The continuing effects of the COVID-19 pandemic on the autistic adult community in Aotearoa, New Zealand

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Abstract

The restrictions and disruptions that were caused by the COVID-19 pandemic in 2020-2022 have affected the mental health of many within the global community. Among these is the autistic community, who experience the world from a different point of view, and who are more susceptible to mental health issues such as anxiety and depression. The continuing disruption to routines, and access to dependable social constructs, rhythms, and rituals that autistic people rely on may have created further distress and exacerbated mental health issues. This research will investigate the lived experiences of autistic adults and how their day-to-day life experiences have changed since the pandemic.

The qualitative methodology of phenomenology using thematic analysis through the lens of the social model of disability was applied to enable focus on what people experienced and felt during and following the pandemic. Purposive sampling and convenience sampling were adopted to recruit potential participants. There were 6 participants recruited and interviewed.

The findings of the study revealed six key themes: 1) adjustments in social activity, 2) increased barriers to mental health support, 3) changes to community connections, 4) diminished overall well-being post-pandemic, and 5) changes to anxiety levels. The sixth and final theme peer-to-peer advice, this theme incorporated suggestions for other autistic persons from participants.

Disability support and health services have failed to keep up with the ongoing needs of the autistic adult community in New Zealand at a time when it was most needed. This study recommends striving for an increase in the understanding of autistic adult diagnoses in conjunction with improvements to autistic adult care. The service workers and health professionals require the ability to significantly expand their skills and knowledge of autism to provide better health outcomes, especially in times of disaster. Such expansions would require funding support driven by policy change.

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To my friends, thank you for your patience, yes, I will now be free to come over for that coffee and catch up.

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Chapter One – Introduction

1.1 Background of the study

In December 2019, the World Health Organisation (WHO) reported the first outbreak of the severe respiratory syndrome coronavirus 2 (COVID-19) (WHO, 2024). According to WHO (2024), by 7 July 2024, there were 775,673,955 confirmed cases of COVID-19, including 7,053,524 COVID-related fatalities globally. New Zealand has 2,629,816 confirmed cases and 4,185 COVID-related fatalities. In addition, several studies report an association between the COVID-19 pandemic and an increase in stress, anxiety, and depression in the general population (Fancourt et al., 2021; Salari et al., 2020; Vindegaard & Benros, 2020; Xiong et al., 2020). Individuals with pre pandemic mental health conditions also reported experiencing increased mental distress during the COVID-19 pandemic (Kwong et al., 2021). The changes and restrictions during the pandemic affected daily routines (Ameis et al., 2020; Bal et al., 2021). In addition, the pandemic negatively affected access to healthcare services and support for *autistic adults (Bal et al., 2021; Bundy et al., 2022; Oomen et al., 2021).

Autistic persons experience the world from a unique perspective and can be more susceptible to mental health problems like anxiety and depression than non-autistic individuals (Al-Beltagi et al., 2021; Patel et al., 2020; White et al., 2009). A meta-analysis of 96 studies by Lai et al. (2019) found the estimated prevalences of co-occurring mental health diagnoses of autistic individuals. These results revealed “28% for attention-deficit hyperactivity disorder, 20% for anxiety disorders, 12% for disruptive behaviour disorders, 11% for depressive disorders, 9% for obsessive-compulsive disorder, 5% for bipolar disorder, and 4% for schizophrenia spectrum disorders” (Lai et al., 2019. p. 2)

The lockdowns and COVID-19 restrictions between 2020-2022 has since caused continuing disruption to the routines and access to dependable social constructs such as the rhythms and 7

rituals that autistic adults may rely on for the security of their comfort and ability to function socially. Literature from this time suggested this context created further distress and worsened mental health issues (Oomen et al., 2021). Overseas studies by Oomen et al. (2021), Javed and Roy (2021), Bal et al. (2021) and Pellicano et al. (2022) (India, Belgium, Netherlands and the UK), revealed an increase in mental health-related issues in autistic persons which they attributed to alterations in the environment and health brought about by the pandemic. They found that the added day-to-day stressors and changes further exacerbated these mental health concerns.

This research will explore the day-to-day lived experiences of autistic adults in New Zealand since the onset of the COVID-19 pandemic. As the world continues to move forward from the pandemic of 2020-2022, a qualitative description of how the pandemic affected the lives of autistic adults in New Zealand will be valuable. Such an analysis provides insights to improve the health of autistic adults, and their access to services, support and overall well-being.

*A note on language

The researcher understands that not everyone in the autistic population prefers the same terminology. In collaboration with the study's reference group and Autism NZ, the terms “autistic person” and “autistic” have been prioritised to represent the belief that being autistic is a vital component of identity to be proud of (Monk, 2022). Many in the New Zealand autistic community prefer these terms.

1.2 Research Aims

This research aims to contribute to existing knowledge about the experiences, abilities and needs of autistic adults, provide valuable recommendations, and inform disability and health policy and practice in New Zealand. These aims were achieved through a study of the lived experiences of autistic adults which explored how their day-to-day life experiences have changed since the onset of the COVID-19 pandemic.

A qualitative methodology of phenomenology using thematic analysis enabled a focus on what people experienced and felt (Sundler et al., 2019). The social model of disability essentially proposes that disability is a product of society and provides a conceptual basis for the present research (Barnes & Mercer, 2004). Purposive, convenience sampling was adopted to recruit participants. Six participants were recruited and described their lived experiences. Participants were recruited via an Autism NZ Facebook recruitment post. The researcher also shared the post with other social media groups including Facebook groups Autism Connections and Altogether Autism. Flyers and information sheets were sent to organisation centres such as Rainbow Hub Waikato.

Potential participants responded via email and were provided with consent and information forms. Semi-structured interviews were then conducted, which allowed for rich discussion based on open-ended questions. The interviews were transcribed, and a thematic analysis was undertaken. The research findings will describe what the pandemic was like for autistic adults and suggest where support is required for autistic adults during and after such life-changing events.

1.3 Positioning of the Researcher

Reflexive research involves the researcher explaining their participation in the research through self-critique and assessment. Reflexivity requires researchers to contemplate how their

personal experience has or has not affected the stages of the research process (Ayton et al., 2023; Braun and Clarke, 2006; Dowling, 2006; Olmos-Vega et al; 2022).

I (the researcher) have a degree in psychology with a background in public health inequities, teaching, and learning support for students with additional support needs. I live with a rare disease/disability and am part of a family with autistic individuals. This combination of lived experiences and education informs my perspectives about autism and well-being, and I bring this knowledge and experience to this research. Whilst I have connections to the autistic community; I am still aware that I am an outsider. This research, with intimate contact with a small number of individuals has afforded observations and interaction with a diversity of autistic behavioural presentations.

An even more considerable diversity has been experienced at a distance via digital meeting places such as social media. My experiences within this community have shaped a view of autistic culture, and opinions of how interactions that occur between autistic persons and the broader social and service environments can be under tension. In an effort to learn how to both appropriately set aside and carefully utilise my preconceptions, I have methodically cultivated the capacity to listen to and reflect upon the reported lived experiences of autistic individuals concerning the COVID-19 epidemic.

My own lived experiences and exposure to autistic persons' life experiences allowed me to perceive injustices such as lack of recognition of inflexible and ableist communication styles when engaging autistic people in conversation. This means there is a conscious effort to self-evaluate all analyses to detect any colouration of this bias. Once the bias is detected and framed, it is added to each participant’s narrative and identified to the reader. This will be elaborated upon in the discussion section, where the researcher seeks to address the rights of autistic adults. The motivation behind this research came about, by seeing my autistic family members'

reactions and interactions during and after the lockdowns and how greatly it has affected their day-to-day lives and health.

1.4 What is Autism?

Psychiatrist Leo Kanner identified "Autism" in 1943 in his study of eleven children with some developmental differences reported by parents, and he found their behaviour was different to those with an intellectual disability/learning disability or schizophrenia (Kring et al., 2018). Smith et al. (2012) described how autistic individuals can struggle with social interactions, emotional functioning, and communication, and may show ritualistic or repetitive behaviours. Autistic adults may find it difficult to strike up conversations with others and may struggle to establish or sustain discussions. The flow of back-and-forth communication contains complex layers of stimuli to interpret and behaviour to adapt to.

An autistic person may have difficulties with stimuli interpretations, creating a barrier to understanding others and following instructions. Stimuli misinterpretation leads to problems understanding non-verbal communication using body language or social cues and rules (Gillespie & Heasman, 2019). Smith et al., (2012) discusses that while holding a conversation, some autistic people can find it hard to maintain eye contact, leading to not recognising emotions. Missing facial expressions and other nonverbal signs can lead to the loss of inferred context for spoken words. Without these cues, it might not be easy to sense the emotions and intentions of others intuitively (Sharkov et al., 2022).

For autistic persons, empathy, and recognising emotional experiences in others by maintaining heightened sensitivity with the additional load of interpretive processing can be an exhausting experience. This makes it challenging for autistic people to maintain relations due to the personal cost of interpreting others and modifying one's behaviour appropriately. This can lead to social othering and isolation when the social group sees them as unable to operate within

social norms or they do not have the energy, will or skill to fit that person into the environment (Rohleder, 2014).

Mainstream social norms can impose on an autistic person the requirement to engage in uncomfortable social activities. In addition, non-autistic people may engage in misguided but well-intentioned attempts to cultivate feelings of inclusion for persons with non-normative behaviours, requiring them to engage in social interactions they would rather avoid. Conversely, Pearson and Rose (2021) note that autistic persons often have adaptions, allowing lowered visibility of differences, leading non-autistics not to notice social tensions. Masking is a word commonly employed by the autistic community to define the suppression of components of oneself and identity in order to "appear normal," whether through conscious or unconscious behaviours. This "masking" is a unifying term to encompass behaviours known as "camouflaging" and "adaptive morphing", and it has been related to a variety of harmful consequences for autistic people, including mental health issues, autistic burnout, and suicidal thoughts (Miller et al., 2021, Pearson & Rose, 2021).

Autistic individuals experience the environment uniquely; for example, they can be hypersensitive to noise, light, or they can pick up on the energy or vibe of their immediate surroundings eliciting sometimes impulsive reactions or meltdowns (Pellicano, 2013). Autistic people can have various co-occurring conditions, such as anxiety, depression, gastrointestinal problems, metabolic disorders, attention deficit hyperactivity disorder (ADHD), learning disabilities and other behaviours, such as injuring themselves and sleep difficulties.

Up to 84% of autistic individuals may experience anxiety (White et al., 2009). Matthews (2016) identified that 26% (12 of 46) of autistic adults in a small study were currently experiencing significant symptoms of depression. The aforementioned emotional recognition problems, sensory sensitivities, social uncertainty, and performance expectations can add to the increased

prevalence of anxiety and depression among autistic people (Rodgers, 2018). Morie et al. (2019) state that the awareness of impairment and negative experiences in the social world are exacerbated by the difficulty that autistic persons have in identifying and interpreting their emotions. Intellectual functioning varies extensively for autistic individuals, from superior intellect to profound intellectual impairment (Al-Beltagi, 2021; WHO (2023); White et al., 2009).

Autistic persons have different needs and abilities, which might change over time. While some autistic individuals can live independently, others have significant difficulties and need care and support. Overall, autistic people may display a range of strengths and abilities, including learning to read early, learning and memorising information quickly, thinking visually, demonstrating academic excellence in complex subject areas, wanting to stick to rules, and being dependable with routines and rule structures (Cope & Remington, 2022).

