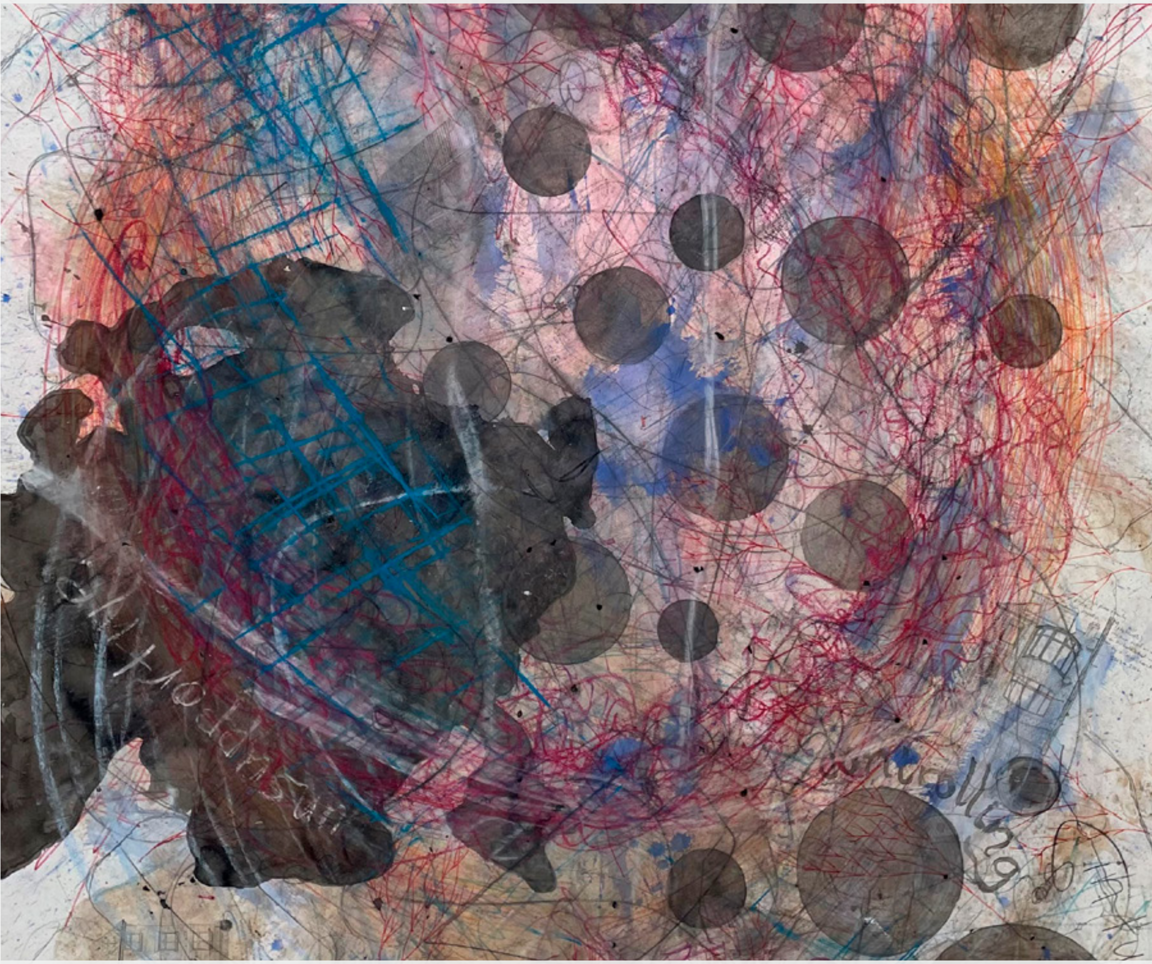
Journal of the Motherhood Initiative

Learning from the Pandemic

Possibilities and Challenges for Mothers and Families

Spring / Summer 2023
Vol. 14 No. 1



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Parenting during a Pandemic: Mothers and Disabled Children in Aotearoa/New Zealand—A Hidden Minority

Every country has its own COVID-19 pandemic story; similarly, every family has their own experiences of lockdowns, isolation, illness, death, struggles, and resiliency related to the pandemic. Although myriad narratives appear about these familial and societal experiences, few explore those of mothers of disabled children; these have been largely invisible, and as a result, this minority group and their needs have failed to be addressed by those who make decisions and plan for public health crises and for the subsequent recovery.

Autoethnography, a qualitative method that coalesces personal experience and research literature to advance sociological understanding, underpins this exploration. The authors are New Zealand/Aotearoa mothers of disabled children. Our approach employs autoethnographic reflection about our pandemic experiences to create meaning, forge identities, and explore power structures. Connections of our family stories enable the creation of an understanding of what has happened in our communities.

