ORIGINAL ARTICLE

QUALITATIVE RESEARCH

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

Racheal Priestley[1], **Polly Yeung**[2], **Lareen Cooper**[2]

[1] Registered Social Worker

[2] School of Social Work Massey University

ABSTRACT

INTRODUCTION: How best to support the wellbeing of mothers raising autistic children is an emerging issue of importance due to the growth in autism diagnoses. While the move to individualised funding has been seen to promote autonomy for disabled people and their family to make decisions about services to meet their needs, it has also received criticisms, leading to inequitable processes and outcomes. The purpose of this research was to explore how individualised funding has impacted on mothers raising autistic children and their wellbeing.

METHODS: A qualitative approach, combining semi-structured interviews and the theoretical underpinning of social constructionism, was used to interview seven mothers in 2020 to discuss their experiences of raising an autistic children and how individualised funding has impacted on them. Thematic analysis was used to analyse the data collected.

FINDINGS: 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.

CONCLUSION: Mothers raising an autistic child in Aotearoa New Zealand face complex funding systems, which are difficult to navigate. Individualisation of disability funding frameworks continues to create barriers and negatively impact the wellbeing of mothers. Wellbeing requires the funding support to see the family as a unit of care instead of the individualisation of a child's needs. Results of this study urge practitioners and policymakers to support parents raising an autistic child in a more flexible and holistic way to meet the unique circumstances of a family.

KEYWORDS: Autism; individualised funding; mothers; wellbeing; disability

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CORRESPONDENCE TO:
Racheal Priestley
racheal@priestley.co.nz

Many countries, including Aotearoa New Zealand, have been shifting disability support from a government-managed to a consumer or client-led approach to enable disabled people to exercise their rights which have been previously neglected and marginalised (Foley et al., 2020; Rummery, 2006). Increasingly, research has focused on discussing how individualised funding can positively impact on disabled people by fostering autonomy to make decisions about services to meet their needs, in a challenge to the traditional top-down approach (Fleming et al., 2019; Yates et al., 2020). While the move to individualised funding is an international trend, existing research has focused mainly on the benefits for disabled people, and the implementation system changes by professionals and service providers (Fleming et al., 2019; Foley et al., 2020).

Individualised funding may provide some flexibility in individual care and choice for disabled children and their family. However, the notion of individualisation varies with people's ability to negotiate the system while the distribution of choice and control across the population is not entirely inclusive or equal (Carey et al., 2017; Malbon et al., 2019). In addition, the care and support for disabled children usually falls to women, which can have negative impacts on their health (Cantero-Garlito et al., 2020). With the growing adoption of individualised funding within disability service provision, understanding how individualised funding influences the wellbeing of mothers raising an autistic child is particularly crucial for practitioners and policymakers. This article reports the findings from interviews with seven mothers, each raising an autistic child in Aotearoa New Zealand, about their experiences with individualised funding and its impact on their disabled child/children and their own wellbeing.

Positioning of the researcher

This article came from the first author's Master of Social Work thesis, which had both a professional and an insider research lens. As a mother raising three autistic children and a registered social worker with extensive experiences in disability sector, it was not uncommon to hear stories of people struggling for years without any support, nor was it uncommon to hear stories of a caregiver facing emotional and physical fatigue resulting in caregiver burnout. The thesis journey was, not only an academic journey, but an opportunity to realise just how important it was to look after oneself while appreciating just how hard it is to add selfcare into an already busy schedule. It is hoped that by sharing the research findings, the wellbeing of mothers raising disabled children would be given more importance.

The use of terminology around autism, specifically the language used to refer to autistic people, has a significant role in an 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 (Vivanti, 2019). Identity first language is considered an appropriate expression of a cultural shift to a neurodiversity perspective. It has been intentionally used to counteract the risk that separating the person from the diagnosis perpetuates a societal view that something is wrong about the diagnosis. Where possible without changing historical context or other academic literature, the term *autistic* has been purposely used throughout this article as a positive and affirming word to replace language such as autistic spectrum disorder or its acronym ASD.

Literature review

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 (Centre for Disease Control and Prevention [CDC], 2022) with an estimate of 0.5–1% of the world's 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).