Approximately 5,437,988 (2.21%) of adults in the United States are diagnosed as autistic. The prevalence of autism in the United States was found to be greater in men than in women. It is estimated that 4,357,667 (3.62%) male individuals and approximately 1,080,322 (0.86%) of female individuals have autism (Centers for Disease Control and Prevention (CDC), 2022). Data on the incidence and prevalence of autism in New Zealand is not currently collected. Therefore, the prevalence of autism in New Zealand is based on international data adapted to the New Zealand population. Based on this data, an estimated 1-2% of individuals in this country are presumed to be autistic (Acraman, 2022). Drysdale & van der Meer (2020) studied the number of new diagnoses between 2012 and 2016 by the Hutt Valley District Health Board. During this period, 1.48 per 1000 diagnoses were made in the 0-19 age group, and males were diagnosed in higher numbers than girls by four times.

Autism is genetic, and these factors have been found to play a role in gender and autism diagnosis; the two leading theories in the research related to genetics and autism are the extreme male brain theory, which suggests that the autistic brain exhibits features that are linked to male brains, systematic thinking and empathic thinking. An English researcher Simon Baron-Cohen developed this theory, through his tests in autism research he revealed that men perform better in pattern recognition and systems than women (Baron-Cohen, 2002).

Another theory is the female protective effect. This theory was noted by researcher Luke Tsai in the 1980s due to autistic females tending to have relatives who had language impairments or autism, while males did not. This theory indicates that females are more resistant to the genetic mutations linked to autism and require more mutations to be present than males to be an autistic person (Zhang et al., (2020); Napolitano et al., (2022)). Supekar et al. (2022) state that females with autism have less overt behaviours compared to males; the study showed that there are differences in the regions of the brain linked to language, motor and visuospatial attentional systems between autistic males and autistic females, providing evidence that autism does present differently across the sexes*.

Navarro-Pardo et al. (2021) suggest that there is also no effective diagnostic tool for detecting autism in females, as the autistic diagnostic tool currently used has been created with the male brain in mind. Therefore there is the possibility that many females are undiagnosed, the most often used diagnostic instruments in New Zealand are the ADI-R (Autism Diagnostic Interview-Revised), a semi-structured interview used by therapists, and the ADOS (Autism Diagnostic Observation Schedule (McClintock & Fraser, 2011)), which is highly regarded for observational evaluation of autism spectrum disorders.

*The researcher is mindful of the difference between research focusing on biological sex vs people's self-identified gender.

The New Zealand autism diagnosis journey for many starts when an adult notices a child having developmental challenges. As children grow and develop over time, they generally meet developmental milestones signifying markers of "typical" growth. These can include crawling to-walking transitions, smiling with intention, using words and sentences, and storytelling. Developmental delays vary and can be noticed early on, for example in infancy, signs such as a delay in when a child starts rolling over, crawling, or walking (Autism New Zealand, 2020). Developmental delay may not be picked up until the child is school age. Discovery often occurs later in schooling, when communication challenges and social interaction issues during the pubescent stage are noticed, such as persons that have difficulty connecting actions to consequences of antisocial or aberrant behaviours that lead to disciplinary motivated investigation.

Observations by parents or teachers are the most common way that a referral for diagnosis occurs (Brown et al, 2020). However, the pathway starts with the GP, who should be monitoring milestones at well-child visits, which are a part of the New Zealand health system checking on child development and well-being. Diagnosis at a young age is important, however, autistic presentation is variable within and between both ages and individuals. New Zealand's access to diagnosis is inconsistent, and teenagers and adults have not had a consistent pathway to assessment (Whaikaha – Ministry of Disabled People and Ministry of Education, 2022). In addition, there is currently no formal pathway for referral for adults in New Zealand. Undiagnosed adults have often been considered autistic retrospectively in criminology studies and documentaries, often too late to have a positive effect on the life course of these people (Rutten et al, 2017).

Self-diagnosed autism occurs when people see autism-related signs and symptoms in themselves or their children without receiving an official diagnosis from a healthcare professional. Many autistic adults, especially women and exceptionally intelligent people, were

undiagnosed as children. These individuals are part of what autism experts refer to as the "lost generation" of adults with autism. Lewis (2017) states that many adults self-identify as autistic and have indicated that there are barriers to obtaining a diagnostic assessment for autism. One example is that it is difficult to have a General Practitioner (GP) identify that an assessment is needed, as they may not recognise the presentation of autism in an adult, especially if the individual has developed masking techniques.

Research by Fusar-Poli et al. (2022) revealed that psychiatrists do not always recognise autism spectrum disorder. It can be confused with other disorders, and there is still a lack of understanding and awareness among other health clinicians. Although, some self-diagnosed adults do not seek diagnosis due to the stigma that is still present with autism, this stigma is influenced by the lack of understanding of autism by professionals and the public (Turnock et al, 2022). A formal diagnosis can also impact life paths, such as prohibiting immigrating to certain countries or being ineligible for military service, although most services treat each case individually and do not automatically disqualify an autistic person from being able to serve (Rob, 2023., Davis, 2021). While the autistic community and its allies are focusing on educating and creating awareness, there is still stigma reduction work to be done, and many environmental changes that need to be addressed.

When commencing this study, the researcher discovered that there is less research on autistic adults than there is on autistic children in New Zealand. Hence there is so much more to understand about autistic individuals in New Zealand and their lived experiences as they age. Anecdotal evidence is buried within service organisations that have barriers between each other for protecting consumer privacy, and due to sector divides, such as medical services not talking to therapeutic services. This means comprehensive information is spread around many detached siloes of data. When a person is in childhood, their school often plays the role of aggregating the siloed data into a fuller picture of the individual, as the individual’s in-school

behaviours are used as the basis of further enquiries (Osher et al, 2014). In adulthood, the siloes become more pronounced, with no common aggregation point for obtaining the rich behavioural schema used by schools in childhood observations. This researcher has identified this lack of an adult aggregation and has endeavoured to provide a “window into the person” by capturing anecdotal evidence directly from those who have lived experiences, in the context of the extraordinary pressures occurring from the COVID-19 pandemic.

1.5 Background of COVID-19 and New Zealand

New Zealand's first COVID-19 case occurred on February 28, 2020. The government responded by implementing a comprehensive and effective national reporting, notification, and contact-tracing system, reinforced by strict social distancing and movement restrictions. This combination of actions effectively prevented the virus from spreading further (New Zealand Government, 2022). Immediately, the government restricted entry requirements into the country, and the few people allowed in the country were put into quarantine hotels. COVID-19 cases in New Zealand had already begun to climb dramatically, resulting in a lockdown of the nation, and a nationwide state of emergency was declared on March 25, 2020; whereby workplaces, schools, and public facilities closed (Henrickson, 2021). The populace was urged to stay home and to limit contact with others outside of their home, save for visiting essential businesses, such as healthcare facilities, pharmacies, and supermarkets. No one was permitted to drive unless heading to one of these destinations (Good et al., 2022). A fourteen-day isolation period within one of many quarantine hotels was implemented for people who resided or had permission to be in New Zealand. Cases were eased, and restrictions were lifted gradually. New Zealand successfully eradicated COVID-19 on 13 May 2020 (New Zealand Government, 2022).

When one Delta variant case of COVID-19 was detected in Auckland in August 2021, New Zealand was placed under lockdown for three weeks. Most of the nation was liberated from restrictions, but Auckland and Northland remained under lockdown since regional border restrictions hindered the spread of the virus. This regional containment approach saw Auckland being placed in restrictions significantly longer than the remaining population. While the rest of the country saw relaxed restrictions Auckland was additionally closed to normal activity twice more, firstly in August and September 2020, then again, the following February and March, adding up to months of exceptional measures Aucklanders had to adjust to.

A more relaxed behavioural system using alert levels referred to as traffic lights had the population playing a more active role in elimination by voluntarily adhering to strategies guided by the particular situational severity of the current traffic light advisory, with red promoting the most cautionary of behaviours and green indicating a chance to be more relaxed while holding onto vigilance. The availability of home testing and vaccines, albeit controversial, were also a part of the decision made to start the path of relaxing the restrictions in NZ. The highly effective contact tracing scanning technology was discontinued in 2022, but the virus continues to spread. As of 22 July 2024, there have been 4,268 COVID-19-related deaths in New Zealand (Health New Zealand, 2024). Many disabled people felt they were left vulnerable with the relaxing of these restrictions.

1.6 Thesis Structure

This thesis presents qualitative research, underpinned by phenomenology which is designed to hear the voices of autistic adults in New Zealand and describe their lived experience. The thesis consists of six Chapters:

Chapter One - Introduction and Background

The introduction provides a brief background of the research and introduces the reader to its aims. This section also introduces the researcher and their positioning in relation to the research. Autism and the COVID-19 pandemic as it was in New Zealand is discussed.

Chapter Two - Literature Review

This chapter examines international and domestic literature on the effects of the pandemic restrictions and lockdowns for autistic adults. This chapter also discusses the social model of disability in depth.

Chapter Three - Methodology

This chapter provides the reasoning behind the choice of a qualitative study method. Phenomenology and the social model of disability were used as lenses in this study. Data collection and analysis using thematic analysis and ethical considerations are also discussed.

Chapter Four - Findings

Chapter four presents an overview of the research participants, and a detailed presentation of an analysis of the major themes that arose from the semi-structured interviews.

Chapter Five - Discussion

This chapter summarises the study's findings and considers existing literature guided by the aims and research questions.

Chapter Six - Conclusion

Finally, the conclusion explores strengths and limitations of the study. Considerations for care, recommendations for research, policy and health service delivery are presented.

1.7 Summary

This study fills a significant gap in research about the lived experiences of autistic adults in New Zealand during and after the COVID-19 pandemic. This is based on the premise that recognising the day-to-day well-being of autistic adults is essential for the mental health of this population and overall health outcomes. The researcher is personally connected to the affected community and is motivated to find better outcomes for this cohort.

Chapter Two: Literature Review

2.1 Introduction

The first chapter summarised the motivation and justification for the research and an overview of autism. This chapter critically evaluates the international research related to the effects of COVID-19 on autistic individuals. Also included is a review of the social model of disability, which serves as the theoretical foundation for this study.

2.2 COVID-19 Pandemic Effects on the Autistic Adult Population

Oomen et al. (2021) investigated the burden of the pandemic on the autistic community in Belgium, the Netherlands and the United Kingdom. Their findings suggest that as healthcare systems became overwhelmed during peak times of the outbreak, most autistic adults lost some or all access to their support systems. Autistic adults are more susceptible to depression, anxiety, and other co-occurring health conditions. It is concerning that the support relied on to help with these challenges was not readily available. Of the 1044 participants in the Oomen et al. (2021) study, 431 were non-autistic and 613 were diagnosed as autistic. The results indicated that both groups found the lack of social contact difficult; for the autistic participants, there were added social challenges. The smaller, highly select social networks of autistic participants meant that any in-person contact reduction had a more significant emotional impact on fear, loneliness, and other stressors for them compared to the non-autistic participants.

Javed et al. (2021) found that the autistic community in India experienced very similar problems regarding support for mental health. They recommended improvement in access to professional help by way of communication technologies (such as Zoom) and comprehensive multifaceted connections with clinicians, physicians, and support personnel. It was suggested

clinicians needed to proactively provide real-time assistance and toolkits for safeguarding mental health, and that such as digital video meetings like Zoom for both remote patient-to-clinician and in-person technological augmentations such as; where external specialists are supporting a clinic session via digital video and audio using a software product. These augmentations are intended to add to the current practices in a way that has a heightened sensitivity to changing needs. Digital communication allows recording and transcription, which can be an augmentation of patient record-keeping (Botelho, 2021). This digital recording is also a means to support further research that could inform pandemic response isolation exacerbated effect mitigation (Sahi et al, 2021). The few available studies reveal that support systems were inadequate and have not evolved fast enough to take advantage of well-established and widely available contemporary technology such as video conferencing.

