsibilities of advocacy, coordination and service management have been shifted from the state or government to parents and caregivers (Simpson et al., 2016). This has added more stress to their already hectic and challenging lives as a family (Malbon et al., 2019). Further research has found that individualised funding such as the Aotearoa New Zealand system can embed inequalities rather than level, which then places more accountability on parents (Gavidia-Payne, 2020; Malbon et al., 2019). Carey and colleagues (2017) argued that an individualised or personalised approach can widen inequalities and inequities in relation to social and health outcomes, unless careful consideration is given to not only the amount of funding that is allocated but also the way funding is conceptualised and allocated. The ability of a mother raising a child with a disability to pursue her 'freedom of choice' is immensely connected with the kind of support available and its accessibility. This suggests that unless the overall wellbeing of the family unit is considered within policies and systems, there will be no improvement to wellbeing. Such concern was clearly articulated by the mothers' narratives.

5.3 Wellbeing for mothers requires seeing the family as a unit of care

Family caregiving is described as an emerging public health concern with a multitude of social, economic, and psychological implications (Talley and Crews, 2007; Young et al., 2020). The wellbeing of families raising autistic children rarely takes centre stage in research and policy (Cridland et al., 2013) with most care and policy systems organised to meet the need of an individual and not address the needs of the caregiver (Karst & VanHecke, 2012; Smith & McQuade, 2021), leaving them community alienated and socially isolated. Findings from the current study aligned with existing research reporting that families want support, which considers the needs of the whole family, along with individual impairment-focused interventions that the child needs (Galpin et al., 2017; Smith & McQuade, 2021). Families are complex systems impacted by individual qualities, family functional factors, and social determinants of health, such as income, ethnicity, caregiver education, and employment (Marquis et al., 2019). There are many social work theories, which investigate the link between the health of a child and the impact on wellbeing for the entire family system. Using Bronfenbrenner's bioecological model of human development, the role of parents is important because they not only meet the most basic needs of the child, but they also provide mediation between the child and the larger society and communities (Predescu et al., 2018).

Ensuring understanding of the whole family unit, as opposed to solely focusing on the autistic child, was particularly important for the mothers to mitigate feelings of being under resourced, under supported and unable to access quality respite to ensure a good quality of life is achieved for the whole family. The research findings from Brock (2015) stated that although individualisation may have opened more possibilities for individual choice, this interpretation of individualisation has minimised the experiences of many others, such as the mothers of children with disabilities. In fact, mothers perhaps face more constraints on choices as they become obligations and a burden rather than something that can provide purposeful and meaningful engagement and outcomes. The research aligns with the experiences of the mothers who have ended up feeling more responsible for the day-to-day care needs of the child while also having to advocate within the system for their autistic child; this is often at the cost of their own personal health and wellbeing needs.

Another prominent social work theory which has been popular in the last several decades as a tool to examine family functioning is that of family systems theory, in which clinicians and researchers assess the entire family. This was described by Minuchin (2012) as "the individual can be approached as a subsystem, or part of the system, but the whole must be taken into account" (p.7). Kovshoff et al. (2017) expanded on this concept more in her research with the view that no individual family member defines the system in isolation, and they reiterated that the individual experience and individual outcomes are dependent upon consideration of the whole family unit. A recent review of literature on the effects of raising an autistic child on the function of a family unit has found that it is not sufficient to look at a child alone without considering the family (Factor et al., 2019). Furthermore, the overall gains of intervention for the child must be measured by comparing gains made by the family as a whole. The wider notion of individualisation has been criticised as leading to more social isolation and fragmentation of society to order to cope with the risks generated by modernisation and individualism (Bauman, 2003).

Models and frameworks of disability have predominantly focused the attention on the individual. Historically, the traditional Western medical model used to understand disability has interpreted it simply as a disease or illness, ignoring the broader holistic dimension that impacted disabled people, especially the impact of society on their lives (Hickey & Wilson, 2017). The emergence of the social model of disability has been able to offer an alternative perspective rather than focusing solely on a person's impairment through the lens of the medical model. The social model considered the obstruction which arose from social exclusion. This change of perspective has challenged society's responsibility to remove barriers that prevented a disabled person to fully participate in society (Bingham et al., 2013; Hickey & Wilson, 2017). This position was expressed in this current study by mothers feeling excluded and unwelcomed in multiple community settings, as well as systems not being able to cope with including the whole family in opportunities such as respite.

The Aotearoa New Zealand Carers Strategy Plan has stated that it is important to recognise that both the carer and the person they support have needs and rights, and they may not be the same (Ministry of Social Development, 2019). However, this was not the case when it came to the individualised funding options. The mothers referenced the rigid and rule-based system as being unable to adapt and respond to both the individual needs of the child and holistic needs of a family, leaving them feeling undervalued and precipitated negative feelings towards day-to-day living and for their futures. While the purpose of individualised funding is to support families raising disabled children to exercise choice and control in pursuit of their goals (Dickinson, 2017), the reality for mothers in this study was that they felt removed from the planning and delivery of their support needs, which was supposed to tailor to their child's needs. Due to the lack of options and flexibility of the current system, the problematic nature of individualisation has so far proven inadequate in accounting for the way these mothers experienced their personal lives, leaving them feeling further disempowered and marginalised. This sentiment is also reflected in similar research in which parents and families felt they were merely instruments in the complex system of funding and allocation processes. Literature also noted that even when the rationale of funding was rooted in a child-centred approach, it was individualistic with limited involvement and consideration of families and their perspectives of wellbeing in the support planning to address the child's need (Laragy & Fisher, 2020; Gavidia-Payne, 2020). Such notions of tailoring support to include the wider family unit will need to depend on parents and families being able to directly navigate complex service systems (Carey et al., 2018). Research has argued that these funding schemes often involve complex system and mechanical governance, which further perpetuate existing social and cultural inequalities, such as literacy skills, socio-economic and cultural status, and they can prohibit mothers from accessing services if they do not have adequate capacity to understand the systems (Carey et al., 2018; Malbon et al., 2019). Narratives as articulated by the mothers' share similarities to existing research to describe the system as difficult to understand, complicated, creating feelings of frustration and taking years, and some decades to begin to understand.