The lifelong nature of autism creates a deep impact on, and challenges for, parents raising an autistic child. Research has indicated that mothers caring for a child with a disability are at greater risk of experiencing negative psychological outcomes and parenting-related stress than mothers of non-disabled children (Oprea & Stan, 2012; Ozgur et al., 2018). Challenges faced by mothers raising an autistic child are directly related to accessing disability support, including obtaining a diagnosis, finding appropriate treatment, costly medical treatments, and therapies, and managing problematic behaviours whilst learning how to navigate support service systems (Minnes et al., 2014;

Weiss et al., 2013). The negative impact of a drawn-out diagnostic process for mothers can result in an increase in anxiety and depression levels (Gobrial, 2018).

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 (United Nations [UN], 2020). Choice is a central driver in both paradigms; however, neoliberalism emphasises choice in a free market, and human rights advocates choice of the person with a disability (Purcal et al., 2014). Individualised funding or personalisation policies vary widely internationally regarding their degree of choice, flexibility, access, and entitlements to funding. However, it has also been criticised for being inflexible to accommodate changes to plans—for example, using funds for different types of therapies (Carey et al., 2019). 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 Goodley (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). 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).

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). 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, loss of support, and discrimination. 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. Htut et al. (2019) have reported that the current disability support services provided by Ministry of Health are complex, fragmented and difficult to navigate. Another study stated 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).

Support from professionals has been reported to help reduce care-related stress (Goedeke et al., 2019), and to play a role to provide valid and trusted information in disability funding, as well as service provision to support the families (Laragy

& Ottmann, 2011). Bennie and Georgeson (2019), however, argued that currently those in social work roles are mainly practitioners who do not have lived experience of, or have a limited knowledge of, disability. This means these social workers will need to negotiate their way through a system somewhat unprepared as more disabled people and their families and whānau require support.

COVID-19 has exacerbated pre-existing difficulties and inequity that 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., 2020). These adverse effects are likely to affect the wellbeing of autistic children and their families, and these 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 at risk of experiencing greater psychological distress as reported in Manning et al.'s (2020) study. 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). 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.

In summary, autism is a lifelong condition that is on the increase worldwide. The impact of raising an autistic child is reported to lower the level of wellbeing for mothers. Aotearoa New Zealand has seen shifts in public policy which has resulted in an increase in disabled people having more choice and control over their lives as well as neoliberal privatisation of social services. A better understanding of how these services and systems impacts mothers raising an autistic child in order to improve wellbeing was the catalyst for this research.

Methods

Study design

Using semi-structured interviews, a descriptive and an interpretive approach to both describe and interpret the stories of the mothers, combined with social constructionism, was used 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. Using an interpretive approach has allowed the researcher to understand and describe the experiences of mothers while also acknowledging the differences of each family situation. Interactions with these mothers and sharing and reliving significant moments of their personal stories, alongside the first author's insider view, provided a broader and more in-depth insight on their perspectives and subjective experiences of being a mother raising an autistic child.

Study Participants

To be eligible to participate in this research, participants needed to be a mother of an autistic child (aged 21 years or under) and receiving individualised funding; currently residing in one of the major cities in the South Island; and able to participate in an interview conducted in English. The reason to specify 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 and circulated to mothers who met the research criteria via friend and work colleague networks. The seven mothers who contacted the first author via email were then sent an information sheet and all accepted the invitation to participate in the research. All interviews were completed between July and August 2020 (Alert Level 1) before the rest of the country (except Auckland) moved to Alert Level 2 on 12 August 2020.

Ethics approval was obtained from the Massey University Human Ethics Committee (SOB 20/07). Voluntary participation, informed consent, respect for privacy and confidentiality and data storage adhered to ethics guidelines. As a professional and a student researcher, the first author 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 the first author potentially had, unintentionally making people see her as the expert when, in fact, the mothers are the experts of their own lives. One participant stated that although reflecting on the past was sad, it was nice to talk about it with someone who understood and also to remind herself of 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.