Anxiety is a common co-occurring condition in autism and occurs at a greater incidence than in the general population (Rodgers & Ofield, 2018). Anxiety for autistic adults was exacerbated by exposure to new or increased stressors brought on by the pandemic. The pandemic produced multifaceted factors that increased anxiety for many individuals in uniquely sensory ways, such as news of economic downturn, loss of work, and loss of regular routines, which resulted in new or increased stressors threatening the knowability of the future (Oomen et al, 2021).

A lot of autistic individuals depend on the structure of routine for their daily lives, disruption of which can increase the likelihood of anxiety. The perceived benefits of isolation were balanced by some participants, who reported that uncomfortable social pressures were removed, letting them relax from having to mask (as defined in Chapter One "What is autism?" section of this thesis) and act a certain way in front of strangers (Pellicano et al., 2021). The findings from Oomen et al. (2021) are consistent with other studies (Javed et al, 2021; Pellicano et al, 2021, Maljaars et al, 2022) and demonstrates how the autistic population have had a deeper and more profound experience with the pandemic.

The autistic individual may or may not cope well with social interactions, but this does not mean they do not want to engage. The challenges in this area are individual, and social masking is often employed to aid people in feeling that they fit in. The study by Oomen et al. (2021) found that during the pandemic, shopping became a trigger for autistic persons with a hyper-sensory response to stimuli. A trigger is anything that generates a stress response in an autistic person. The stimuli might be sensory (loud sounds or bright lighting) or emotional (frustration or rage). When confronted with certain stimuli, autistic people may have meltdowns, which are uncontrollable reactions to sensory or emotional overload. It's important to recognise that these triggers differ from person to person (Rios, 2023).

The removal of the sensory overload that an outing provokes creates relief for hyper-sensory-autistic persons who find outer environments overwhelming (Thye et al., 2018; Lefebvre et al., 2023). It is not surprising that the first lockdown period was met with relief for some (Mosquera et al., 2021), as societal pressure and expectation were no longer an issue. A study by Maljaars et al. (2022) exploring the impact of COVID-19 in Belgium, the Netherlands and the United Kingdom found that autistic adult participants had a more positive social life experience than non-autistic adult participants during the lockdowns and restrictions.

Self-care for many within the neurodiverse community is already difficult without the use of added pressure of an accelerating sense of "impending doom" proximal to the pandemic. These encroaching thoughts are on top of the dormant cognitive schema of any past trauma, if present, which are brought back into the front of the mind by this current dark sensation (Greenberg, 1995). The combination of new and past sensations invades the current mental space, and this stress/anxiety is manifested in physical symptoms such as nausea, hyperventilation and shaking. For some, this resulted in self-harm ideation, more frequent panic attacks, and being locked into distress loops where dark, gloomy, and panic-inducing thoughts dominate (Pellicano et al., 2021).

The pandemic affected the global economy, and economic security and work security were compromised for many in society, resulting in feelings of a lack of control over the future (Fridell et al., 2022). In addition, social distancing regulations created feelings of safety and personal security for some autistic people, who then found difficulty tolerating others who disregarded the precautions intended to protect the community.

2.3 The Social Models of Disability

In the late 1970s and early 1980s, a group of people based in the UK with impairments began exploring how they could change attitudes to address the discrimination that they were collectively experiencing in society. They wished to create a society that is fully inclusive of all, no matter the impairment (Barnes & Mercer, 2004). The Union of Physically Impaired Against Segregation (UPIAS) and the Disability Alliance created The Fundamental Principles of Disability document in 1976.

UPIAS (1976) defined disability as:

> Disability is the result of the interaction between people with impairments and an environment filled with physical, attitudinal, communication and social barriers.
>
> The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have impairments and thus excludes them from the mainstream social activities. (UPIAS, 1976, p.14).

The groups agreed upon the following principles:

1. The documentation states that disability is a result of societal factors.

2. The documentation also emphasises the need to take a comprehensive approach to tackling disability, including income, mobility, and institutions, rather than treating them separately.

3. disabled persons to take an active role in their own affairs. The participation and engagement of disabled individuals in their own affairs is critical. (UPIAS, 1976, p. 3)

These ideas have fundamentally altered the meaning of disability and impairment, splitting them into two distinct categories. Impairment is a condition of the individual, whereas disability is a societal construct. This formed the basis for the social model of disability (Barnes & Mercer, 2004; Woods, 2017).

Oliver (2004) further developed the social model of disability. He utilised the ideas and definitions of disability and impairments from UPIAS and other disability advocacy groups. Michael Oliver was an academic who, through teaching a postgraduate class, conceptualised the social model of disability to allow health professionals and social workers to focus on social and environmental barriers, and not on the person with the impairment. Oliver aimed to enable equality for those with impairments in social and environmental contexts and to use the model to challenge disablism.

The social model does not challenge disablism at the individual experiential level, where differences may not be in focus for the observer. The model has a schema, a pattern of recognition of disabling factors and environments, holding a risk that impairments that appear as if they are outside of contemporary sociocultural behaviours remain invisible. It follows that what is unobserved is not considered, showing that ideologies of disability present barriers to equitable interaction for that individual (Thomas, 2004). This would suggest that the social

model of disability, as Oliver implemented it, is outdated and incomplete, while its intent remains true to the original ideals of the UPIAS (1976).

Such challenges to model relevance have seeded conversations, research, additions and adaptations over the years, such as the Extended Social Relational Model of Disability, which came about due to the criticism that the social model does not refer to the experiential and cultural aspects of disability (Thomas, 2004). The extended social relational model of disability builds on the social model of disability but focuses on the experiential and cultural aspects of disability in addition to the socio-structural barriers. It acknowledges that disablement stems from physical structures and psycho-emotional and cognitive spaces within dominant power dynamics, which limits impaired individuals' well-being (Thomas, 1999).

> "Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments." (Thomas, 1999. p.60.)

In summary, the extended social relational model emphasises the interrelationships of location, disability, and society, providing insight into the experiences of marginalised populations in confined settings.

Jonathan Levitt (2017) argued that the social model reflects the time it was developed. It has enabled the reduction of physical barriers for many, including himself, over many years. Levitt discusses whether it could reflect current social constructs and locations and whether this would increase the impact of reducing barriers for people with impairments. He discusses a re-invigoration of the social model in this context by posing five questions:

> (1) Which aspects of the negative influence of society on disability (other than barriers to inclusion) are particularly worth focusing on, and how can these be effectively addressed?

(2) What ways of using the model (apart from a practical tool) seem promising, and how can these ways be fruitfully implemented?

(3) To which groups of people (other than disability professionals in developed countries) is it important to disseminate the model, and how can it be conveyed effectively?

(4) Is it a good idea to present the social model in a manner that is contradictory (as opposed to complementary) to other models, or that implies it is the only model conducive to emancipating disabled people?

(5) What should be the primary goals of the social model, and what steps can we take to achieve these objectives? (Levitt, 2017 p.589-594)

Richard Woods (2017), in response to Levitt's belief that the social model has been successful for all impairments, believes that it has only been successful for those with physical and sensory impairments and that any neurodivergent impaired persons have not been included. Woods qualifies this by discussing how the social model of disability focuses only on physical barriers, such as folding canes and signs in braille around buildings for individuals with visual impairments. Hence there is an exclusion of societal barriers that affect the neurodiverse populations. For example, autistic persons use a massive amount of neurological energy on conforming to societal expectations, demands and norms, and this often leads to burnouts, meltdowns and psychological harm for the autistic person (Woods, 2017).

The primary model used for many years in relation to autism and studies on autism has been the medical model, which is critically viewed in this use because of the focus on what the autistic individual cannot do (Anderson-Chavarria, 2022). Autistic people are frequently judged based on how closely they align with the behaviours, social skills, and cognitive processes of non-autistics. This comparison can lead to a deficit-based understanding of autism,

where the unique strengths and abilities of autistic individuals are overlooked. Autistic people face mistreatment for a variety of reasons, the most common of which is the terminology used to define autism. The language chosen to describe an issue influences how others approach it (Beardon, 2017; Woods, 2017). Autism is mainly discussed as a condition and a deficiency. This is a significant barrier that must be addressed through the social model of disability (Woods, 2017).

The social model was not used for autistic individuals in the past because the challenge of modifying behaviours is not evenly distributed between non-autistic persons and autistic persons, with the autistic person making all the behaviour adaptions (Crompton et al, 2020; Edey et al, 2016; Sasson et al, 2017). Navigating the non-autistic culture requires autistic individuals to adapt to situations and environments that do not suit their sensory processing modality, for example, a sensory busy environment will be particularly stressful for a hyper-sensory-autistic person, whereby being in a busy place can cause emotional and mental health harm to the autistic individual (Thye, 2021). The challenges experienced by autistic persons in their environment have been largely ignored by society. All these factors have systemically discriminated against autistic individuals.

Addressing this could involve applying the social model to the sensory challenges confronting autistic people and acknowledging that each autistic person is the expert on their autism due to the unique sensory schema of each individual (MacLennan et al., 2021). This contributes to improved autistic self-advocacy and empowerment and lessens the psychological damage brought about by trying to conform to dominating societal demands (Woods, 2017). Also, there is a need to create a society that is aware of and participates in creating inclusive spaces and experiences. The National Health Service (NHS), (2023) asks the question, "How can we support autistic children and young people?"; they answer this with; autistic individuals do not

need to be taught social skills in a typical way, as that is not who they are; it is a different way of socially interacting.

The social model of disability highlights the importance of environmental and societal elements in defining disabilities (Shakespeare & Watson, 2001). COVID-19 brought about changes to environments, both physical and social, and these societal and environmental changes affected the vulnerabilities of autistic persons (Ameis et al, 2020). The societal barriers and changes to the environment may have intensified already sensitive functions in autistic individuals. In terms of public health messaging during COVID-19, understanding the significance of the environment in the lives of autistic people based on the social model of disability would have been beneficial. For example, broadcasting messages across accessible forms may have eliminated barriers and aided in maintaining their routines while also helping them become accustomed to the required modifications in living with COVID-19. Gouzman et al. (2023) state that while the social model of disability was established many years ago, it has become more relevant today, as there has been a significant setback for the disabled community across the globe created by the COVID-19 pandemic.

To date, no current research has been found that discusses the experiences of autistic persons during the COVID-19 Pandemic in conjunction with the social model of disability.

2.4 New Zealand and Autism Through the Lens of the Social Model of Disability

The New Zealand Disability Strategy aligns with the social model and emphasises the rights and well-being of disabled people, achieved by promoting inclusion, accessibility, and equal opportunities (Ministry of Social Development, 2024). The legislative background of the 2000 Disability and Public Health Act arose from the domestic voices being heard. New Zealand is a signatory in the establishment of the UN Convention on the Rights of Persons with

Disabilities (CRPD), which recognised the rights of all with disabilities globally, and this formed a basis for enacting protections (Barnes & Mercer, 2003).