Supporters of individualised funding have argued that there is strong evidence that reliance on natural supports is effective in achieving better outcomes across a range of measures for families and people with disabilities (Bennett & Bijoux, 2009). The results of an American study in 2017 indicated the need to enhance informal support networks for parents raising autistic children, showing that older parents who had strong networks had a reduction of carer burden (Marsack & Samuel, 2017). The reality for the mothers of this study was that they were not able to rely on informal or natural supports because family and friend relationships ended, which was also reflected in other research, demonstrating that natural supports fell apart when raising a disabled child (Brock, 2015). Many of the study participants expressed that with the friendships that they were able to maintain, they did not want to burden them with any additional expectations of providing support for their disabled child. This view is also shared in a recent Aotearoa New Zealand study indicating that parents raising autistic children did not perceive friendships to be a significant source of support (Shepherd et al., 2020). The study's findings also stated the lack of perceived support from friends was attributed to not wanting to burden them and or not wanting to lose a friendship because of the challenging behaviour or lack of understanding around autism. In Brock's (2015) research, she argued that it was not because mothers raising a disabled child did not want to receive support but was more about the perception of support from those in their personal communities. Brock's participants reported that the perception of having a friend to listen and not being judged was more pivotal than deciding to include a friend in their support network. It is interesting to note that while those who have supported individualisation such as Giddens (1991) agreed for more opportunity and freedom in (re)structuring social support networks, individualisation has been criticised for leading to more isolation experienced by parents raising a disabled child, which suggests that there is an ambivalence about the existing understanding of the origins of individualisation.

The mothers discussed feelings of being unwelcomed in multiple social environments and people’s homes due to the behaviours of their children, creating a detrimental impact on wellbeing through the disruption to forming and maintaining friendships because they felt labelled as a bad parent raising disobedient children, the concept of ‘peripherality’ can explain this phenomenon. According to Shearn and Todd (2000), peripherality was used to describe the way couples in their study who felt excluded from other families with children because they were unable to conceive. This was shared by the mothers in the current study who felt that they needed to acquire an identity which would position them better within societal expectations to avoid social stigma or exclusion (Home, 2008; Schertz et al., 2020; Shearn & Todd, 2000). The dominant ideologies of ‘good mother’ or ’good parents’ have added pressure for these mothers to present themselves as if they were managing well when out with their child in the community, whilst the neoliberal notion of individualisation and conformity continue to perpetuate inequality and discrimination against disability (Tabatabai, 2019). Neoliberalism emphasises individual responsibility, a limited social safety net, and narrow governmental accountability and this further accelerates and deepens stigmatising processes, injustice, and exclusion against disability (Charmaz, 2019).

Numerous challenges emerge frequently in research on the subject of parenting disabled children due to the complex combination of higher care needs and reduced autonomy (Home, 2008; Neff & Faso, 2014; Shearn & Todd, 2000). Studies have shown that mothers raising an autistic child compared to typically developing children reported higher rates of mental health issues, anxiety, and depression (Broady et al., 2015; Pertiwi & Irwanto, 2020; Reddy et al., 2019). There is also considerable evidence that there is a high level of stress in the parenting role (Duarte et al., 2005; Factor et al., 2019; Green, 2003; Safe et al., 2012). These studies are reflective of the experiences of the mothers in this study, who all stated that they felt their wellbeing was negatively impacted due to raising an autistic child. Some mothers mentioned that they had been diagnosed with depression and were now prescribed antidepressant medication, which they believed was because of the stress they had to deal with in their lives. Almost all the mothers felt that their wellbeing was not factored into the current government's system to support children/people with disability as a unit. Findings of the current study have highlighted that while individualisation may have opened up possibilities of freedom of choice for people who have the capability to align with the criteria, mothers did not experience this same freedom of choice, autonomy and self-agency due to the dominant ideologies such as good mother theory and structural inequalities and barriers stemming from lack of adequate and appropriate institutional support. To enhance wellbeing and quality of life for mothers and their family units, the system needs to be able to integrate anti-oppressive and rights-based approaches to a holistic assessment and funding allocation process which considers the wellbeing for mothers and recognises her contribution (Laragy & Fisher, 2020; Thomas, 2020)

5.4 Unwelcoming system creates further despair and social exclusion

Research has identified that the most reported unmet need for parents of disabled children is that of access to information (Tracey et al., 2017). This was reflected in the current study where most of the mothers reported that they were being denied information and have found the system to be complicated to understand with regard to the rules, creating confusion and a sense of frustration regarding these barriers. Challenges for these mothers are seen in existing literature in which parents and/or caregivers reported that even when information was made available, the information was hard to understand. Furthermore, it was not suitable to their family or their child's needs which made them feel a lack of inclusivity, was culturally insensitive and overwhelmed with too much information to decipher (Malbon et al., 2019; Simpson et al., 2016; Tracey et al., 2017). Because of these challenges, Malbon et al., (2019) argued that families are often then forced to use social media, personal networks, or peers to complement what information is being received. All the mothers said that due to the COVID-19 lockdowns, they had to turn to Facebook to ask for help to find out what could or could not be purchased with funding; however, they received contradictory advice from different parents and sources, which have left them second-guessing what was accurate.