Data collection

Upon receiving an email consent from participants, a mutually agreed time and venue was arranged. The primary method of data collection was the use of semi-structured interviews which was described by Carey (2017) as the best format for social work research as these 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 interview questions explored mothers' personal circumstances including relationships within the family and in the community, how they defined wellbeing and how they came to have individualised funding and their experiences on using this to improve their wellbeing. The insider researcher lens enabled an understanding of the culture and ability to know how best to 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). Each interview lasted between 50 and 110 minutes. Once the interviews were completed, they were transcribed verbatim by the first author. A copy of the interview transcripts was emailed to the participants for review.

Data analysis

A thematic analysis of the interviews was carried out. 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 used for its strengths in helping to identify, analyse, and report patterns or themes in the collected data (Cartwright, 2020). During the process of transcription and rereading the transcriptions, emerging patterns and themes began to highlight some of the statements that captured these themes in the mothers' 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.

Trustworthiness

Multiple means of investigator triangulation (Lincoln & Guba, 1985) were used in this study to reduce potential bias in data collection and analysis. Member checking was achieved by all participants who signed the transcript release document after reviewing the transcripts. Credibility was considered by reflecting on the first author's bias as the researcher, triangulation of data sources and theories. Confirmability and dependability were achieved using field notes during the research process as well as the end product, allowing the researcher to describe the participants mothers' stories which guided the research.

Findings

The seven mothers were reported to be aged between 30 and 50 years of age. Most of the mothers ha 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 (see Table 1).

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 some sub-themes, using direct quotes from the study participants to help with interpreting the phenomena.

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.

1.1 Dealing with grief and loss in relationships

The complexity of relationships for mothers raising an autistic child often results 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 demand of raising an autistic child often puts strain on a range of relationships resulting in connections prematurely ending.

> I don't have deep friendships because my experience is so different from other people and other parents. (Alice)

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

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

*Pseudonymous were used to de-identify participants' real names.

likely to end in divorce or separation. Four of the mothers interviewed had separated from the father of the child.

> It's like it has embraced our entire lives. Like I never would have thought possible. It impacts your marriage, your other children, your work life, your social life, your everything. (Julie)

The negative impact from losing personal and social relationships 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. Due to the barriers of cost and time, only one participant mother received some regular counselling. Another participant 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.

Respite breaks were seen as important but difficult to arrange with many relationships structures negatively impacted. Participants certainly wanted more respite support, and understood the value of these breaks, 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. 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.

1.2 Social stigma and burden

Cultural norms and societal motherhood beliefs have been strongly linked to the expectation of the *good mother* discourse, which was 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 made them feel anxious and eventually avoid situations where they felt they would be judged.

> 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". (Heather)

> 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 his behaviour is so unacceptable. (Maggie)

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, the reality for mothers raising autistic children was different in that they were often negatively judged in social situations and there was little financial support offered to make that self-care possible.

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 concerns about the complexity of the funding systems, which made them feel anxious, stressed, and disenfranchised. Nadia described the process to get individualised funding as *one of the most stressful times of her life.*

2.1 Assessment process – Unwelcoming, oppressive and complicated

The needs assessment process was often the first step and first introduction to the disability funding systems and was described as oppressive, disjointed and complicated. The participant mothers 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. The person who was ultimately responsible to make the funding decision was not the person who came to do the assessment. This process created a lack of confidence for the mothers that their child, and their needs, would never be fully understood.

> Having to prove how much of a challenge it is to people… You actually just had to lay on how much of a deficit it is, and the celebration of the child is absolutely lost. (Heather)

> 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. (Anne)

2.2 Funding is to be individually and wholistically focused

Feedback from the mothers indicated 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.

The concept of being able to access support early or as needed was also linked to personal wellbeing by many other mothers. Maggie stated, "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." This feeling of frustration, powerless and hopelessness that funding issues were simply a battle and barrier was echoed by all participants:

> 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. (Maggie)

Every mother 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 adjustable. 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." For them, wellbeing represented 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.

2.3 More barriers and stress from a confusing system

While many of the mothers had been using individualised funding for several years, including two mothers who had been using the individualised funding system for longer than 10 years, there was still significant confusion around the funding guidelines. Having the responsibility to constantly try to navigate the complex system to seek information about the autistic child's funding has made them feel that they were being put in a vulnerable position, often resorting to social media to ask questions, especially during the COVID pandemic. Social media is described as an unreliable source of information as it could cause unnecessary anxiety due to the credibility of the information that was being presented. Nadia stated she would call the funding host to try and clarify a purchasing question without success, and would end up seeking answers on social media, "I generally found that out on Facebook".