Further protections in policy between 2016 and 2022 saw autism-specific guides and professional development tools made available by the Ministry of Health (Ministry of Disabled People, 2022). While there are positive and relevant guidelines in the document to aid with positive interactions by health professionals, teachers and educators, the tonality of responsibility reflected in the document is reversed. The tonality of document language implies the responsibility of accommodating abilities is the role of the impaired person. This is conveyed in the instructional bias of modifying the impaired persons' behaviours to fit into social constraints by learning how to "act" suitably. This inferred obligation further imprisons impaired persons within an additional personally high-cost behavioural layer of which autistic persons already have a significant burden. "Autistic people should be taught social skills…" (Ministry of Disabled People, 2022, p.34). The tone of this guiding document asserts that to be included, the autistic individual must put in the "work" to learn how to adapt to society, whether in an educational, work, or community setting. The consultation process leading to the formation of this guiding document endeavoured to represent the voices of autistic individuals. This process captured an example of how the autistic individual may feel about the implication of this burden of change in the "voices" section of the document:

> "I am tired of having to do 100% of the changing, and there is no change with most people without autism." Anonymous (Ministry of Disabled People, 2022. p. 6).

While the intentions and the existence of such are positive for social advancements, inequities like the above bias example persist and can dominate the narrative and subsequent implementation.

Many disabled individuals still struggle with self-determination and full participation in society. The New Zealand Disability System transformation aims to address these challenges. The Enabling Good Lives approach seeks transformative change in disability support services. The establishment of the Whaikaha - Ministry for Disabled People has reinforced the country's commitment to partnership and ongoing system transformation that is aligned with the principles of enabling good lives. New Zealand's adoption of the social model reflects an ongoing commitment to creating an inclusive society where disabled people can thrive and participate fully (Ministry of Social Development, 2024).

Research conducted by Nazari Oranaki et al., (2024) and McBride-Henry et al., (2023) focused on disabled person's COVID-19 experiences in New Zealand, while these extensive studies include those with autism due to being a part of the disability community, there is no current, research identified that primarily focuses on autistic adults and their COVID experiences in New Zealand.

This research aims to answer the following research questions.

1 How did the COVID-19 pandemic lockdowns, restrictions and ongoing impacts affect the day-to-day experiences of autistic adults in New Zealand?

2 What needs to happen to improve health outcomes for autistic adults in New Zealand?

3 How can marginalisation in the autistic adult population be reduced following dominant adverse events?

2.5 Summary

This chapter reviewed the relevance of contemporary and historical frames of reference in which to describe ability and disability as a social construct and, therefore, society's responsibility to deconstruct the elaborate attitudinal and systemic barriers that occur that

segregate those who live with impairments. This review of available material suggests that the body of research on adult autistic persons pandemic experiences is insubstantial, demonstrating the need for more examination of their lived experiences. This lack of academic response provides some validation for exploring this research question and our imperative to fully describe the journey in a manner that facilitates the examination by other scholars. Investigating the history and application of the social model of disability showed persistent societal bias and systemic barriers. The awareness of these, colours and guides the research methods presented in the next chapter, research that seeks to provide a means to understand how these barriers and biases shaped the experiences of adult autistic persons living in New Zealand during the COVID-19 pandemic.

Chapter Three: Methodology and Methods

3.1 Research Design and Methodology

This study was underpinned by a qualitative phenomenological methodology, which guided data collection and thematic analysis. The Austrian-German philosopher Edmund Husserl developed descriptive phenomenology in 1954, explaining a methodology whereby the researcher sets aside their expertise and seeks to examine the topic as the participants experience it (Charlick et al., 2016). According to Austin et al. (2014), phenomenology aids researchers to investigate participant experiences, feelings, and ideas to elicit the meanings behind an individual's experience. Sundler et al. (2019) explained how individual researchers' preconceptions are still acknowledged, and researchers critically analyse their assumptions, utilising what they know to inform what we may be missing owing to prior assumptions. Phenomenology guides researchers to be open to the participants' subjective perspectives and meanings. According to Charlick et al. (2016), deriving themes from phenomena through the lens of the participant's experience situates the participant as the expert in their own experience.

When researching the experiences of autistic adults, phenomenology provides participants with the opportunity for their unique sensory processes to be revealed and analysed meaningfully to their experience, hence providing the participant with a voice (Howard, 2019, Zahavi, 2018). The need for this voice is strengthened by the broad diversity of unique individual sensory schemas where each autistic person has filtering based on a mix of hyper-sensory, hypo-sensory and seeking-sensory reactions (Thye et al., 2018., Lefebvre et al., 2023). This makes applied phenomenology appealing when no pre-existing literature exists to anchor to and where sense-making in behavioural assessment in schools is so challenged by this lack of literature. In the case of this research, the pandemic is a new and under-researched context in terms of the

experiences of autistic adults. While phenomenology supplies a framework for disseminating the participant experience, a macro view further aids in understanding how and why societal protocols and environments shape these stories (Zahavi, 2018). The researcher advocates that this richer analysis would incorporate an evaluation of the societal level adjacent impact on the individual experience, allowing some understanding of what exterior factors shaped these stories.

While phenomenology provided the methodological basis for gleaning participant's lived experiences through their own means of expression, the social model of disability provided the wider contextual basis for the interpretation of findings. Oliver (2022, p.18) describes the social model of disability as focusing on the environmental, cultural and economic barriers affecting disabled persons' lives, such as discriminatory health and support services, inaccessible transport, buildings, education and working environments. Discriminatory content is also consumed in society through the media, which often presents negative narratives concerning disability, which, over many years, has created a negative cultural bias towards disability (Orcan, 2019). These behaviours affirm the valid basis of the social model of disability – i.e. that disability is an outcome of society. Disabled persons confront barriers that restrict them from participating in society, for example, a notice or sign that an individual with a visual impairment is unable to access or a building that is inaccessible for wheelchair users due to the lack of ramps (Malcolm, 2022). There are also social and psychological impediments, such as stereotypical attitudes held by non-disabled people regarding disabled persons (Rohleder, 2014; Turnock et al., 2022; UPIAS, 1976). Assuming that a disabled person "cannot do" something puts the disabled person at a disadvantage. These barriers, according to the social model of disability, are what render a person disabled. It is critical to recall that, according to the social model of disability, impairment and disability are not synonymous. A functional

issue in the body or mind is an impairment. Disability is the experience of being unable to participate in society due to the limitations imposed by society (CDC, 2020; UPIAS, 1976).

When analysing data, the researcher used the social model of disability as a lens to interpret how societal factors shaped autistic adults' experiences of the pandemic. In particular, participant's accounts of how the wider environmental and societal context affected the day-to-day functioning of this population. Whilst the philosophical stance of phenomenology usefully elicited accounts of participants' lived experiences "through their eyes", the social model was used in analysis to interpret how society has created disabling and enabling interactions for autistic individuals (Howard et al., 2019).

3.2 Ethical Consideration

Ethics approval was obtained from the Massey HREC (approval number OM3 23/18) before interviews took place. Massey University (2017) states that participants have the right to be fully informed. The researcher guaranteed that participants were fully informed by comprehensively disclosing the research objectives and providing consent forms. It was ensured that participants knew their replies were confidential and that they could withdraw their involvement at any time up until data was analysed. The researcher acknowledges that autistic individuals can occasionally be overly nervous about the unknown, and this can lead to repressed narratives or outright withdrawal (Bertelli et al., 2022).

The quality of consultation with participants for this research was critical to safety and data validity. The researcher used a reference group of autistic individuals to ensure the trustworthiness of the research and that the non-autistic view would not dominate in this study. The use of reference groups aids the researcher in understanding the study population's social behaviours and helps create a study that uses the correct terminology and speaks using the

voices of the population (Tanksley et al., 2019). The provision of feedback throughout the research journey by a panel of three academic supervisors enabled the researcher to ensure the reliability of the data encoding.

3.3 Researcher Reflexivity

Sundler et al. (2019) defined critical analysis as separating various researchers' assumptions by reflecting on which preconceptions they each bring that may influence their interpretation of the facts. The voices presented and the variations of narrative styles voluntary subjects will comfortably employ to tell their lived experiences are distinctive from the preconceptions of the researcher. Acknowledging one's views promotes increased openness and awareness of new and novel ways experiences can be portrayed by others. With a diverse background and worldview, the researcher has a greater experience of shared narrative styles, providing an openness to even more new ways of communication, leading to reflective discourse which helps with openness to novelty in the subsequently organised interpretations to communicate the lived contexts within the data accurately.

The analysis method was selected to accommodate the reality experienced by each participant while considering confounding potentials that the environment, the ways of telling and the interpretations of stories can introduce (Ayton et al., 2023). For example: the researcher was mindful of the colouration of participants stress when reliving adversity while telling of their lived experiences under the significant societal pressures of the pandemic. In addition, this research provides the novelty of empowering autistic individuals to comfortably use an unpressured voluntary voice about their New Zealand Covid-19-linked experiences is intended to provide a tapestry of freely lavished colours to this research.

3.4 Participants and Recruitment

Adults aged eighteen and older who were formally diagnosed as autistic or who self-assessed as autistic participated in the study. Self-assessed autistic adults refer to those who identify as being on the autistic spectrum and have not received an official diagnosis from a healthcare professional. In a study by Lewis (2017), it was reported that many adults felt that medical professionals appeared to have had minimal knowledge and understanding of autism across all ages and had stereotypical opinions regarding the diagnosis of autism. Such as believing that if the person does not show certain "autistic" behaviours they cannot be autistic, these behaviours are: showing lack of empathy, social inadequacy, being detached or other stereotypes associated with autism. It's important to acknowledge that adhering to these stereotypes oversimplifies the intricacies of autism and does not accurately represent the uniqueness of each individual.

Access to diagnosis is also a lengthy process due to the lack of readily available psychologists; long waiting lists in the public health sector can mean decade-long delays (Overton et al., 2023). The researcher feels that these individuals should not be excluded, as it would be an affront to their autistic identity. This research was discussed with Massey University supervisors, who pointed out that formal diagnosis for some adults can restrict life choices such as immigrating to some countries and participating in some vocations and professions. Input from Autism NZ via email and the research reference group was sought during preparation; their expertise and values were applied through participation in context formulation discussions, shaping the use of terms and language, and the researcher requested the assistance of Autism NZ networks to aid recruitment. The researcher also used social media to reach those outside these networks who could be eligible to participate in this interview-based research.

Seven people responded to an invitation to participate, five via Autism NZ Facebook research recruitment post, and two other participants via social connection. None responded to the posters, and six eventually consented to participate in the research. Table 1 describes participant demographics: three participants identified as male, two as female and one as transgender. In addition, four identified as NZ European, one as a Māori/NZ European, and one participant did not wish to disclose their ethnicity. As seen in Table 1, ages ranged from 20 years old to 55 years old. One participant lived with parents, siblings and grandparents, another lived with a spouse and two children. Another participant lived in a shared home with four other disabled people and staff, another participant lived with two other disabled persons, another participant lived with their partner, and one participant lived alone with their cat.

Table 1.

Participants self-reported demographic characteristics.

Age	Gender	Ethnicity	Highest Qualification
20	Male	Māori European	School (Learning Support)
55	Male	Pakeha/English	Technical Diploma
44	Male	NZ/European	Certificate in Biculturalism
35	Female	NZ/European	Certificate in Arts
28	Female	Pakeha	Honours Degree
34	Transgender	Not Identified	Certificate in Creative Arts

3.5 Data Collection

Data was gathered via semi-structured interviews conducted in a conversational style with open-ended questions. This allowed for an uninterrupted flow exchange in a pleasant, relaxed setting. Subtle natural-appearing conduct adaptation occurred in regular conversations to

discover common ground and comfort (Green, 2017). Collins & Stockton (2022) note that while researchers do their best to maintain an open mind during interviews, their character adds a "natural colour" to the atmosphere and can provide reassurance. Autistic individuals can have acute, unique sensory skills and processing, which can present in their ability to read a completely different set of cues than those that non-autistic people rely on. This can potentially create distrust when another person is inauthentic or intrusive (Norris et al., 2020; Gowen et al., 2019). The study reference group of two autistic individuals provided insight into social cues and assisted with clarifying first-person understandings of the lived experiences that participants reported. However, both the reference group and researcher acknowledge the individuality that comes with each person's autistic experience, hence generalisations cannot be made from qualitative studies of lived experience (Ayton et al., 2023).