Developing an equitable and fair approach to the allocation of individualised funding in some countries has been identified as a challenge (Lord & Hutchinson, 2003; Thomas, 2020). Individualised funding has become part of the disability sector in several countries, including the USA, United Kingdom, Canada, Australia, and Aotearoa New Zealand, with most having an assessment that determines an individual's allocation of public funds (Purcal et al., 2014). The needs assessment process is described as a process aimed to extrapolate a level of need through a medical or individual deficit model, which requires people to identify all the things they are not able to do because of their impairment, which reinforces inequities and often results in peoples unique needs going unmet (Morrison, 2021). Feelings of frustration and discontent from the mothers from this study have also been echoed in the academic review of the Canadian system with families expressing some concerns of the procedures and the levels of funding allocated (Lord & Hutchinson, 2003). Similarly, families who took part in the review of the Australian NDIS system also noted a lack of confidence in the assessment process (Laragy & Fisher, 2020). Another recent review of the Australian NDIS system reported that some participants indicated frustration with the assessment process that it was brief, administrative-like and prevented the family from having time to talk about their concerns for the child and themselves. Of note, one participant in the Australian study commented you had "one shot" to get it right in anticipation of future needs (Gavidia-Payne, 2020). The Australian and Canadian assessment process is comparable to the Aotearoa New Zealand assessment process, with an assessor meeting the family for the purpose of "needs assessment" and this is usually the first time meeting the family and over a period of a few hours. From this meeting, an assessment of predicted need would be generated which would then heavily influence support needs and funding recommendations. This has once again placed a huge amount of pressure on parents/mothers to make the right choice for the child's care, putting them under the mechanism of the ideology of 'good mother' and if anything went wrong, the parents/mothers would need to fight against the system to advocate for their child's needs, indicating that they would be constantly negotiating their existences within the boundaries of 'good parent' and 'good mother' that monitor their responsibilities and obligations.

Aotearoa New Zealand research conducted by Milner et al. (2016) stated that the needs assessment process separates the carer and care recipient needs, which limits the scope of the assessment to identification of care and support needs of the recipient and this process has been criticised for being largely insensitive to other attributes likely to have had an impact on the health and wellbeing of carers. The inconsistency and insensitivity in needs assessment was found to impact negatively on families of children on the autism spectrum in which parents reported they were feeling let down due to the disability support system being inadequate and adversarial (Galpin et al., 2017). Most of the mothers who took part in this study shared a similar view that the assessment process they went through did not give them any confidence that the assessment process truly reflected the need of their family and that they were doubtful that things would improve. A review of individualised funding literature prepared by the MOH in 2009 reported that individualised funding should not be deficit-based but must be equitable and reviewed regularly. They also highlighted that funding should be adequate to ensure satisfactory access to support identified is met and finally decisions about allocation should be transparent and fair, based on valid methods to determine funding (Bennett & Bijoux, 2009). More recent studies have articulated those users of individualised funding continue to feel the process of establishing and review of individualised funding was inequitable and one-sided (Fleming et al., 2019). The criticisms of the individualised funding were clearly reflected in the current research from the mothers expressing strongly that they have not been heard, not been valued, and have been taken for granted.

Narratives derived from the mothers have consistently critiqued the current funding and support system to be complex and difficult to navigate, further creating barriers to wellbeing for the families. Their accounts of experiences were reflected in research that has noted the challenges of being the user of individual budgets, including a lack of information and advice, increased stress to families; and the complexity of managing individual funding (Bailey et al., 2021; DePape & Lindssay, 2014; Dickinson, 2017; Dew et al., 2013). Research has found families were more likely to achieve better outcomes when the process was easier, and they felt fully included in the support planning and budget setting process (Dickinson, 2017). An aspiration mentioned frequently by the mothers was the desire to have strengths and/or goal-based conversations to create a positive expectation that it will get better. To promote capabilities for a person with a disability, public policies need to allow individuals to convert resources into capabilities (Trani et al., 2011). The capability approach, developed by the economist Amartya Sen, is a framework which can bring new insights to the traditional views of wellbeing within the field of disability studies (Kurowska & Javornik, 2019; Robeyns, 2016). According to the capability approach framework, wellbeing is multidimensional where each relevant dimension is unique. People, and especially autistic people, can experience very low levels of wellbeing in some dimensions and very high levels of wellbeing in other dimensions (Kurowska & Javornik, 2019). The capability approach distinguishes itself from traditional approaches, which have a narrower view rather than more holistic approaches which promotes understanding in a more comprehensive approach (Yeung, 2019). It has been reported by Dubois and Trani (2009) that it is necessary to change the way information for assessments of need are collected about families and how data is analysed. Data collection needs to look at participation, values, and barriers to choices as well as available resources (Trani et al., 2011). The research goes on further to state this is even more important for children and those with severe disabilities as they are reliant on parents or caregivers.

Studies have found that a predictor of carer burden and higher levels of negative wellbeing among carers is linked to reduced support either from informal sources such as family or friends as well as lack of support from formal services (George et al., 2020; Marsack & Samuel, 2017; Savage & Bailey, 2004). Raising an autistic child is described as a 24 hours, seven days a week job for parents, sometimes on their own or they become isolated due to the demands (Altiere & Von Kluge, 2009; McKenzie & Chataika, 2017). This contributes further to the loss of support from friendships and extends to the loss of family supports when family is unable to accept the autistic child or children (Altiere & Von Kluge, 2009), resulting in mothers remaining or becoming further isolated (Safe et al., 2012). Autism research has shown that families who are raising an autistic child experience increased financial hardship and poverty when compared to children with other developmental disabilities (Bishop-Fitzpatrick & Rubenstein, 2019; Reddy et al., 2019). This financial burden means less resources to address some of the negative health and wellbeing challenges faced by mothers which may be reduced by accessing therapy. Research, however, has suggested that mothers also feel burdened because of the costs and time demands for therapy (Safe et al., 2012). All the mothers expressed a desire to look after themselves and all commented that they would like to do something regularly that was focused on their specific wellbeing needs. Only one mother in this research was having regular time to focus specifically on her wellbeing needs and this was only made available because she had been able to negotiate a subsidised rate. According to the neoliberal ideology, a good citizen or a parent or mother is autonomous, independent and takes personal responsibility (Runswick-Cole and Goldey 2017). However, if disability service support and funding is truly designed to empower people's quality of life, such empowerment cannot be done by an individual, but it should be grounded in community for common good and shared goals. The neoliberal requirement of reliance on parents as individuals to fix the issues only creates inequality of access to supports, resulting in more stigma, discrimination, and social exclusion.