The authors' reflections on their pandemic experiences are woven together with stories of how governments, schools, public health organizations, disability organizations, healthcare providers and communities directed us and responded to or failed to address our needs. We have identified five interwoven themes throughout our stories: anxiety, invisibility, devalued lives, coping, and advocacy. Together, as an outcome of the autoethnographic study of our pandemic experiences, we offer ideas for survival to pass on to mothers for future disasters and crises. Furthermore, we have developed recommendations for organizations and others living with disability.

Like other countries, Aotearoa/New Zealand (Aotearoa) has its unique experience of the COVID-19 pandemic and the associated lockdowns. There are stories that highlight the pandemic's impact on communities, families, and individuals. These stories exist across myriad life intersections and include experiences of lockdowns, unexpected deaths, illness, and health system crises. In addition, many people experienced career changes, altered working patterns, and financial challenges because of the pandemic lockdowns. There were also relational stories of new friendships and families and partnerships flourishing. But for some, these involved struggling and endings (Boschee Ellefson). Narratives about domestic violence and bored school children as well as stories of gardening, joining fitness programs, bird watching, and sourdough bread baking have emerged in the media (Knight), and slowly these stories are appearing in research (Lee et al.).

Literature is beginning to emerge about mothering and COVID-19 exploring its effects on mothers with disabled children (Hochman; Power). Yet the small yet growing body of literature is primarily focussed on clinical issues, such as pregnancy and antenatal care (Goyal et al.). For example, one study from Saudi Arabia quantitatively compared quality of life (QOL) of mothers of nondisabled and disabled children during the COVID-19 lockdowns (Awaji et al.). Mothers of disabled children reported significantly lower QOL, had higher support needs, and had significant concerns about the deterioration of their children's medical conditions and about obtaining medical supplies. Petri Embregts et al.'s qualitative research concerning the Netherlands, which involved interviews with five mothers, highlighted that mothers of disabled children needed respite from their caring responsibilities. They also required advanced coping skills to assist their children for prolonged periods. The mothers in this research relayed that they needed the support of educators who could provide them with the tools they needed to continue their children's education during periods of isolation. Most recently, some autoethnographic studies have explored the issues of mothering disabled children (Bonnitcha; Brulé; Pozniak and Kraus de Camargo). These emerging stories have begun to address the trauma of lockdowns, the injustices of remote learning, and the challenges of securing paid carers; these researchers have also started examining some of the long-term effects of the pandemic on mothers and children.

We, the authors of the reflections contained in this article, are mothers of disabled children in Aotearoa. We have coped with the pandemic, lockdowns, and recovery period. Our specific needs are largely unknown, and our struggles before, during, and in what we hope is the aftermath of this pandemic, have gone unnoticed. We are an invisible minority; this partly stems from a lack of time and energy to tell our stories. When we have spoken, made submissions to official bodies, involved the media (Good; Good and Lee; Stuff.co.nz National Education), and tried to tell our stories, our employers, unions, governments, health systems, schools, and communities have not heard us or taken action. Disabled adults, children, and their families were forgotten in the COVID-19 pandemic and have also been ignored in its recovery as well as in the planning for future disasters.

We do not yet know how mothers with disabled children have managed to conduct home-based therapy programs while negotiating healthcare systems, schools, and government mandates. Furthermore, there are few insights into how working mothers of disabled children managed the practicalities of supervising and educating children with significant educational and support needs while maintaining their familial relationships as well as their careers. With our stories we wish to let our families, schools, employers, and communities know that disabled children, their mothers, and their families need more support. Their lives need to be valued and changes need to be made.

Aotearoa, Disability, and Parenting

Aotearoa is a country of five million people, with an estimated 24 per cent identifying as disabled. Estimates are that 11 per cent of children aged between zero and fourteen years are disabled (Statistics New Zealand), and the top three impairment types for children are learning difficulties, psychiatric or psychological impairments, and difficulty with speaking (NZ Ministry of Health). Most commonly, impairments were reported to be present at birth (NZ Ministry of Health). Despite its commitment to social service provision, and its reputation for its universal, tax-funded national health service and no-fault accident compensation scheme, health inequities for disabled people persist (Goodyear-Smith and Ashton; Perry et al.).