The researcher allowed participant's responses to the interview questions to guide the interviews, which encouraged deeper introspection, and sensitive interactions to avoid distress (Danker et al., 2016). A Likert Scale was used to provide valuable insight into participants' emotional states, allowing the researcher to look at the degree of anxiety the lockdowns and restrictions may or may not have caused. A Likert scale is a common scale used in questionnaires, and is used to establish a participant's feeling spectrums for example: how did you feel about… they have answers to choose from that vary between very satisfied to very dissatisfied or strongly disagree to strongly agree (Bhandari & Nikolopoulou, 2023; Kaplan & Saccuzzo, 2018; McLeod, 2023). This form of question is easy for participants to interpret and can provide a rich capture of participant feelings.

Each consented interview was audio and/or video recorded, either through stream capture (Zoom) or with an onsite face-to-face camera or audio device. The generated files were saved

on the primary researcher's PC. During the collection phase, the researcher found that those who are non-speaking or other impairments alongside their autism were accommodated with the option of answering the interview questions by email. The researcher provided email questions, and two of the six participants responded this way. Two participant interviews were conducted via Zoom, and two were in-person interviews. Two participants reviewed transcripts, two were written interviews, and two were not interested in a review.

All participants wanted to access a summary of the study's results. All participants will receive a copy upon completion of this research. Data collection carries confounding risks that require best-case mitigation; an example witnessed in prior work by the researcher was a support person talking for their client in a way that was contrary to the client's feelings. The carer imposed their narrative and views instead of being representative of their client. This was confounding due to the carer's voice replacing the client's, therefore compromising the client's agency through abuse of trust. This confound has been negated in this research by the sole support person's voice being assessed for narrative, consistency and voicing.

3.6 Analysis

This research uses thematic analysis, underpinned by phenomenology, to understand and correctly interpret the meaning of the participants' stories. The social model of disability gave the researcher a framework to bring context to these experiences in relation to the behaviour of society and its effects on the participants.

Braun and Clarke (2022) originally developed thematic analysis for psychological research. This method is flexible and has been adapted for use in many forms of research. Thematic analysis allows the researcher to identify, analyse and interpret themes or patterns in data. This approach is beneficial when exploring people's opinions, views and lived experiences of an event or topic.

Using thematic analysis, the researcher first becomes familiar with their data, reading and re-reading; they then highlight sections of the data and create a coding system using the data they found meaningful and exciting (Claufield, 2024). This creates an overview of what is recurring in the data. This data is then broadened into themes, where the codes become more focused, and any codes that seem irrelevant to the research question are discarded. These potential themes should inform the purpose of the research. The themes are then reviewed, and each theme is addressed in the results section of the research. Pellicano et al. (2021) applied thematic analysis of autistic narratives effectively during a pandemic, supplying a viable model to adapt to suit this research. This study considers participants as experts in their own experiences, establishing equity of participation between the researcher's disclosed and now-useful bias and the participants' lenses of life.

The researcher then used the Office Word transcription tool to mechanically transcribe audio from the interview video. The transcription was checked for accuracy, and those participants who were asked to view transcripts were encouraged to do so. Allowing the researcher to check their understanding of themes and contexts and to reflect that their own perceptions and knowledge are aligned with the participant's debriefing verified intentions. With the narrative validated, the coding activities commenced.

The transcripts were subjected to numerous interpretive coding iterations. During data collection, the researcher regularly analysed patterns and prospective themes using Braun and Clarke's reflexive thematic analysis (RTA), which allows for reporting of the meaning and authentic experiences of the participants (Pellicano et al., 2021; Braun & Clarke, 2022). The researcher reviewed the transcripts several times, taking notes on recurrent occurrences, early thoughts, and stakeholder reflections before creating and applying codes, as seen in Table 2 below. The data and codes were then reviewed to uncover themes through broader shared

meanings, which were refined using the six phases of thematic analysis. In phase one, familiarisation with data, a significant amount of time was spent reading and re-reading each of the six transcripts, and notes were taken. In the second phase of generating codes, each interview was systematically read to identify any patterns emerging in the data. At this point in the process, codes appeared that were not expected, such as the richness of reported positive social interactions; other codes proved more prominent than the initial methodology planning dictated, such as descriptions of anxiety, and the quality of participants' advice. Some codes were anticipated from reading research during the literature review. This led to the analysis approach becoming inductive and deductive (Braun & Clarke, 2006).

Table 2

Overview of research analysis methodology and narrative evolution.

	Researcher lens	Participant lens	Social Model of Disability Lens	Codes and Themes
Phase One Initial reading (Familiarization)	Unexpected sensational richness	Service negativity	Service insensitivity	Basic mapping of sensations to achieve rudimentary codes
Phase Two Code Generation	Participant comfort validation	Unexpected increased socialisation	Types of advice to others	Codes highlighted throughout transcripts
Phase Three Theme generation	The bidirectionality of the effect of circumstances on sensations	Alignment of individual situations to supplied prompts	Examination of co-occurring conditions, both potential and presented	Summative examination of codes for themes to emerge from
Phase Four Theme Refinement	Alignment of interview prompts to themes	Reconciliation of prompts to sensation weighting	Sensations paired with societal-attributed root causes	Concise theme naming and descriptions reached
Phase Five Theme Validation	Confirmation of service deficit	Situational alignment to sensations, confirmation of participant meanings	Thematic Exploration Within Social Model of Disability	Theme meanings examined and tested against biases and models
Phase Six Writing up Coloration	Comparative review of own prejudice to both found data and literature	Summative formation of experiences into thematic language	Articulation of thematic relationships	Findings and themes validified/ Relevance of research narrative

The collected data was then grouped into participant experientially weighted evolving codes, using an appropriately reflective title for each code. This was repeated until the codes became clear, taking four iterations each where the transcripts were read and encoded. Phase three of the analysis allowed a re-analysis of the coded data; this involved organising the data into

themes. In the process, it became clear that some themes had more support than others. During the fourth phase, the data that formed the themes were refined until six themes were presented, and names were given to the themes. In phase five, text was selected to help confirm the collected data.

3.7 Summary

This chapter outlines the qualitative approaches and strategies used in this research for data collecting and analysis. Ethics approval was obtained before commencing the research project. Six people were recruited for the study. The researcher conducted and transcribed the interviews. Six stages of thematic analysis were used to examine the data. The next chapter covers the six themes discovered during the data analysis.

Chapter Four: Findings

4.1 Introduction

The current study explores the experiences of autistic adults in New Zealand during and after the pandemic restrictions. These findings shed some light on the lived experience of the autistic participants and help us understand the profound impacts of the COVID-19 pandemic on this population and some possible steps toward remediation of some of the negative impacts.

Six themes will be presented here. Five themes were evident from a thematic analysis of the research interviews and transcripts: 1.) Adjustments in social activity, 2.) Increased barriers to mental health support, 3.) Changes to community connections, 4.) Diminished overall well-being post-pandemic, 5.) Changes to anxiety levels. The sixth theme is presented as a within-design summative theme. Participants were asked if they had any advice for other autistic persons, and this theme serves as a summary to the findings section.

4.2 Characteristics of Participants

A total of six participants were interviewed as part of the research. During the lockdowns, participant one lived with their mother, father, brother, two sisters and grandmother. Participant Two lived with their wife and two children. Participant Three lived in a supported care home with four other disabled persons and care support people. The fourth participant lived with their partner. The fifth lived with two other disabled persons and had regular care support, and the final participant lived independently with their cat and had a care support worker come once a week or as needed.

All six participants identified that they had other impairments alongside their autism, including sensory issues, pervasive development disorder, epilepsy, high anxiety, depression, vision

impairment, deafness, attention deficit hyperactivity disorder, catatonia, post-traumatic stress disorder, obsessive-compulsive disorder, and a variety of other neurological disorders.

4.3 Theme One: Adjustments in Social Activity

Participants described contrasting adjustments to the number of social experiences they had. These manifested in a range of emotional effects that seem on the surface to be not attributable to pandemic-provoked social adjustment. However, the intensity of these emotional effects were shown to have increased as a result of pandemic social experiences. This theme is divided into the sections "increased social activity" and “decreased social activity", each with findings reported from positive to negative, including any potentially disclosed causes that aid in explaining the emotional framing.

First, participants were asked how social they consider themselves overall in order to ascertain if they were inclined to seek social opportunities and may have avoided places where social activity may be expected of them. One participant works in a highly social environment and seemingly can block out most of the need to attach or interact:

“*While I am around many people at once, I am not socially connecting with them”* (Participant Two).

Psycho-social aspects of autism and other common comorbidities mean the affected persons often experience barriers to social connection and activity. This leads them, over time, to develop behaviours to cope with interfacing with the world. In what may seem contradictory, in some cases, an autistic person can have “social superpowers” (Limburg, 2019). A good illustration of this was a tendency that Participant Two described to selectively focus thoughts and filter out senses to exclude other people, ignoring them entirely or having limited interactions and low emotional attachment to those other people. However, these strategies may also be part of a masking strategy to help Participant Two in coping with social situations or as

a presentation of social code compliance. Autistic persons may be masking their actual inner sensations to appear more neurotypical to others:

"*...people view me as a very social person, ... but I dislike people in general. People are gross*" (Participant Three)

The mode of social activity has a significant effect on the social tolerance and cognitive load of an autistic person; for example, a digital interaction that uses video and audio (like Zoom) has a more significant sensory load than an interaction that has only audio (like a telephone call). Although, an audio-only format puts greater stress on a person with auditory sensory processing disorder (Gonclaves & Monteiro, 2023). Another example is the contrast in social load between an in-person interaction with all its physical stimuli being quite different to that of an interaction of reading words on a screen. A specific text-only example is the stress of typing the correct responses within the tight context of a single-topic social media forum, putting pressure on a hyper-sensory person in real-time and a hypo-sensory person ruminating about its correctness for long periods afterwards (Thye et al., 2018; Lefebvre et al., 2023). It is then helpful to articulate the framing of each reported element within the appropriately described situations. The conversational style of five of the six interviews provided the researcher with this valuable clarifying context. The participants disclosed the social setting, whether digital or otherwise, as a part of the storytelling. Another participant reported a preference for a mostly online-based social experience in addition to family unit-style interactions with housemates and live-in support persons.

In the in-home, family unit, or during the social contact restriction period, close contact groups significantly differed in socialisation type and intensity from those outside of these paradigms. This is due to the emotional attachments, comfort level, and familiarity with those in more

regular and closer proximity. Most participants talked about sticking to a group of select friends and family, with two participants feeling that they are very social:

"I am social ... but it is my own way" (Participant Four)

One participant said their social activity level was the same as pre-pandemic levels, and the remaining five participants had various changes to their activity levels:

Increase in Social Activity

This finding was not anticipated due to the social impairments that many autistic adults live with day to day and is explainable in the diversity of sensory stimuli modalities having some prefer the modes that became dominant due to lockdowns, such as online and digital communication (Sahi et al., 2021). Most of the participants felt that they have had an increase in social connections during lockdowns and post-pandemic:

"I had more social activity during lockdowns than before them" (Participant Five)

Participants mentioned that they felt they had more social activity than usual because everyone made more of an effort to check in with each other during lockdowns, for example, parents were checking in more than usual.