5.5 Summary

This chapter has provided a discussion on the key themes, which came from the stories of the mothers which related to their experiences of wellbeing through raising an autistic child, and the literature. The discussion was conceptualised in the areas of the problematic nature of individual funding, increasing choice and control for mothers to pursue a better quality of life and wellbeing and the funding and support system which generates feelings of despair and creates more barriers to achieve optimal wellbeing. The final chapter will focus on presenting a summary of the findings, limitations of the study and implications for practice, policy, and future research.

Chapter Six – Conclusion and Recommendations

6.1 Introduction

In this research, the impact of individualised funding on the wellbeing of mothers raising autistic children in Aotearoa New Zealand was explored. Results from the mothers have shown that raising an autistic child often means the loss of social connection, the loss of family relationships and family support and they have continued to face institution and structural barriers to access services. While the intention of individualised funding was to increase freedom of choice and autonomy for mothers to choose support services that would enhance their wellbeing, the mothers reported that the disability funding systems are complex and often difficult to navigate. The individualisation that underpins the funding system did not seem to have opened more possibilities for mothers to create better wellbeing. Instead of empowerment, mothers caring for disabled children became customers or clients who were forced to enter into a market-driven and competitiveness-focused environment to rely on their own personal responsibilities to "shop" for their own wellbeing. If choice is to be valued to support these mothers, the current research has shown that freedom to seek expertise, information, and knowledge remain ambivalent under the individuality of funding that has enacted through the marketisation in disability service delivery. Based on this context, studying the wellbeing of mothers raising autistic children is complex and confounded by the convoluted notion of choice and freedom. With the limited research and literature in this area, particularly in Aotearoa New Zealand, this research aimed to add to the body of knowledge by exploring these mothers' perspectives. This chapter will provide a summary of key findings, followed by limitations and discussions of practice and policy implications.

6.2 Summary of the key findings

Despite the goals of individualised funding to promote autonomy and choice under the banner of a person-centred approach to empower and liberate disabled children, people and their families, results from the mothers have shown that the impact and consequences of these goals were troubling. The move from ‘clients’ to ‘consumers’ requires individuals, in this case mothers raising autistic children, to locate themselves within the neoliberal market that focuses on profit, efficiency and individual achievement to determine successful outcomes. When these are translated into motherhood, particularly raising a disabled child, this shapes the discourse of ‘good mothers’ or ‘good parents’ underpinning the funding system, creating discrimination and exclusion through actions and attitudes of wider society towards the mother and child. Good parenting and the neoliberal influence are described by Runswick-Cole and Goldey (2017) as redefining parenting into an individualised task filled with responsibilities and obligations. Snyder and Mitchell (2010) argued that the neoliberal model of inclusion focuses on tolerating disability without substantial structural changes or at times, making the system far too complex to navigate for assessment, support, and service delivery (Ryan & Runswick-Cole, 2008). With the logic of efficiency, neoliberalism requires parents or mothers to provide material wellbeing and care to disabled children while relieving the state of responsibilities (Luxton, 2015; Tabatabai, 2019). For mothers, to make time to look after themselves can be seen as doing ‘what’s best for their kids’ but the action of looking after themselves may be seen as selfish or about self-interest. What they are asking for is to resist the individualistic view of achieving wellbeing to opt for inclusive way to look at motherhood, disability, and deep interpersonal connection. Narratives from these mothers have highlighted that motherhood and parenting cannot be accomplished in isolation but needs to or should be reimagined as a collective way to challenge the dominant discourses. This lack of imagination is described by Kafer (2013) as the ‘ableist failure of imagination’.

Choice and self-determination may give rise to control, which are key principles in a person-centred disability funding model, closely aligning to some of the social work ethics to support and empower people who are disadvantaged, vulnerable and oppressed. Results from this study, however, showed this imperative was neither clear nor benevolent. The mothers felt that to pursue an improved quality of life, viewing the family as a unit of care via relational-based frameworks in assessment and support provision was paramount. The ideology framing individualised funding is that disabled children and their family are placed at the centre of care. A strong relationship between clients/service users and service providers has been seen to empower disabled people and their families to make informed decisions (Lord & Hutchison, 2003). However, mothers in the current study expressed a lack of confidence in the assessment process and felt they were not really understood and never really supported, leaving them feeling frustrated and powerless in the process. The individualised funding system was seen to be rigid, difficult to navigate, focused heavily on the individual with limited consideration of families and their perspectives of wellbeing further perpetuating existing social and cultural inequalities. While the ideology of empowerment and involvement is pivotal to disability support for mothers' wellbeing, findings of this research revealed ongoing ambivalence of this process, particularly influenced by the neoliberal and market agenda that guides disability services. The mothers felt it was important to make improvements and to increase flexibility on how funding can be used. Mothers are the experts of their lives, and often are the key to finding solutions to problems which have been barriers to this success in the past. Concepts that would improve wellbeing are reducing social judgement and stigma, having better support, and understanding, from health professionals. Solutions to address the strain on relationships also need to be considered such as access to counselling to address both personal and relationship issues.

6.3 Limitations of the research

Seven research participants were interviewed and while this number was not representative of all mothers raising an autistic child, it provided rich narratives to illustrate the challenges these mothers have faced constantly and the love, hope and resilience they have got to support their disabled child and family. As an exploratory study, the research did not intend to recruit participants based on ethnicity; however, a range of ethnic identities were included in the study through convenience and purposive sampling, including myself as the researcher who identifies as Māori. In my personal and professional experience, there is limited research on autistic children and adolescents specific to Aotearoa New Zealand that includes reporting ethnic identity. However, a recent study of recently diagnosed autistic children aged from 0–19 and focused on the Hutt region of Aotearoa New Zealand found that 55.2 percent identified as Aotearoa New Zealand European, followed by 23.6 percent Māori, and 4.3percent as Pasifika (Drysdale & Van der Meer, 2020). As such, future study needs to consider the importance of ethnicity and culture to be brought into developing person-centred and relational practices not only for the behaviour of those with autism, but also the interpretation that parents or mothers' wellbeing may be viewed or impacted. Despite the study not intending to focus on ethnicity and disability, this body of work adds to our understanding of mothers and families to inform social workers response to mothers within an Aotearoa New Zealand context.