No research has been identified that explores the experiences of mothering during the pandemic within the context of Aotearoa. However, before the pandemic, Charissa McBride et al. researched the experience of parenting disabled children (children with severe food allergies) in Aotearoa. Participants reported challenges in accessing information and appropriate healthcare; they reported being socially isolated and experiencing negative public judgment, anxiety, and stress as shared experiences. They cited difficulties in ensuring their children are safe at school, and the cost of living with a disability was challenging. In another study conducted about parenting disabled children, before the pandemic, Carey-Ann Morrison et al. wrote about Aotearoa parents and their need to advocate and be activists on behalf of their disabled children. In this research, parents shared accounts of family life with disabled children in which the child's needs were not met, their rights were not honoured, and they received inadequate support across education, social, and health spaces. These authors explored how nondisabled parents of disabled children faced and countered ableism in Aotearoa and then fought for positive social change. Jane Lee researched the experiences of single-mother-led families with disabled children in Aotearoa, and her research highlighted the impact of social isolation, loneliness, and socioeconomic challenges on these families as well as the lack of information and support they received; Lee, however, also highlighted ways that single mothers with disabled children recrafted their identities in a positive way. In addition, Gretchen Good et al. explored advocacy as disabled and nondisabled mothers of disabled children in Aotearoa ("Social Model Mothers"). In this article, our stories, which are told in a series of unique reflective and autobiographical essays, include the experiences of disabled and nondisabled mothers and the challenges we faced during the 2020-2022 COVID-19 pandemic in Aotearoa. From these essays, we develop and offer lived-experience recommendations for social transformation for a more inclusive, safer, and less ableist country and world.

Methods

To fill the gap and advance knowledge about the experiences of mothers and their disabled children in Aotearoa throughout the COVID-19 pandemic, our essays employ an autoethnographic method, which uses our lived experience as mothers of disabled children. Autoethnography examines everyday reality to advocate for changes in policy and practice and to push for social justice for our families and others like ours (O'Hara); this approach to developing new knowledge has also been used by other mothers of disabled children (Zibricky). Autoethnography allows for imagination, innovation, and a range of voices while maintaining academic quality, rigour, and informative academic research (Stahlke Wall). Here, we will share our stories and then investigate shared experiences that can inform recommendations for change. In keeping with the autoethnographic approach that has guided this research, and since the cultural context forms the basis for any ethnographic reflection, our telling begins with an explanation of the context, which weaves together literature, research, and our experiences. The individual essays are then offered within the contextual matrix.

Our Cultural Context: The COVID-19 Pandemic and the Aotearoa Experience

Aotearoa 2020

Aotearoa had one of the strictest lockdowns in the world, and on March 26, 2020, we were required to self-isolate; the New Zealand Government gave us 48 hours' notice to prepare. The lockdown aimed to eliminate the COVID-19 virus. Lockdown meant that our borders were closed to international travellers; citizens and permanent residents who did return to Aotearoa were required to undergo two weeks of isolation at government-managed hotels guarded by the army. There were travel restrictions, as people could only visit their local area, as well as a contact tracing requirement. All education also moved online

(Baker et al.). Essentially, we all stayed home unless purchasing food or accessing healthcare. There was a general sense of cooperation with, and acceptance of, this approach to prevent the spread of and eliminate COVID-19 within our community; New Zealanders were labelled the "Team of Five Million," and the government worked hard to regularly communicate with us (Beattie and Priestley; Good et al., "Access"). The result of this initial lockdown led to COVID-19 being eradicated, and after approximately nine weeks of strict isolation, we were essentially able to return to normal everyday life in Aotearoa. This was celebrated as a national success; however, the families who relied on support from special educators, carers, or therapists to support disabled children were left reeling, as they tried to recover and revive support systems that in many cases had taken years to build. Support had dissolved (Ministry of Social Development; Stuff.co.nz National Education).

Aotearoa 2021

Aotearoa returned to a strict lockdown again in response to the arrival of the Delta variant in August 2021; this lockdown lasted for three weeks. Once again, schools closed, and all but essential workers remained at home. For those with disabled children, it meant being schooled at home with little school support, and no additional carer support in the form of respite care or extended family. In addition, therapy appointments were cancelled. The lockdown in Auckland, the largest city in Aotearoa, continued for months, and internal borders around Auckland, where the Delta variant was prevalent, were enforced. Fines and arrests were imposed upon those who breached the borders. All other locations could return to a "new normal"; this meant we needed to wear masks when we were in public spaces and track those whom we came into contact with to minimize the impact of spreading the virus.

In 2021, Aotearoa began to distribute vaccines; there was a requirement that all those who worked in health, disability services, and education be vaccinated. These measures helped us to feel safer, yet COVID-19 continued to impact disabled adults and children in disproportionate ways, which remained largely unrecognized (Ministry of Social Development; Stuff.co.nz National Education; Good et al. "Access"; Roguski et al.).