In the digital domain, the ease of low stimuli contact has had a lasting effect on the number of relationships, in some cases causing increases. For example, one participant attends augmentative and alternative communication (AAC) Zoom groups and is involved in disabled persons' organisation huis. Another attended their dance classes via Zoom, which they would have typically attended in person. They have resumed post-pandemic attending classes in person with friends. The participant found they interacted with more people online via emails and social media and have since continued having this more significant number of connections in person and online.

"I have more people in my life than before Covid-19" (Participant Six)

It would appear that the break from the pressure of in-person contact during pandemic social restriction periods gave rise to a willingness to have more physically present social interactions once those restricts ceased: One participant mentioned that now they can go to their campus instead of online, and they have more chances to connect socially in person with people.

"I go to campus for uni classes now. More of a chance to hang out with people" (Participant Four)

The break from in-person interactions also provided space to evaluate previous social settings and determine what is more preferred: One participant found a new in-person group that was more appropriate for their age and has since formed new connections, enjoying this new group as a safer space. During the pandemic, they struggled with doing school chats via online mechanisms such as Zoom. Even in this relatively low stimuli setting, feeling different from the group was sufficient to provoke reluctance to participate. It appears that the shifts in social contact modes had a self-deterministic effect on their choices once the opportunity to resume in-person contact arose.

Digital contact modes do not suit all autistic persons, with some having the need and preference for physically present contact. One participant mentioned having to make accommodations to be social, as it was a lot harder during lockdowns. For example, they arranged meetings in their driveway and other settings where they could have socially distanced visits from friends.

The absence of in-person social exposure during lockdowns allowed respite from contact stresses while providing an opportunity to ease back into settings with fresh energy. Participants disclosed being more inclined to do more socially exposed activities, such as shopping, due to becoming more accustomed to the patterns of increased social interactions.

"I go shopping more now…there are more people in my life" (Participant Six)

While it was not the people that were missed for some, it was the lack of ability to go to places during pandemic restrictions. Visiting these places post-restrictions with an increased compensatory frequency that made up for lost opportunities and had the consequence of more social exposure.

"I do more shopping now; it is exhausting…and realise just how bad crowds make me feel" (Participant Four)

Decrease in Social Activity

Acquiring primary needs such as grocery shopping was described as a painful chore for some, with the overwhelming combination of crowds, loud noises, and large open but enclosed areas. The restrictions that came with the initial pandemic lockdowns allowed many retailers to create an online experience for their customers so that people could still shop.

"…*prefer online shopping*…" (Participant Five)

Well-documented pandemic labour shortages made order fulfilment often a case of "first in first served". Two participants say they shop a lot less than before COVID-19; they prefer to shop online and find the access to shop from home helpful and much more manageable. During the lockdowns, they found it was harder to grocery shop online, as all the delivery time slot spaces would fill up a week in advance, so they would have to go to the store physically when it was tolerable to stand in large lines outside the store with many other people. This resulted in autistic shoppers having to choose between going without or facing the socially restricted supermarkets in person.

"…*shop less, to avoid big crowds*…" (Participant Two)

Many of these retailers and services continue to provide online shopping delivery after lockdowns lifting, allowing those who find in-person experiences challenging to have access

to needed goods. A participant mentioned that their family continued to have restrictions on socialising for a long time after the lockdowns ceased. They are still cautious about large social spaces and gatherings and have continued wearing masks and social distancing where they feel appropriate, such as on public transport and at social events.

4.4 Theme Two: Changes in Community Connections

The participants' various routines, ways of doing things, cultures, beliefs and social norms inform how community connections function. Participants were asked about their overall day-to-day experience during lockdowns. The lockdowns benefited the life balance of one participant who said they had a rigorous routine, with schoolwork dropped off at home, and enjoyed having family around them all the time. Another had contrasting experiences of a disrupted life balance, describing how "stifling" they found lockdowns. This led to them being unable to express themselves creatively and losing work opportunities. The day-to-day chores dominated with the participant, feeling they had to be more resourceful about keeping the house routines intact. They found things to keep themselves and their family occupied and developed plans to get groceries, scripts from the pharmacy, and other supplies. Many businesses found ways to continue operating by developing remote working strategies; a participant mentioned that their work provided the ability to work from home. The participant did, however, find it hard to make plans, they always got cancelled due to the changing restrictions and did not know whether the plans would happen.

Community Connection

A participant mentioned that they now have an augmentative and alternative communication (AAC) group that meets online, which helps them connect with others who use AAC; they tend to feel better after this connection with this community. Online community connections, often the sole form of connection, were in greater focus for many during minimal periods of social

contact. This focus may have contributed to strengthening the community and those individuals within. A participant mentions how the time in lockdowns was reflective for some in the community and that some people have come through it more resilient and stronger than pre-pandemic.

Community Disconnection

Autistic persons can often feel the need for the nearby presence of other people while not interacting with those persons; this interaction is social play, similar to the parallel play of young children; the person is near but has no connection or need to interact (Crompton et al., 2020; Elbeltagi et al., 2023). This social parallelism can seem like an emotional fuel and a sense of connection and belonging. Removing this proximity isolates the person from filling up their emotional and spiritual "tank", and results in them feeling alone and disconnected. These feelings can persist after much of the physical proximity opportunities have returned. Many of the participants continue to feel disconnected within their communities.

"The vibe in the community feels worse now" (Participant Two)

It is common for non-autistic persons also to feel isolation-induced disconnection and, as a result, have altered behaviours towards others (Provenzi & Tronick., 2020). One participant mentioned that people seem more uptight and distressed when you talk to them, just in general, like shopkeepers, service industries and medical facilities.

"The community feels disconnected" (Participant One)

One participant singled out the medical community as having evolved into an impersonal culture with observable personnel tensions.

The COVID-19 lockdowns and restrictions may have caused disruptions in people's lives that have continued since, resulting in an altered worldview, feeling and seeing the world differently than before, affecting their attitudes and actions.

"People seem uptight, almost distressed most of the time" (Participant Two)

Another participant reflected on social tensions, observing:

"…people generally seem unwell in their minds, spirits, and community" (Participant Two)

One participant has expressed annoyance at the lack of measures to protect the most at risk in the community. Mask-wearing is almost non-existent, and the community has fewer sanitising stations and less social distancing. They feel that the rules have gone, but COVID has not.

4.5 Theme Three: Increased Barriers to Mental Health Support

Autistic persons are high users of mental health services due to the social, cultural, emotional and neurological friction against a neurotypical society's behaviours and expectations (Crompton et al., 2020; Lai et al., 2019; Tsai, 2014). This theme exposes the service access experiences of participants. During the lockdown and social distancing pandemic periods, functional access to all types of health was significantly reduced for all of society (Sabetkish & Rahman, 2021). For those already marginalised by neurotype-based socialisation barriers, such as autistic persons, the more critical mental services became unreachable in many instances. One participant talked about the lockdowns making everything "*three times as bad as it usually felt"*. They had no emotional support and access to much-needed mental health professionals, and this has been impossible due to the services being over-subscribed.

"I just have a counsellor … no mental health support like psychiatrists… which I need…" (Participant Four)

"I tried to reach out for help. But instead, I ended up catatonic…" (Participant Four)

The participant was not able to get appropriate support when they were in the hospital and mentioned that the health services need more training:

"Mental health certainly needs training in autism and catatonia, especially when they present together" (Participant Four)

One participant said that they, at one point, were not in a good place, deciding to seek help from their GP. Their GP could not help at the time and recommended that the participant try to contact other health services themselves.

"There are people I know in worse situations who would have no way to be able to help themselves in this way" (Participant Five)

One participant had good support through their school and family but had no other support during the lockdowns and restrictions; another participant found that it was not easy to get any mental health support.

"I mean, it was not perfect before the lockdowns, but the access to mental health supports got a lot worse" (Participant Two)

Full-time care home residency provided one participant with good all-around support. Another participant had access to excellent support networks online and felt socially supported; however, they encountered access barriers to mental health support.

"There was no mental health emotional support available" (Participant Four)

"Mental health support was hard to get" (Participant Five)

"I can't access mental health support now because they are too busy" (Participant Four). One participant lost their carer support hours as they could not use these hours during lockdowns and is now on lower carer support hours due to apparent low usage over the lockdowns.

"...getting better, but delays due to backlog from COVID" (Participant One)

Another participant discussed how it was not easy to get any public mental health support being autistic:

"Just that is extremely difficult to get any public mental health support when you are autistic, even harder when you have trouble speaking" (Participant Four)

Because they have trouble speaking and using AAC, it was assumed they had an intellectual disability when they did not. After the lockdown, one participant had an in-person general GP appointment, which at the time led to a more social conversation that revealed to the GP that they had high anxiety—prompting the GP to start the participant's treatment for anxiety, including talk therapy and medication.

4.6 Theme Four: Overall Health and Well-being Diminished Post-Pandemic

As lockdown and social-isolation measures were eased, access to health services began to recover somewhat; however, the load on these services was extraordinary due to the lapses in treatment access for long periods. Another unhelpful factor both during and post-pandemic has been the shortage of healthcare workers, with many of these workers either unwell, looking after family, or otherwise unable to work. Even after the end of social isolation measures, variants of COVID were still circulating throughout the population, and many reported "suffering" from "long COVID". The CDC (2024) state that long COVID is a label given to a range of symptoms that have originated with being exposed to the virus and subsequent long-term damage, with these illnesses contributing to the load on health services.

The background of the previously reported themes and that of society, in general, provide a context to view the overall health and well-being of the participant's post-pandemic stories. The intense resonance of this theme is that well-being is low. When read in conjunction with

other themes, it would seem the participants are stuck in a poor health modality with raised susceptibility to ongoing complications:

"I keep getting sick…" (Participant Four)

Most of the participants had some health issues during the isolation periods, and most participants identified that their health was indeed worse now than pre-COVID. Some participants mentioned that they were getting sick more often now than before the pandemic.

"I have worse health now… although not covid related" (Participant Six)

"My health is worse now …I had COVID bad and had a heart attack" (Participant Three)

Most participants mentioned mental health as being significantly affected by the pandemic period, and one participant noted the ongoing difficulties getting any mental health support and questioned if the barrier was autism or pandemic related.

"My mental health is worse" (Participant Five)

The health service delays meant a participant only just got their autism diagnosis after the lockdowns, a process that was started before the pandemic. It is unhelpful that there is a lack of autism awareness and appropriate training resources throughout the health sector, which would mean the chances of any of our participants having ill-fitting services are high; as such, this was be reflected in their experience stories.

Two participants had better experiences than the other four, one seemingly physically unaffected and the other finding resilience from movement. One participant had good physical health with no changes occurring throughout the lockdowns and restrictions; another participant felt that their physical health had improved slightly due to being able to do small, consistent exercises but said that their mental health suffered.

"Because I did not require any external gym or sport equipment ... I was able to improve physically" (Participant Two)

Contemporary thinking would suggest that this participant, due to physical activity, would have enjoyed a more excellent vitality baseline. That is to suggest that their mental health could have been worse if they had not engaged in regular physical movements.

4.7 Theme five: Changes to Anxiety Levels

This theme encompasses the presentation of anxiety in three subsections: one, prior to the pandemic, pre-existing conditions and the risk of anxiety co-occurring conditions; two, pandemic-linked contributing factors, and conditions revealed during the pandemic, such as those conditions that were affected by pandemic-linked triggers; and three, continuing post-pandemic; the participants' stories up until the time of interview that contain effects of historic and pandemic factors.