Another limitation that is important to note is that mothers who chose to participate in this research may have a stronger emotional and energy capacity and time not just to share their stories, but also to advocate strongly to improve the system than those who are more vulnerable due to additional challenges and circumstances. Given the study used a convenience and purposive sampling, generalisability of the results to all mothers raising autistic children would need to be cautioned. Finally, as I position myself as insider researcher in this research, there may be some biases in the analyses and interpretations. However, regular research supervision, fieldwork notes, and auditable trails were constantly used to protect the credibility of data to avoid biases.

6.4 Implications and recommendations for social work practice

Narratives from mothers have discussed the lack of understanding of professionals in working holistically to support autistic children and their families. Academic literature has suggested that the social work profession has not yet taken a leadership role in supporting autistic people and their families (Bishop-Fitzpatrick et al., 2018). Given this lack of leadership competence and knowledge among social workers in the field of disability, to achieve best practice outcomes in supporting wellbeing within families, practitioners need to fully understand the impact to the wellbeing of a mother raising an autistic child. To maintain this competency, an Aotearoa New Zealand registered social worker needs to be able to demonstrate they can work respectfully and inclusively with diversity and difference which includes working with disability (Social Workers Registration Board, 2021). Social work education and training shapes professional practice and currently there appears to be a gap between curriculum and practice with disability as a specific field of practice having a low profile within the social work profession. Bigby et al. (2017) and Roulston (2012) stated that there is a risk that disability issues only surface as a specialist option in postgraduate study, which is often too late in the training program to create holistic practice insights. As governments embark on changes to disability systems, it is key that social workers and health practitioners will be able to practice confidently, competently and with a deeper knowledge of disability. To achieve and maintain this competency, it would also be necessary for social workers to continue to participate in education and professional development about autism and wider disability issues on an ongoing basis.

In late 2021, the Aotearoa New Zealand Government announced the establishment of the Ministry for Disabled People which acknowledges that the current system created barriers for disabled people and families to achieve ordinary life outcomes due to complex systems. The new ministry is described as aspirational, and a true transformation of the way government serves disabled people and their families with promises that the new ministry will have a larger range of functions working within the principles of Enabling Good Lives (Ministry of Social Development, 2021) and that families will have more control and choice about the support they receive (Small, 2021), giving hope that there is an opportunity with the new ministry being developed to consider the impacts on families and their wellbeing.

Social work research demonstrates that choice relies on informed decision-making, and whilst individualised funding increases choice, social workers need to ensure such opportunities are available to all groups, particularly the most disadvantaged and vulnerable to facilitate the options of choice for the individual (Laragy & Fisher, 2020). As social workers, we are trained to use a variety of tools, models and methods which consider a person in a holistic perspective. The ecosystem perspective provides social workers with the opportunity to consider the wider holistic system that a child is part of, and it also provides an opportunity to advocate for change at a community or political level (Payne, 2014). This perspective can also begin to challenge the negative consequences, such as, solely considering a disabled child through an individual lens which can embed inequalities (Malbon et al., 2019) and widen inequalities and inequities to health outcomes (Carey et al., 2017). This person-centred holistic approach in practice could be the social worker taking the time to get to know the family, ascertaining what family success through their personal circumstances looks like, and then working with the family to develop appropriate plans to achieve those goals.

Comparison of the mothers' narratives with those of other studies has confirmed the stereotypes and social stigma felt by mothers raising an autistic child, which can have a significant impact on many aspects of their lives and have a detrimental impact on wellbeing. Findings from this study also demonstrated a need to challenge societal social norms that create barriers for mothers and to avoid them becoming socially isolated. Social workers in the disability field will need to be knowledgeable of approaches and models that can be used as tools to help address these stigmas and poor outcomes for both the child and their family. The social and medical models of disability have challenged some of the disability inequities; however, they still focus predominantly on the individual (Hickey & Wilson, 2017) and a more holistic approach to care is required in all planning. The capability approach can be a useful tool for social workers to explore an individual's expectations and their possible pathways of support to realise those expectations (Kjellberg & Jansson, 2020). It can also be used as a framework for social workers to challenge the dominance of neoliberal ideology and promote social justice and human rights (Gupta, 2015).

Social workers will need to become strong advocates to support the wellbeing needs of mothers through this more holistic lens, and to ensure these wellbeing needs are considered in the planning and delivery of disability funded support; otherwise, carer burnout and fatigue will continue to be an ongoing issue in Aotearoa New Zealand. As an insider researcher myself and as a professional working in the field, witnessing caregiver burnout being a reason a child needs to leave the care of a mother, is a concerning trend that needs to be better understood. Having this deeper understanding could potentially avoiding a tsunami of children not being cared for by a parent and the associated long-term negative impacts to the child and their family. During this research, I had a change of professional roles, and it has become transparent this is a more significant emerging issue than I had first thought. This insider knowledge reaffirms the significance of this research topic in ensuring caregivers wellbeing is given more priority to avoid this potentially becoming a bigger problem for Aotearoa New Zealand families and the state.

Access to information was identified as the most reported unmet need for parents of a disabled child (Tracey et al., 2017). Consistent with this evidence, this research also found that participants found gaining access to information was a barrier, with some mothers stating they felt they were being denied information, and when information was shared, they found it to be difficult to understand. It will, therefore, be important that social workers are educated and understand the disability funding pathways which are available to families by linking into information sessions run by local NASC services or attending local training opportunities supported by parent groups or NGO organisations. This would ensure families are able to navigate what is considered a complex system and have access to all entitlements available to them.