The lessons learned from being in our first lockdown had a positive impact on the second lockdown. For example, additional services were available, such as online delivery of goods and educational materials. In addition, schools had developed approaches to support families through the provision of online lessons. As a result, to a certain extent, the 2021 lockdown was easier. However, the experience remained overwhelming for mothers of disabled children (Stuff.co.nz National Education); this group of mothers struggled immensely because of the extensive workload associated with caring for their disabled children. The fear of COVID-19 and its impact on disabled children or disabled parents required many families to isolate more extensively than others. Moreover, the experience was made even more unbearable if mothers were also in paid employment and unable to take time off (Rogers et al.).

Aotearoa 2022

In early 2022, the Omicron variant managed to evade Aotearoa's strict border controls. As a result, Aotearoa's government introduced a new traffic light system to minimize the spread of the virus in the community. The new system no longer involved lockdowns. The effort to keep the pandemic at bay meant that virus fatigue set in, and the previous sense of unity within the Aotearoa community was changed by various anti-vaccination and anti-mandate factions (Wikipedia), which resulted in disruptive protests similar to those seen around the world.

Globally, social isolation and anxiety remained a great concern for parents of disabled children (Hill; Wanjagua). COVID-19 also continued to affect disabled adults and children and their families in Aotearoa despite the country's well-managed system to contain its spread. Disabled adults and children were abandoned in the sentiment that everybody will eventually be exposed to Omicron, and "only" those with underlying health conditions will be affected severely or die (Meredith). In 2022, children and teens had access to vaccinations and there were mask mandates in schools for a time, but few provisions were made to make vaccinations safe and accessible for disabled children. To further compound the challenges, no guidance was provided for children who could not understand social distancing or tolerate masks, or COVID-19 testing. As a result, families with disabled members struggled to manage isolation and illness. In September 2022, all mask and vaccine mandates were eliminated in Aotearoa, making the world suddenly seem like a much more dangerous place for vulnerable adults and children.

Our Stories

Our pandemic experiences in Aotearoa can be summarized with five overarching themes: anxiety, invisibility, devalued lives, coping, and advocacy. These themes are derived through our autoethnographic reflections and a deductive process that involved an in-depth collective analysis of each experience. These themes are presented within the narratives' context and woven throughout our stories; we invite readers to identify and engage with these emergent themes.

Our families' stories, like so many others', now include multiple deaths within our extended families and the inability to attend funerals or to help the children process these significant life events due to COVID-19 restrictions, which caused us to experience anxiety. Some of us had to make decisions to keep children home from school and to continue to isolate as the Omicron variants surged throughout 2022; this resulted in feeling invisible and that our children's lives were devalued. These decisions had to be made without support from schools and communities, and as a result, we struggled to cope. As our family stories evolved, our message remains one of advocacy: Do not neglect the needs of disabled children and adults in planning for disaster or pandemic management and recovery.

Gretchen—The Burden of Planning, Coping, and Advocating

I am Mum to two children who each live with Down syndrome. My children also experience autism, ADHD, hearing and vision impairment, epilepsy, and immunosuppression. When schools closed and lockdowns were introduced, our family lost a morning carer, a beloved godmother who provided paid afterschool care, blindness specialists, speech therapists, occupational therapists, teacher's aides, teachers, hippotherapists at Riding for Disabled, Special Olympics coaches, dance tutors, and church and t-ball communities. Friends and neighbours, too, disappeared from our community. I am vision impaired and was using a wheelchair in 2020, and like my children, I am immunocompromised, which has added to our anxiety, coping strategies, and advocacy challenges with COVID-19.

Our children, like many other disabled children, thrive on routines and relationships, which help to maintain their behaviour and wellbeing. They require intensive, one-to-one supervision and cannot be expected to learn independently or even play on their own while I work. They struggled to keep a safe social distance from others, wash their hands thoroughly and independently, and tolerate a face mask or COVID-19 testing. Their vulnerabilities became more pronounced and were the cause for much anxiety.

The anxiety of protecting my children took its toll on my sleep, productivity, and wellbeing; the children sensed this stress. At the first cough symptoms, we had to attempt testing for COVID-19, sending us into waves of anxiety, as we wondered how we could isolate one or more family members if necessary or manage a hospitalization. Medical appointments are a part of our regular life to maintain and monitor our children's hearing, vision, as well as their gastro and orthopaedic health, but many routine appointments were cancelled, yet we still had to make multiple urgent trips to the hospital. These trips were frightening. We preferred to remain safe at home in our bubble.