When interviewing Maggie, it became apparent she was still using information that was out of date. Maggie was surprised to hear changes had been made to the system for over 6 years; yet, she had not received any information regarding these changes. Finding information out years later that there had been a change, ended up creating feelings of anger and grief for these mothers. Mothers knew that they had been financially stretched and using the family income for years to pay for something that could have been supported through individualised funding. Many of these families have other typically developing children in their care, so using the family income to pay for disability-related costs that could have come from the child's funding also made families feel they had been denied opportunities to use their family income for their other children.

The vulnerability and additional stresses were highlighted in the experiences of these mothers. There had been times that 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 lockdown 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." All of the mothers felt it was important that improvements be made as to how funding changes should be communicated to families to create equity of access.

Discussion

Results of the study show that mothers raising an autistic child have faced a multitude of challenges that negatively impacted on wellbeing. 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 of funding has not been able to respond to the unique circumstances of families, especially for mothers raising autistic children. 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 view that funding fails to meet the needs of mothers of autistic children, because it seems that funding decisions are linked to the perception of wellbeing in terms of individual benefit, rather than collective good. The impacts of neoliberal influences on funding and allocation of resources, whether implicit or explicit, somehow accelerates and deepens the injustice processes to dichotomise *good* mothers as those who can cope versus those who struggle as *bad* mothers (Charmaz, 2019). Mothers in the current study did not necessarily enjoy the freedom of choice that having access to individualised funding was supposed to purport. 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 only in an individualised context—and only if it enhanced their children's wellbeing. Research on disability studies has argued that mothers of disabled children are often forced to take a liminal position because they are often not disabled but can experience forms of disablism (Ryan & Runswick-Cole, 2008). The focus is often so much on the child that mothers' needs are "hidden" and ignored.

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). 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).

The responsibilities of advocacy, coordination and service management have been seen to have shifted from the state or government to parents and caregivers (Simpson et al., 2016), adding 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 them, which then places more accountability on parents (Gavidia-Payne, 2020; Malbon et al., 2019). 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 the holistic needs of a family, leaving them feeling undervalued. These experiences precipitated negative feelings towards day-to-day living and for their futures, which can widen inequalities and inequities (Carey et al., 2017). This suggests that unless the overall wellbeing of the family unit is considered within policies and systems, there will be no improvement to wellbeing.

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). Many of the participant mothers expressed that with the friendships that they were able to maintain, they did not want to burden their friends 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, particularly when they did not want to burden them or lose a friendship due to challenging behaviour or lack of understanding around autism (Shepherd et al., 2020). Findings of the current study have highlighted that mothers did not experience the anticipated 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 their contribution (Laragy & Fisher, 2020; Thomas, 2020).

Implications and recommendations for social work practice

Narratives from mothers of this study have discussed the lack of understanding of professionals in working holistically to support autistic children and their families. Research 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). In Aotearoa New Zealand, any registered social worker needs to be able to demonstrate they can work respectfully and inclusively with diversity and difference, this 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) 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 programme 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 practise 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 (Simpson et al., 2022).

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 and promises to have a larger range of functions working within the principles of Enabling Good Lives (Ministry of Social Development, 2021). Families will also 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, especially with the long and ongoing impact of COVID 19 on disabled children and their family and whānau.

Limitations of the study

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 was included in the study, including the first author who identifies as Māori. Currently, there is limited research on autistic children and adolescents specific to Aotearoa New Zealand that includes reporting ethnic identity. However, a 2020 study of recently diagnosed autistic children aged from 0–19 and focused on the Hutt region of Aotearoa New Zealand found that 55.2% identified as Aotearoa New Zealand European, followed by 23.6% Māori, and 4.3% as Pasifika (Drysdale & Van der Meer, 2020). As such, future studies need to consider the importance of ethnicity and culture to be brought in 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.

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, and socio-economic and cultural status (Malbon et al., 2019). Numerous challenges faced by mothers in this research are confirmed across other existing literature and research which include economic disadvantages, the loss of significant relationships, social isolation, stigma, 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 as a collective of care.

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