6.5 The impact of COVID-19 on disability

Aotearoa New Zealand, alongside the rest of the world, has been exposed to the COVID-19 pandemic and Aotearoa New Zealand has had to adapt and make changes to systems because of it. The government imposed a nationwide lockdown at the highest level of alert from March 25 to April 28, 2020. Whilst not a contributory factor to this research as data collection occurred after April 28, it is important to comment on COVID-19 as this is a more significant factor in care of disabled children and their families. Families of disabled children reported a decline in mental, physical, and psychosocial health (Chen et al., 2020, Kalb et al., 2021) and mental and emotional exhaustion (Mbazzi et al., 2021) from the lockdown and other COVID-19 restrictions. This research has shown that mothers are already significantly challenged physically and emotionally, and it will be important for health professionals to understand that COVID-19 restrictions will be adding to that. There are also learnings from this specific period of time which have forced communities to think and act differently, for example taking a more collective approach to caring for each other, such as, the promotion of caring for elderly neighbours, communities could also be encouraged to check on other vulnerable communities, such as, families with disabled children in their care.

Potentially, there are opportunities for further research into some of the benefits that have emerged during the lockdown periods for families. Anecdotally, within the autistic community, there are multiple reports of autistic children enjoying the lockdown environment. Families reporting that children had less periods of elevation or episodes of challenging behaviour. The Aotearoa New Zealand Government also made some changes to how carer support can be used, with more flexibility of the rules and forms could now be emailed rather than posted (Ministry of Health, 2021). Both these changes have been appreciated with extensive positive feedback within the disability community.

6.6 Conclusion

Mothers raising an autistic child in Aotearoa New Zealand face complex systems, which are difficult to navigate and impact on their wellbeing. Research has argued that this complexity of systems may further perpetuate existing social and cultural inequalities, such as, literacy, socio-economic and cultural status (Malbourn et al., 2019). Numerous challenges faced by mothers in this research are confirmed frequently across other existing literature and research. Mothers raising autistic children often experience economic disadvantages, the loss of significant relationships, social isolation, poor mental health, high levels of anxiety, depression and stress.

Individualisation of disability funding frameworks continues to create barriers and negatively impact the wellbeing of mothers. Results of this study urge practitioners and policymakers to consider both the individual needs of the autistic child as well as the needs of mothers.

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Appendices

Appendix A

Ethics approval

-----Original Message-----

From: humanethics@massey.ac.nz <humanethics@massey.ac.nz>

Sent: Monday, 8 June 2020 7:05 pm

To: Racheal.Priestley.1@uni.massey.ac.nz

Cc: Human Ethics <gmhumeth@massey.ac.nz>; Cooper, Lareen <L.Cooper@massey.ac.nz>; Yeung, Polly <P.Yeung@massey.ac.nz>

Subject: Human Ethics Application SOB 20/07 Approved

HoU Review Group

ReviewerGroup

Dr Polly Yeung

Ms Lareen Cooper

Researcher: Racheal Priestley

Title: An exploratory study on how individualised funding in Aotearoa New Zealand impacts the wellbeing of mothers raising autistic children.

Dear Racheal

Thank you for the above application that was considered by the Massey University Human Ethics Committee: Human Ethics Southern B Committee at their meeting held on 08/06/2020.

On behalf of the Committee, I am pleased to advise you that the ethics of your application are approved.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

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

If you wish to print an official copy of this letter, Please logon to RIMS (https://aus01.safelinks.protection.outlook.com/?url=http%3A%2F%2Frims.massey.ac.nz%2F&data=02%7C01%7Cracheal.priestley%40hohepacanterbury.com%7C1088314e5ce4470c2c3208d86584255f%7C57b727f150294fbda564cf73bfc47abb%7C0%7C0%7C637370965529711497&sdata=SHcYg%2FpR04dmrwwBEfdMh0sC6MB3%2B9zCn7BVUejPztM%3D&reserved=0) , and under the Reporting section, View Reports you will find a link to run the Ethics Committee Report.

Yours sincerely

Professor Craig Johnson

Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Appendix B

Request to help recruit document and flyer

Kia ora Koutou

My name is Racheal Priestley, and I am studying towards a Master of Social Work through Massey University.

As part of my study, I wish to undertake research on understanding how Individualised Funding in Aotearoa New Zealand impacts the wellbeing of mothers raising autistic children. I am writing to request your assistance in circulating my recruitment flyers to potential participants.

I wish to conduct interviews with SIX to EIGHT mothers. Selection of participants will be based on the following criteria.

- Has a child (under the age of 21) diagnosed with autism, currently living at home, and been receiving Individualised Funding
- Are current residing in the greater Christchurch area and
- Are able to participate in an individual interview conducted in English for 60 to 90 minutes

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

If you have any questions, please contact me on my mobile [redacted] or through my email [redacted]