The teaching resources from schools, government, and online searches were not appropriate for our children. They required technology that our children had not mastered and intense supervision for every lesson. We managed to teach basics and attempted to keep up with sign language skills, speech skills, positive behaviour programs, and physical therapy. But we missed the expertise of the educational specialists who adapt our children's learning programs, make enlarged visual and tactile learning tools for them, and lovingly support what we teach at home. We, as parents, had to cope and do it all. As mother to my children, I ended up creating learning materials each night, for each child, which robbed me of sleep.

Our children missed other adults and children and showed signs of grief, depression, and regression in their learning, speech, toileting, and social skills. We worked hard over the years to help the children master skills and regulate emotions and behaviours—facing regression was thus heart-breaking.

Blindness and other disability support agencies were limited in what they could provide in lockdown. Specialists could not go to their offices to enlarge or create tactile schoolwork or other learning resources. Peer support gatherings, parent support groups, and camps were cancelled.

We were stretched, tired, and worried, which affected our ability to be productive in our jobs. As the mother, I know I carried the bulk of the worry and responsibility for planning our days. We did not know how long the pandemic would last. When some children were allowed to return to school, ours could not because of medical fragility. For this reason, they were sent home from school earlier than their classmates, so we experienced lockdown at home for longer than most.

I read so much about how people used their lockdown time, and I admit to pangs of jealousy when I heard about people working without interruption, reading novels, watching Netflix, making crafts, baking, cooking, and organizing house and garden. There were endless Facebook posts about families creating elaborate and successful study schedules for their children. This did not happen in our household. We were isolated and invisible, yet nobody had any privacy, rest, or downtime.

In 2021, vaccines became available, and with that, a campaign began with other mothers to make vaccines accessible. Despite a dedicated disability government COVID-19 hotline, informed assistance has never been available in my experience. My children could not endure the invasive COVID-19 test and this, too, became a campaign—to find alternative, less invasive ways of testing disabled adults and children.

In August 2021, all of Aotearoa went back into our strictest lockdown level. This time, it seemed some lessons had been learned, and our family had better ways of managing a lockdown. We found some successful ways of scheduling and teaching our children. Zoom worked for some therapies and some social contact for my children. Schools supplied us with some appropriate learning materials, and we were allowed to order a broader array of items online, such as books, craft materials, toys, and games. I created some learning stories to help my children understand COVID-19, lockdown, mask wearing, and vaccinations. We were granted a travel exemption letter, which allowed our family to travel out of our neighbourhood to run at a beach—a safe, open space.

The year 2022 brought me, as a mother to two disabled children, more difficulties than even the most severe lockdowns. Vaccine and mask mandates loosened, and I had to make difficult decisions constantly on how to keep my children safe from COVID-19. Despite raging Omicron variants, and more deaths and hospitalizations and cases than before, most children went to school, and we were expected to return to work. To keep our children safe, I kept them home and tried to teach them again. But this time, there was no community support or support from schools; friends were carrying on with their lives, and we were viewed as being overly anxious.

I have urged our Ministry of Health to make booster vaccinations and antiviral medications available to immunocompromised children. The advocacy work is difficult and time consuming, with few positive outcomes. I have not seen colleagues in twelve months. My mother, father, and dear aunt all died, and because our borders were closed, I could not travel overseas for their funerals. My children have lost skills we worked so hard on. We will have to start all over again by teaching them about attending church, behaving in a restaurant, sitting in a movie theatre, playing sports, playing with other children, using money, shopping with a list, and waiting in lines. The cost has been great. It has been a lonely journey. Our support system has not been rebuilt because of a severe shortage of support workers.

Where is the outrage? Where is the advocacy? Where are the non-disabled activists who have our backs? COVID-19 has been a wake-up call regarding the indifference disabled adults and children face from governments, employers, communities, schools, and even our villages of friends and families.

Jane—Single mothering, Bearing the Load, Feeling Invisible, and Trying to Cope and Advocate

I am a mother of seven children. Four of my children are still at home, and one of them is on the autism spectrum. I parent alone, work full-time, and study part-time. Prior to the first lockdown, I had a live-in babysitter who provided childcare and supported me with the overall running of my household.

I reflect on my life as a single mother of neurotypical children and a child on the autism spectrum going through the first lockdown. As with other families, there were a lot of unknowns and many changes in my household. My live-in babysitter understandably decided to return to her home country at the beginning of the lockdown. At the same time, my ex-husband and I agreed that he would move back into the family home for the duration of the lockdown to make coparenting simpler for us both. Due to lockdown requirements, we both began working from home, which involved negotiating to take turns with the childcare role while the other completed paid employment obligations. Unfortunately, both of us living under the same roof only lasted a short amount of time, and for the rest of the lockdown, our household returned to just me and my children. My primary employment at that time was a face-to-face role as a social worker, and although I worked from home during the lockdown, I felt the anxiety of knowing I could not continue to work from home once the lockdown ended and my colleagues returned to their desks.