Each sub-theme period has the scaffolding components of pre-existing contributing factors, events, and reported outcomes. The stories of each participant have a weighting bias towards one or more of these periods, which is apparent in the emotional levels and amount of disclosure. While anonymity prevents a deeper understanding of individual pathologies, examining the chronological scaffold is enough to glean an abstract summation of timelines across the group of participants.

The likelihood of those with autism also having co-occurring conditions that include anxiety is high (Al-Beltagi, et al., 2021; (WHO) (2023); White et al., 2009). Anxiety itself, along with the neurological patterns typical of autism, tends to increase rumination susceptibility across the entire population. Combine this with the hypo-sensory processing delay of events present in many autistic persons who have a sensation of being stuck in a loop of processing events over and over. Demonstrating a likelihood that the autistic participants would have a

background of an extraordinary anxiety experience in contrast with the general population due to these additional sensory pressures (Thye, 2017). With this sensitivity in mind, the participants were asked about their anxiety experiences.

An anxiety question was asked during interviews with multiple parts intending to draw out the experiential story. While the parts within this included specifics such as a Likert Scale anxiety-level indication (see Table 3) and a request for any anxiety changes due to pandemic period effects, there was also the inclination of most participants to provide a history of anxiety.

Anxiety Before Lockdowns

Baseline anxiety presented by participants before COVID-19 onset varied in duration and severity. One participant was diagnosed and treated for anxiety from the age of 13. Another participant had separation and transitional anxiety, adolescent and early adulthood treatment for adverse childhood event trauma and PTSD. In addition to high social anxiety that was primarily hidden by masking behaviours. They were not being treated for anxiety before the pandemic.

Anxiety During Lockdowns

Most participants had high anxiety during the lockdowns, with four participants registering a retrospective five on the Five-point Likert scale for anxiety.

Table 3

Likert scale of anxiety

Participant	1 Low Anxiety	2 Low to medium anxiety	3 Medium anxiety	4 Medium to high anxiety	5 High Anxiety
1	x				
2					x
3					x
4					x
5				x	
6					x

Note: These results show participant anxiety levels during the lockdowns and restrictions

One participant mentioned feeling more anxious than usual and worried about their family and community. This anxiety is the highest during the periods of lockdowns and restrictions. Mask-wearing was another reason given for raised anxiety about having to wear them and people not wearing them. Three participants experienced uncertainty which led to anxiety due to the quick changing of the public safety rules, making it stressful trying to remember what they needed to do while out in public:

"I was watching out for the changes and was very anxious about what was socially acceptable… the shifts in regulations were an extra thing I had to process" (Participant Five)

"…I could not follow … could not remember all changes…" (Participant Six)

Anxiety After Lockdowns

One participant was diagnosed with high anxiety after the lockdowns:

> *"I was receiving help for depression and a few other health issues and was having a routine check-in. We started to talk, just in general, about COVID, and the GP said that he recognised that I was experiencing high anxiety, so then we set up a treatment plan"* (Participant Two)

4.8 Theme Six: Peer-to-Peer Advice

At the end of each interview, the participants were asked what advice they would offer their peers about coping with the post-pandemic society. While each participant has unique traits and pressures, there is an element of shared experience for most autistic persons, making a peer-to-peer advice platform generally helpful and relevant. As the question was framed within a study about the pandemic and its effects, each participant would have been mindful of both their own, and experiences they have heard or can imagine others have had, making any advice razor sharp in relevance to the given context. As such, the advice and the meanings that can be derived from these could reveal the participant's story that has not been exposed in other themes or questions.

One participant illustrated a perception or history of being misunderstood, and helpfully offered reassurance to others to push past any fear of disclosure to clarify or repeat themselves to obtain understanding, presumably from a support service or person:

"Do not be afraid to say you are confused" (Participant Six)

Altering the mode of communication may be required to obtain such clarity:

"ask for other ways of communication, like virtual appointments" (Participant Six)

"Be more open; let people know when you need help… How you are feeling is not unreasonable". (Participant Five)

In a previous theme, a participant complained about the lack of accommodation for the medically vulnerable individual post-pandemic despite the ongoing infections of the COVID-19 virus. Another participant helpfully suggests keeping oneself safe and providing a behavioural model of safe practices for the services personnel to observe and adjust their service practices.

"Have a mask with you at all times"

"Use social stories around rules and guidelines for doctor visits and health services." (Participant Six)

It would be expected that service personnel, along with much of society, have been given to think that life is back to normal. This factor, even if just observed and not spoken out loud, amounts to pressure on the autistic to comply with this worldview, even if unrealistic:

"Take your time getting back to pre-pandemic… Surround yourself with family and friends" (Participant Four)

Services may forget about the needs of some, making it helpful to provide reminders of continued vulnerabilities to these services. Those who are at risk and keeping in regular contact help remind services to maintain or adjust policy. Meanwhile, the client avoids their needs being forgotten or overlooked by being a "squeaky wheel" a person who gets noticed by being noisy:

"Keep connected as best you can with the services." (Participant One)

The participant who earlier disclosed in a prior theme the benefits of movement to overall vitality was urged to share this with others, along with another participant who had their own self-care experiences deemed worthy of sharing:

"Find ways to keep active and moving". (Participant Two)

"Self-care, do things that you enjoy'. (Participant Three)

The within-autistic community origin of this advice does not automatically imply that the same advice may not be obtained elsewhere; however, given the weight of health services lapses reported by participants, it does suggest that such advice may have been readily available. It

follows that the voice of this community is important, especially when society fails them due to service lapses and extraordinary events.

4.9 Summary

These results presented a range of experiences and issues faced by autistic adults during and after the COVID-19 lockdowns and restrictions. These results have indicated that there has been a change in the social, health and community environments surrounding autistic adults and that many have experienced high anxiety around the pandemic and have found it difficult or near impossible to get mental health care and support.

The following chapter discusses these themes in relation to previous literature and the social model of disability.

Chapter Five: Discussion

5.1 Introduction

This research explored the lived experiences of autistic adults and the ongoing effects of the COVID-19 pandemic in New Zealand. The data explored rich accounts of autistic individuals' experiences using their own words and perspectives. The social model of disability was used to interpret the participants' experiences of societal attitudes that were both disabling and enabling for autistic people during COVID-19 restrictions and lockdowns. Thematic analysis resulted in six themes: 1.) Changes in social activity, 2.) Changes in community connections, 3.) Increased barriers to mental health support, 4.) Overall health and well-being diminished post-pandemic, 5.) Changes to anxiety levels and 6.) Peer-to-peer advice. This sixth chapter situates the findings of this research in light of the existing international literature. Recommendations for policy and practices that support autistic adults are also discussed in regard to the study findings.

5.2 Changes in Social Activity

The COVID-19 lockdowns stimulated a change in the nature of work and recreation from in-person to remote (AL-Habaibeh et al., 2021; Towner et al., 2022). This research revealed changes in social activity, for some autistic adults this represented a novel surge in remote interactions that has generally been sustained since (e.g. "*I had more social activity during lockdowns than before them*" (Participant Five)). Resulting in in-person interactions becoming more frequent once isolation rules eased, "*I have more people in my life than before Covid-19"* (Participant Six). Communities based in digital environments such as social media and special interest online discussion forums grew in membership, traffic, and special focus sub-niches emerged and grew (Towner et al., 2022). The specificity of sub-niches would garner a dedicated following and a devout, supportive membership, such as the AAC community group finding

an online space supportive of their augmentative communication modes. Growth in these potentially supportive groups and shared online experiences fostered a sense of belonging (Sahi et al., 2021), even if just a shared mission of adaption to events unfolding, stimulated growth in engagement and a drive to be a part of the group's purpose. While this digital culture was not new, the isolation-induced motivation of individuals to engage realised significant user amplification in duration and intensity of experience.

In the digital domain, the social model of disability emphasises how online environments may reinforce or reduce obstacles experienced by disabled persons. Digital everyday worlds include online interactions, activities, and experiences (Botelho, 2021). Autistic adults and others with impairments face obstacles in the digital culture, such as accessibility - ensuring that digital material is available to everyone, visibility, and raising the profile and voice of people with impairments.

During the COVID-19 pandemic, this novel emphasis on digital communications was overwhelming for some with greater hyper-sensory sensitivity, while others with lower sensitivity adapted well. Historically, Maljaars et al. (2023) reported that online communication shifts cause unique tensions. The shift from in-person meet-ups to virtual interactions presented challenges to the cognitive load of these social changes from increases in frequency. Cognitive load refers to the mental effort required to process information during learning or problem-solving. When capacity is exceeded, any further input becomes challenging, and the brain feels full (Kalyuga, 2011).

Individuals with autism may experience cognitive overload more frequently owing to impairments in sensory processing, social communication, and executive functioning. Zhu & Aryadoust, (2022) report the shift in emotional load from the alteration of interaction codes of

conduct, showing an increase in cognitive load of sensory filtering and subsequent interpretation under an alteration of stimuli.

Conversely, some enjoyed digital communication opportunities due to the narrowing of stimuli compared to the broader immersive stimulation of in-person environments. This was consistent with Sahi et al's. (2021) research, which explored non-autistic virtual interaction during the pandemic. They found a reduction of stimuli was often offset by an increase in the frequency of exchanges, sometimes negating the gains in comfort. This was similar to our findings with some of the participants seeming to thrive socially in virtual environments *"I had more social activity during lockdowns than before them"* (Participant Five), while others experienced heightened stress from the increased amount of online contact compared to prior in-person contact required to obtain domestic and ability support (Zhu & Aryadoust, 2022).

The cultural shift to online environments represented an attack on those with sensory needs better served by in-person exchanges. However, it also provided an advantage to those who required lip reading that would be blocked by in-person mask-wearing *(*e.g. *"masks made it hard for me to understand people*" Participant Three). The current research results along with Pellicano et al. (2022) and Oomen et al. (2020) reveal the difficulty some found in online environments and that the absence of face-to-face interactions has, for some autistic individuals, led to feelings of isolation.

Online shopping became essential during lockdowns. The predictability of online transactions provides comfort for those who find security in routines. However, the initial lockdown resulted in online grocery ordering slots quickly becoming full, even those reserved for disabled persons. *"There were no slots left as there was so much demand, so one of us had to go to the supermarket, which was frustrating",* (Participant Five). This left some having to go to the store in person when they preferred online ordering. In this research, those showing a

hyper-sensory tendency felt they still limited interaction in crowded or busy spaces due to ongoing spread (Thye, 2017). "*We shop less, to avoid big crowds…"* (Participant Two). These results are also evident in Oomen et al, (2021).

5.3 Community Changes

For autistic persons who relied on day-to-day in-person contact from support persons and assistance in obtaining services and goods, the lockdowns represented an attack on their capabilities. Some individuals partially overcame this procedural attack of social distancing and enforced isolation by adapting digital connections to their existing social networks (Maljaars et al., 2023). Participants reported employing strategies like virtual meetups with interactive groups, disability groups, and peers, and structured communication such as increased email or other messaging channels. However, these digital strategies did not replace the primary support care removed due to the pandemic restrictions as the effects of the severe reduction in basic needs accessibility remained, for example: *"I could not get the help I needed"* (Participants One and Six).

No unique or specific support was given to protect the continuity of support for the needs of autistic persons during the lockdown periods. This resulted in a decline in care for those in care homes experiencing erosion of their quality of daily lives, attributable to the lowered support staff availability. For those not in care homes, the removal of the regular in-person contact from friends and support workers resulted in loneliness. For example, the removal of logistic support by staff that would have ordinarily shielded autistic persons from being exposed to the sense of overwhelming that occurs from adjacency to crowds (e.g. "*I do more shopping now; it is exhausting… and realise just how bad crowds make me feel*" (Participant Four).