You can also contact my research supervisors

Dr Polly Yeung & Ms Lareen Cooper

School of Social Work

Massey University

06 3569099 ext. 83514 or ext. 83519

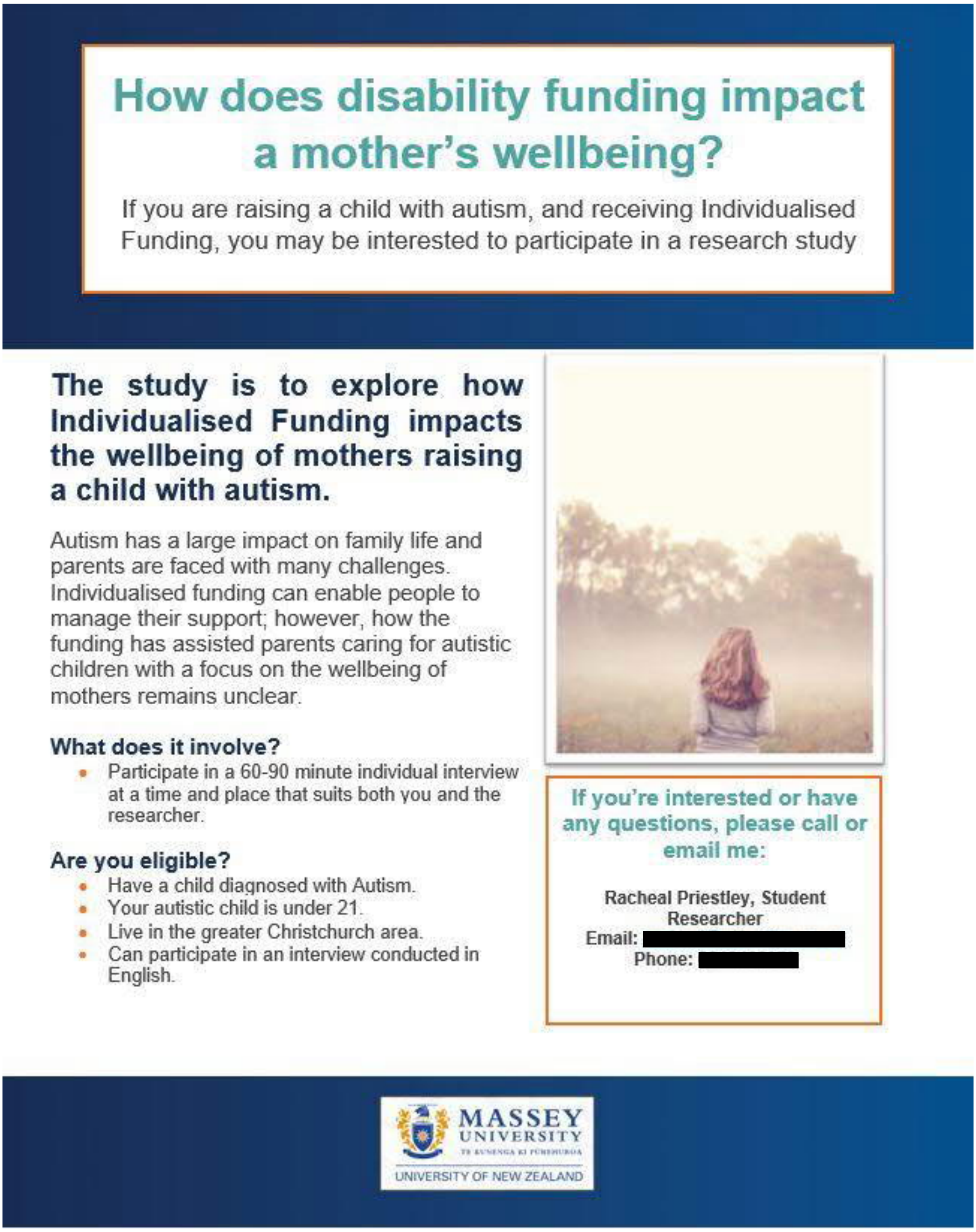
P.Yeung@massey.ac.nz

L.Cooper@massey.ac.nz

Thank you for your assistance.

Kind regards.

Racheal Priestley



How does disability funding impact a mother's wellbeing?

If you are raising a child with autism, and receiving Individualised Funding, you may be interested to participate in a research study

The study is to explore how Individualised Funding impacts the wellbeing of mothers raising a child with autism.

Autism has a large impact on family life and parents are faced with many challenges. Individualised funding can enable people to manage their support; however, how the funding has assisted parents caring for autistic children with a focus on the wellbeing of mothers remains unclear.

What does it involve?

- Participate in a 60-90 minute individual interview at a time and place that suits both you and the researcher.

Are you eligible?

- Have a child diagnosed with Autism.
- Your autistic child is under 21.
- Live in the greater Christchurch area.
- Can participate in an interview conducted in English.

If you're interested or have any questions, please call or email me:

Racheal Priestley, Student Researcher
Email: [redacted]
Phone: [redacted]

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Appendix C

Information sheet.

An exploratory study on how Individualised Funding in Aotearoa New Zealand impacts the wellbeing of mothers raising autistic children.

Introduction

My name is Racheal Priestley and I am currently a Master of Social Work student at Massey University, undertaking a research thesis. I am interested in exploring how Individualised Funding in Aotearoa New Zealand has supported mothers raising autistic children. Aside from being student research, I am also a mother of four children, and three have been diagnosed with autism.

Purpose of the study

Autism is a lifelong development disability characterised by impairments in language skills, social behaviours, and cognitive thinking. It can have a profound impact on family life and parents are faced with unique challenges as caregivers within the home and community. Although Individualised Funding can enable disabled people to directly manage their disability support, few studies have investigated how the funding has fully assisted parents caring for disabled children. The aim of this study is to explore how Individualised Funding impacts on mothers caring for children diagnosed with autism. Due to the nature of the study, you may be asked some questions regarding your relationship with your partner. This research will employ a qualitative research approach by using semi-structed individual interviews with mothers of children with autism in Aotearoa New Zealand

Invitation to the study

I would like to invite SIX to EIGHT mothers to take part in an individual interview who

- Have a child (under the age of 21) diagnosed with autism currently living at home and been receiving Individualised Funding
- Are currently residing in the greater Christchurch area
- Are able to participate in an individual interview conducted in English for 60 to 90 minutes, there will also be information provided prior to the interview which may take 30 minutes to read
- You will be also required to fill in some forms which may take 10 minutes

Priority will be given to the first eight mothers who respond and meet the criteria for participation. If you agree to participate in the research, we will arrange a time and venue to conduct the interview which suits us both. Before the start of the interview, you will be asked to sign a consent form. I will send you the interview questions for you to think about before the interview. The interview will be digitally recorded and transcribed by me. You will be sent the transcript of the interview to review to ensure it accurately captures your views, this may take you 30 minutes to read.

During the interview if you feel distressed or uncomfortable about any of the topics and discussions, I will offer you a break or the option to stop and rearrange another time to finish the interview. You are welcome to bring a support person to accompany you for the interview if needed. A List of support services will be made available for you at the end of the interview, which you can contact if you wish.