My three youngest children reverted to cosleeping with me, which was understandable during the uncertainty of the lockdown. Once our lives settled, over a matter of weeks, my neurotypical children were able to be coached back to sleeping in their own beds. For my child with autism, this took approximately a year.

During the lockdown, I received phone calls from service providers, checking to see how I was getting on. Although these phone calls were nice at the beginning of the lockdown, because the service providers could not actually do anything, the phone calls started becoming more of an inconvenience. At the beginning of the lockdown, I appreciated that they were checking in on me, but the novelty quickly wore off, and I thought to myself, *I am barely coping here, but there is nothing anyone can do to help me.*

My son with autism was receiving reading support at school, which ended when the lockdown began. Regular schoolwork was sent home for the final few days of the school term; however, my need to prioritize paid employment was greater than my need to supervise schoolwork, and my way of coping with this was to only supervise a minimal amount of schoolwork with my children. The school holidays during lockdown brought some relief. Still, the new school term brought with it the anxiety of the requirement for me to take on, once again, the role of home-schooling teacher alongside also being a mother and main breadwinner. I was mindful of not burning out.

The lockdown reminded me of how uniquely my son with autism understands and perceives the world. The social distancing rule of two metres was strict in his mind, and he worried that if someone came closer than what he thought was two metres, he would catch the virus. Seeing his distress pulled at my heartstrings, and I needed not only to emotionally support him but somehow soothe myself and hold back my own tears. I attended online workshops giving advice and tips on parenting during the lockdown. There was little to no mention of parenting disabled children and little mention of single mothers. My family felt invisible—present but not acknowledged or accommodated. I was expected to cope like a "normal" two-parent family with neurotypical children. I should have done more to advocate for families like mine, but it was taking everything I had just to cope and get through each day.

When the lockdown ended, I was lucky enough to find another short-term babysitter, and I returned to my face-to-face social work role. However, later that year, I moved to a part-time capacity as finding suitable and sustainable childcare was proving too much of a challenge. At this time, I also needed people in my life to remember that my family would take a little longer to adjust to the postlockdown way of doing things. I wanted my family to be part of this rebuilding, of making a new normal where we looked after everyone, including families with disabled children. I wanted our family's perspective and experience to be valued.

In August 2021, our country went into another lockdown. This time our family felt more prepared, and it also felt like schoolteachers had more of a realistic expectation about what could be achieved by parents supervising schoolwork at home. Similarly, employers seemed to have more of an understanding of the juggling of parents who are employed. This was in stark contrast to the first lockdown, where my extra mothering responsibilities felt invisible, and I was barely coping, which placed an incredible amount of emotional strain on me. The weather was getting warmer, and we pitched our tent in our backyard and slept in it for quite a few nights. I was eligible to get vaccinated, and as soon as my children were eligible, they were vaccinated, too. Some days during that second lockdown were hard, but I could draw on the resilience that I had built up during the first lockdown. My son with autism was almost a year and a half older than he was during the first lockdown, and he was able to draw on feeling nurtured and safe during the first lockdown to support him through the second one. All my children understood that the lockdown would not go on indefinitely, and we made the most of being at home together.

Throughout 2022, I have watched the divide grow between people who would be severely affected if they got COVID-19 and those who would not and who suggested that everyone is done worrying about COVID-19. For our family, the social and emotional aspects of COVID-19 affected us the most, and these have been adapted to. But I feel like, as a country, we are leaving people behind. After the first lockdown, I wanted my family to be part of our post-COVID-19 rebuilding—that is, making a new normal in which kindness is valued, and we look after everyone, including families with disabled children. I am not sure that I am seeing this.

Karen—Navigating Invisibility, Anxiety, Coping, and Advocacy

I am a mother of four children, two of whom are disabled. My daughter has a rare disease that has caused an intellectual disability and epilepsy, among other challenges; she requires constant supervision. One of my sons also has an intellectual disability and is hearing impaired. I live with my children and my husband and work full time. To manage, I employ a cleaner and a nanny who collects my two disabled children from school. We also use respite funding to pay for supported sporting activities for my son, and we attend a disabled sports group for my daughter so that she can participate in community activities. All these forms of support stopped during the lockdown.

My experience of the lockdown in 2020 was somewhat traumatizing. The supports that allowed me to stay afloat and stay in paid employment disappeared; my life is a finely balanced act in ideal situations. My caring workload and household labour more than doubled during the lockdown; this challenged my ability to cope. My husband was going into the office, as he was classed as an essential worker; this left me with the responsibility of homeschooling and managing my four children alone while holding a full-time position. At the time, my work situation was very stressful and with a high degree of complexity, and lockdown coincided with the most difficult period of my career. It felt like a perfect storm of challenges, and I struggled to stay my typical calm self and felt anxious. I have many memories of asking my children to wait whilst I was in Zoom meetings with distressed team members. One time, my daughter built a pretend computer. When I finally got free of a meeting and could spend time with her, she sat there tapping away at her computer and told me she was too busy to spend time with me. My heart sank as this was the last message I ever wanted to send my precious child, yet she clearly received it.

While working, my children painted the inside of my house, ripped the wallpaper off the walls, used nail polish on the floor, and rubbed playdoh into our carpet; these are a few highlights. My daughter, a foodie, also took our precious and rationed food purchases and created many (not surprisingly) inedible dishes. I ended up resorting to locking food in my car so we would have something available to eat. The struggle to address such challenges made me feel invisible.

Online school was another adventure; teachers expected my two disabled children to participate in online learning. Online class meetings were held, but my daughter could not join for longer than a few minutes. The special education teacher did her best to provide some virtual educational activities, but she would wander off, as online approaches to learning did not hold her attention. My son had one-on-one sessions with a teacher aid, which he attended but was rude and obstructive to her, leading to increased guilt on my part and a sense of helplessness around supporting my children accessing meaningful education. On top of this, I was trying to support my neurotypical sons to stay engaged in schooling with little success; they both struggled significantly with losing their friend groups. I felt powerless to manage my employer's expectations of me and meet my children's needs, which fuelled my anxiety and challenged my coping skills.

As a result of the work challenges I experienced during the 2020 lockdown, I applied and successfully changed my role within the organization where I work. My new role, though busy, is significantly more flexible, with no staff management responsibilities. I also decreased my work hours to four days a week for a number of months; this meant that the second lockdown was substantially easier to manage, and I could be more responsive to our children's needs. That said, while in work meetings, my youngest still found ways to damage our home and creatively avoid her schoolwork by hiding her tablet. I had developed some skills in managing lockdowns; these included getting the youngest children up earlier and completing their schoolwork before I started work. This had the bonus of them taking an afternoon nap, leaving me about forty minutes to focus uninterrupted on my work. I also worked in bursts—focussing for twenty minutes, then checking in and spending ten minutes with the children—which meant they felt better connected to me, and their behaviour was more manageable. If it had not been for my role change, I would have needed to resign or take an extended leave of absence.

When COVID-19 began circulating again in 2022, my husband and I chose to keep my daughter home from school because her rare disease meant she was at significant risk from the virus. My disabled son was beginning high school, so we thought it best to continue to send him to allow him to settle into his new school. I used my role flexibility to work from home and took on the responsibility of continuing her education. Given that the other supports I have in place to keep my life progressing smoothly were not interrupted, having my girl at home was a pleasure. We focussed on her schoolwork before I started work and during my lunch break, and she seemed happy and settled but did miss her school friends; we felt like we were in an invisible bubble.

My daughter moved her bedroom into my office, so while I was working, she would play on the floor or take afternoon naps, but we were together. It gave me a taste of being locked down together as favourable rather than traumatizing. I am grateful for a flexible role that allows me to work from home when and as I need to. Our decision to keep her home turned out to be prudent, as all her classmates contracted COVID-19 during the first four months of 2022, although we needed to advocate to protect her. Now she is settled back and enjoying her classroom again.

Discussion

Our combined autoethnographic research has highlighted how the experience for mothers of disabled children in Aotearoa consisted of five themes: anxiety, invisibility, devalued lives, coping, and advocacy. This research offers unique and valuable insights because it reflects the experience of parenting disabled children during one of the strictest lockdowns globally; it led to the removal of all supports and highlights the role that society plays in supporting families with disabled children. As mothers of disabled children, we hope to help others understand the needs of our families by telling our stories and suggesting strategies for social change. We systematically analyze our personal experience and used a social model of disability lens to unpack how things were and how they could be in the future. A social model of disability identifies that disability is socially created and that disability is imposed upon those living with impairments (Bricher).

The pandemic has exposed longstanding inequities in our health, education, and social systems and has highlighted how the communities are not responsive to, or aware of, the needs of disabled people (Brennan; Mhiripiri and Midzi; Shakespeare et al.). The underlying discourse within our society is that a disabled life is not worth living (Feldner et al.). There has been no acknowledgment of the additional burdens placed on families with disabled children, including financial, emotional, and practical challenges. Disabled children receive even less recognition than disabled adults in disasters and in this public health crisis (Ronoh). In fact, little is known about mothers raising disabled children (Zibricky).