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

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

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

Project Contacts

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

Student Researcher	Research Supervisor	Research Supervisor
Racheal Priestley Mobile [redacted] Email [redacted]	Dr Polly Yeung School of Social Work Massey University 06 3569000 ext. 83514 P.yeung@massey.ac.nz	Ms. Lareen Cooper School of Social Work Massey University 06 3569099 ext. 83519 l.cooper@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee, Southern B, Application SOB 20/07. If you have any concerns about the conduct of this research please contact Dr Gerald Harrison, Chari Massey University Human Ethics Committee: Southern B, telephone 06 3569099 ext. 83570, email humanethicsouthB@massey.ac.nz

Appendix D

Consent form

An exploratory study on how individualised funding in Aotearoa New Zealand impacts the wellbeing of mothers raising autistic children

PARTICIPANT CONSENT FORM

I have read and I understand the Information Sheet attached. 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 enough 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 agree/do not agree to the interview being sound recorded
2. I wish/do not wish to have my recording returned to me
3. 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 ___________________

Appendix E

Transcription Release

An exploratory study on how Individualised Funding in Aotearoa New Zealand impacts the wellbeing of mothers raising autistics children

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

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

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

Signature ______________________________ Date ________________

Full name [printed] ____

Appendix F

Interview Questions

An exploratory study on how Individualised Funding in Aotearoa New Zealand impacts the wellbeing of mothers raising autistic children

One to One Interview

Researchers welcome and introduction of self, along with instructions for participants.

Thank you for participating in this interview today and I would like to acknowledge the time you have put aside for this; it is much appreciated.

Researcher's background shared

Setup for ground rules and protocol

- Every answer is important, there is no right or wrong way to answer
- If you wish to take a break, please say so and feel free to leave for a few minutes
- Do you have any questions?

Guiding aims and Checklist

Some background information from the participants (including family background)

- I would appreciate if you could share a little about you, how many children do you have, do you have close family nearby, what is your relationship status and is there anything else you would like to share?
- What is it like to raise a child with autism?

Exploring a mother's definition of wellbeing

- What does wellbeing mean for you?
- What do you think wellbeing would mean for families raising typically developing children?
  - If there is a difference, why do you think this is?
- What things do you consider as important that contribute or improve you your family's wellbeing?

Exploring participants experience with getting and accessing Individualised Funding

- How long after diagnosis did it take to get Individualised Funding for your child?
  - What was it like during the waiting period?
  - How did that affect you and your family?

- Can you tell me what was your understanding of the funding guidelines for Individualised Funding when you were applying for it?
    - Do you know what it can be used for?
    - How much support did you receive to enable you to work out what Individualised Funding could be used for?
- Reflecting on your experiences, how have you found your funding host or NASC regarding providing you information about Individualised Funding in a way that is easy to understand?
- Tell me how Individualised Funding has made significant support /contribution /improvement to you, your autistic child(ren) and family? Reflecting on natural supports such as friendships, do you think there is a place for Individualised Funding to be used to support these relationships to contribute or improve wellbeing as a mother?
- How would you like to see Individualised Funding provide more support around the challenges you face with Individualised Funding not meeting your needs?
- What sort of recommendations would you suggest on how Individualised Funding could create more positive outcomes for mothers' wellbeing, and why?

Exploring the importance of social support towards achieving wellbeing

- Can you tell me who is your support network?
    - Why are these people important to you?
    - How often do you see or access them?
    - What and who helps you to get through a challenging day or issues when it comes to your autistic child and family?
- When you think of friends (including work friendships) with typically developing children, do you talk about your experiences of raising an autistic child?
    - If yes, how have you found the experiences with friends/work colleagues who do not have disabled child(ren)?
    - If not, what are the reasons of not talking about your experiences of raising an autistic child?
- Reflecting on natural supports such as friendships, do you think there is a place for Individualised Funding to be used to support these relationships to contribute or improve your wellbeing as a mother?
- Do you have friends who also have autistic children?
    - Have you found this friendship to be helpful to your wellbeing?
    - Can you tell me a bit more about why it has or has not been helpful?

Exploring wellbeing and relationships

- Earlier on, you talked about your current relationship status, you mentioned that…you are still with the father of your autistic child
    - How are the duties and responsibilities of caring for your autistic child shared between the two of you?
    - In what ways does your partner support you and your health and wellbeing when raising your autistic child(ren)?
    - What kind of things do you and your partner do as a couple without your autistic child?
    - How do you feel about using Individualised Funding as a respite option to support and strengthen your relationship with your partner as a couple?

    -
- You are not with the father of your autistic child(ren)
    - Tell me why you are no longer with your partner?
    - What is the current role of the father of your autistic child(ren)?
    - Who has access to Individualised Funding support? Both of you? Tell me what the arrangements are? How do you think your current partner contribution to the autistic child(ren), other sibling's and the whole family has helped or hindered your overall health and wellbeing?
- What kind of support do you need if you want your ex-partner to make a more positive impact in this family, particularly to the autistic child(ren)?
    - How do you think Individualised Funding could be used to achieve that positive impact?

Identify what supports or developments to Individualised Funding would improve the wellbeing of mothers raising autistic children

- What professional support do you currently receive to help you with your overall health and wellbeing?
- You mentioned…. As part of your professional support
- Is your GP aware that you have an autistic child in your care? Do you use your GP for support?
- Have you ever needed to go to your GP for medication to help cope with your personal and family issues?
- If you have not accessed your GP, what are the reasons? What other support would you like to receive?
- What do you think are the most important supports for mothers' wellbeing in raising disabled children?
- If you were to change anything around disability funding support to help mothers' wellbeing, what would it/they be and why?

After sharing your experiences today has there been anything you think has been missed if after leaving you would regret not sharing? Or would like to share separately?

Conclusion

- Thank you for participating, I really appreciate the time you have taken today to share your valuable knowledge and experience
- A transcript of the notes will be provided to you for your feedback.