The dominant culture in Aotearoa did indeed share anxiety with us during the pandemic, and that shared experience was comforting and empowering. But as the pandemic went on, as mothers of disabled children, we began to recognize that although we may all be in the same storm, those of us caring for disabled children are in a different boat to those not managing disabled lives—similar to the experiences described by authors May Friedman and Emily Satterthwaite and on the blog by VONNE. We had added responsibilities of keeping our vulnerable children safe, and occupied, mentally well, and educated with little support. We three mothers, and many others, had to manage professional workloads and financial concerns associated with disability.

The long-held disparity between men's and mothers' roles and responsibilities for caring for children and others was exacerbated during lockdowns. Guilt, dissatisfaction, and relationship stress were experienced by mothers who ended up doing most of the childcare, home education, and domestic duties (Cummins et al; Vandecasteele et al.). Pamela Kreeger et al. identified that lockdowns allowed for extra time and space for academic men to research, write, and publish, whereas for women, more time was needed for childcare, unpaid work, service, and teaching. In Aotearoa, we might have felt like part of a unified community in some respects, but women were burdened, and women with disabled children were invisible. None of the literature cited mentions disability.

The "Team of Five Million," which we were proud to be a part of, did not consider our children's needs. We want our health, education, and social government agencies to invite disabled adults and families of disabled children to the planning table, so our voices can be heard and our communities' unique needs can be met through thoughtful planning and management; furthermore, our voices need to be incorporated into the management recovery plans developed for future disasters, public health, and humanitarian crises.

Throughout 2022, we felt invisible. Schools somehow forgot that their disabled students needed adapted curriculums, digital devices, therapies, familiar routines, and friendly supportive teachers, teacher aides, and specialists. Health systems forgot that safe adapted spaces and protocols are needed for some disabled children for vaccinations, testing, and regular medical and therapeutic appointments. Vaccines were not available for vulnerable, immunocompromised children for many months after they were made available in other parts of the world. And today, even severely immunocompromised children have no access to antiviral medications in Aotearoa. Our lives were invisible to the media. Where were the stories of other families like ours?

Disabled lives are often devalued. To our horror, as mothers of disabled children, we had to acknowledge that in a medical triage situation, our children may not receive the medical care they need (please see Hole and Stainton for additional information on this issue). There is a long history of devaluing disabled lives, and this was demonstrated between 2020 and 2022 from the medical, educational, and social perspectives. We need political guidance, legislation, and practices that recognize the needs of disabled people and their families. We need responsive provisions that demonstrate that our society values these lives. The pandemic has revealed that society has a long way to go in acknowledging and valuing disabled lives with dignity and offering ordinary medical, educational, and social opportunities to the growing population of disabled persons (Vorhaus). We need to promote empathy, compassion, understanding, and legal and moral obligations to acknowledge human dignity, human rights, alternative methods of communication and education, and all human value and potential.

The third theme within our shared stories is coping. Each of us had moments when we felt we were no longer coping. But in reality, we had no other option but to find coping strategies. Some of us devised ways to maintain our professional jobs while creatively educating and entertaining our children. In addition, extensive time was spent researching what our children required to continue therapy sessions, how to educate them while at home, and how to care for them in medically fragile situations. Finding other mothers who shared our journeys helped. Some of us worked for change through advocacy and academic work (see Good; Good and Lee; Greig; Stuff.co.nz National Education).

Throughout 2022, when other children and mothers were at school and work taking calculated risks in social situations, some of us had to remain isolated to keep our children safe. This required extensive inquiry, which deviated from government suggestions, meaning we had to defend our decisions to schools and medical personnel. Finding other families who also voluntarily isolated throughout early 2022 helped us feel less sequestered.

Coping also involved trying to enjoy our children and families, with the opportunity to engage intensively in our children's education and daily rhythms. Although we were continually reminded to "take care of ourselves," this mostly involved ensuring our children were safe and for us as mothers finding some peace in the realization that they were.

This autoethnographic study has explored the lived-experience of mothers of disabled children in Aotearoa; our stories are unique and contextualized in some of the restricted COVID-19 lockdown mandates globally. As three professional, academic women, we acknowledge the relative privilege we have and understand that our positions afford us the opportunity to advocate for our children and other families. Despite the low expectations others may have of our children, we know they will grow, learn, work, have relationships, and contribute. We need to let the world know this; however, sometimes that requires creating a media presence, submitting recommendations to official bodies, and negotiating with health, education, and welfare systems. It can also involve supporting other mothers and helping ourselves and others to develop confidence in our skills as advocates and activists.

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