Since the relaxation of social restrictions, support personnel shortages from staff attrition and illness absences have meant that service had not been restored to pre-pandemic levels, leaving many with needs continuing to be unmet, such as unfilled support hours creating care deficits. The post-pandemic funding cuts by the sixth coalition government signalled that there is likely to be a further decline in much-needed healthcare due to a lack of funds (Forbes, 2024). Although the funding cuts did not specifically target disability services, the pattern of service delivery by the New Zealand health system since the dawn of the neoliberal era in the 1980s has shown very little progress in delivering basic human rights to disabled persons (Forbes, 2024). This is despite being a signatory to the CRPD, which embraces the social model of disability (Barnes & Mercer, 2003).

Some may see the formation of Whaikaha in 2022 as a sign of progress by way of having a specific funding agency for the deliverability of outcomes (Whaikaha-Ministry of disabled people, 2022). However, at the time of writing, progress will not occur under a policy for reduction in funding reach directed by political leadership seeking a narrowing of scope to achieve budgeting goals (Forbes, 2024). This has the effect of narrowing what care is available due to many care use-cases, for example: some respite funding no longer fit the funding criteria. This respite funding cut attacks the vitality of carer personnel, affecting quality, continuity and capability of carer service delivery due to increases in stress and fatigue (Burns, 2024; Graham, 2024).

Cultural shifts have arisen due to communication adaptations within the emergent social distancing culture that significantly pressures autistic persons to do most of the work in adapting to social changes. Adaption places a significant burden on the processing capabilities of the autistic individual to fit into the new modes. Rivera-Figueroa et al. (2022) state that autistic individuals navigate a world that operates on neurotypical norms. Autistic individuals may struggle with executive functioning, such as social cues, and this can make engagement

in a shared space challenging for the autistic person. This can lead to an inability to connect with others (Donno et al, 2023).

The friction between their unique perspectives and societal expectations can lead to significant emotional and mental challenges, without direct support or instructions on how to adapt, the participants' felt society has ignored diverse needs. This adaptation burden combined with the weight of shifting social expectation challenges are added stressors. These loads can lead to depression, anxiety, and suicidal ideation due to social, cultural, emotional and neurological friction. In this study, this occurred to the extent that one participant was hospitalised. Variations in communication styles, hyper, hypo and seeking sensory sensitivities, and social expectations can present neurotype-based socialisation barriers an autistic person has to expend some effort to adapt to.

Meanwhile the non-autistic, while having some external adaption pressures, have the support of the mass of similar neurotypes that dominate culture, form the rules of behaviours, set the manner, and form the adaption takes. The dominant non-autistic ways rule the environment in which autistic persons must follow conduct not designed for their way of thinking, feeling and communication. Non-autistic people may struggle to understand autistic personalities and behaviours owing to variations in interpersonal and verbal communication styles. This is sometimes referred to as the "double empathy problem" (Chown, 2014; Milton, 2016; Mitchell et al., 2021).

Autistic individuals may communicate differently than persons who are not autistic, making it difficult for non-autistic people to grasp what autistic people are trying to say or express. Similarly, non-autistic individuals struggle to understand how autistic people think and feel. Some may believe that autistic persons are uninterested in making friends or interacting with others. These misconceptions might result in prejudices and misunderstandings (Mitchell et al,

2021). This prohibitive adaption cost is born entirely on and within the autistic person, with society seemingly oblivious to the complex layers of anxiety and dangerous mental health issues it introduces. It is the role of society, as per the social model of disability, to at least share the costs of cultural shifts and provide a means for treating the problems it creates.

This research found that there was a change in what support was available from organisations and community groups, and how appointments were carried out during lockdowns. Going to a place of employment and interacting with co-workers halted for some, while others could work from home, thus creating many changes to routine and environments simultaneously. The interaction with people in the community disappeared almost overnight, disrupting the sameness that autistic individuals often rely on. This in-space disconnection could explain why some autistic people in this research found the lack of socialising during the pandemic difficult *"People seem uptight, almost distressed most of the time."* (Participant Two).

In colleagues' behaviour, post-pandemic in-person dynamics within the workplace had the tension of shifting rules and accommodations, such as mask-wearing and distancing, rarely observed despite continued community transmission of COVID-19 variants. Participants had adaptions to counter this behaviour "*Have a mask with you at all times*" (Participant Six). This tension of having to provide additional adaptions to counter others' behaviours that seem illogical to the autistic person presents a burden to autistic persons.

The autistic modalities of the hard-wired inclination to strenuously and pragmatically process these illogical behaviours are amplified in conjunction with the number of perceived behaviours. Put simply, the more that is observed, the greater the processing burden. The experience of countering these illogical behaviours heightens the risk of being stuck in a stressful rumination cognitive loop. It is in attempting to solve this contra-factual behaviour, which defies all repeated reasoning attempts, which creates cognitive energy drain and stress.

For Participant Six, this was presented when the widely known fact that removing protections appears dangerous as transmission can quickly occur, became a trigger to ruminate the illogical behaviours observed *"...I could not follow ... could not remember all changes..."* (Participant Six).

Autistic people frequently confront issues in external environments, and this is due to a lack of understanding among professionals and the general public on what they need. The social model of disability acknowledges that environmental barriers limit an autistic individual's involvement in society and affects their independence (Woods, 2017) *"The community feels disconnected*" (Participant One). The model challenges us to create a world that considers everyone's needs and challenges us to remove any barriers to promote equitable participation and dignity for all (Malcom, 2022).

The isolation created by the pandemic lockdowns and restrictions has impacted social support networks, creating a social disconnect for some individuals. Social connection is essential for adaption and coping mechanisms that allow humans to function even in a world in crisis (Matos et al., 2021).

Many individuals have viewed life differently since the pandemic. Society was forced to look deep into the collective vulnerability that was faced *"The vibe in the community feels worse now"* (Participant Two)—highlighting that what matters is the interconnectedness of relationships, well-being and feeling safe and socially connected. This research highlighted a community disconnect, the feeling of people being more detached and less approachable.

Autism, in its definition, states that autistic persons may have some form of social detachment. Autistic people may not be interested in or able to comprehend the complicated flow of interpersonal interactions instinctively due to processing the environment differently than non-autistic people *(e.g. While I am around many people at once, I am not socially connecting with*

them" (Participant Two). Crompton et al. (2020) and Elbeltagi et al. (2023) state that some autistic people prefer to engage in activities alongside others. Although it may appear that they are not actively communicating with each other, the presence of others can bring social enjoyment. Like parallel play, social parallelism is emotional energy that can elicit a sense of connection and belonging. Even if silent, the shared environment provides links to those around them.

In this pandemic environment of extraordinary social friction, feelings of loneliness can be emphasised and lead to anxiety, depression or other health problems. Matos et al. (2021) state that social support is a crucial predictor of how people manage adversity in large disasters that impact communities and populations, and it is linked to both enhanced resilience and posttraumatic development. The focus during the pandemic was to identify, monitor, and contain the spread of the virus and to communicate to the public as much as possible the measures required to keep this disease contained.

This research highlighted that some autistic individuals did not readily understand public health information and that non-autistic persons would ignore public health guidance. Consequently, this behaviour catalysed friction from the autistic person being unhappy with the non-compliance with epidemiological advice "*Having to wear masks, but also having to deal with other people not complying with mask-wearing, gave me anxiety"* (Participant Three). Mask-wearing and compliance to protect others waned after the initial restrictions were removed, which presented a lack of measures to protect at-risk populations in New Zealand. This creates an access barrier to life-saving information. At the same time, there was a New Zealand sign language interpreter for Deaf persons, there was access to alternative communication, such as Easy Read format on the appropriate public health websites (New Zealand Government, 2022).

While these accommodations were made, those with processing disorders which commonly co-occur in autistic persons still found understanding the rules and guidelines difficult *"I was watching out for the changes and was very anxious about what was socially acceptable… the shifts in regulations were an extra thing I had to process*." (Participant Five). Processing disorders that co-occur in autistic persons are a "double jeopardy" that compounds the unique filtering that changes the meanings expressed by non-autistic persons to autistic persons as discussed by Gonçalves & Monteiro (2023). In the case of auditory processing disorders, the actual language used may be heard as something else or not heard at all, without adaptions autistic persons may make guesses, which may not match the communicators' intention.

COVID-19 and the ensuing lockdowns and restrictions led to disrupting changes to community connections, such as closures of organisations, businesses, events, and cancelled programmes, affecting daily and weekly schedules and routines (Oomen et al., 2021). This current research identified how autistic adults are adaptable to different situations and that some can adhere to changes in routine. In contrast, others will navigate the changes in routine at the expense of their mental health. According to Smith et al., (2012) autistic individuals may often insist on sameness, such as specifically placing objects and adhering to rigid routines. This provides regulation of emotion and can alleviate some of the anxiety felt by many autistic persons. Deviations from any routine that the autistic individual has in place can cause a spike in anxiety (White et al., 2009). Routine is a powerful force for autistic individuals and helps to provide a space of comfort and knowability. Adherence to these routines can become crucial for autistic individuals. In some cases, a change, no matter how minor, such as an environmental change, can be a trigger for stressful rumination (for example) that makes these changes a challenge mentally and emotionally.

The autistic individuals in this research noted that a feeling of disconnection had caused stress. People in shops or front-facing organisations were found to be less than patient or

accommodating, sometimes frustrated, and having nowhere to aim but at those they come in contact with. The financial burden of having a business closed for so long, even with New Zealand's COVID-19 business aid packages, was distressing. During the pandemic, health and other service workers faced immense stressors and long hours; some still feel exhausted today (Rink et al., 2023). The rapid adjustments required due to the pandemic moved the healthcare system to focus on safety and efficiency; the strict guidelines and PPE equipment, along with quick virtual meetings, took away the human feeling from healthcare interactions (Sagar et al, 2020). The pressure within the healthcare system created tensions in personnel relationships; many health services suffered from communication issues, and the dynamic of uncertainty and fear within the professional community filtered through into front-line care (Filip et al., 2022). However, some had fantastic resilience and balanced this efficiency with empathy.

This study suggests services are not addressing the unique needs of autistic people from the lens of those persons. The findings highlight the tension between societal disability constructs and those constructs of the individual’s perceptions of agency whereby the client has a sense of clarity of what they need. At the same time, the service behaves as if it cannot sense the clients' needs, seemingly oblivious to anything exceptional being required.

Cultural perceptions are often obtained from contemporary media sources, many of which are fictional works. The theatrical portrayals of autistic persons having obsessive and fixative behaviours are often unkind while being reasonably accurate for some autistic persons. Examples include Rainman (Levinson, 1988) and The Good Doctor (Shore, 2017). All these works have the autistic person winning in unusual ways and seeming to brush off society's disablement as it is nothing of concern nor requires any significant effort for society to accommodate.

The non-autistic person, when relying on these media for a window into autistic life, can be forgiven for seeing autistic persons as having the tools to win the challenges in entertaining ways and not needing support to obtain those wins, an aspect shown in Levinson (1988) that the non-autistic brother exploited his autistic sibling to obtain gambling profits. And that when interacting with an autistic person, they need not concern themselves as the autistic person will find a way to win the day, as shown by Levinsons theatrical portrayal of the autistic person being aloof or by using redirection around their non-autistic brothers' caustic disbelief of autistic behaviours and confrontational attitude to lack of conformity to non-autistic norms. In Levinson's illustration the non-autistic person places the entire burden of operational adaption on to the autistic person. Relying on fantastical theatrical storytelling represents an endangering disablement in the form of a structural failure to provide tools for those in professional contact with autistic persons to understand the culture and ways of autism communication.

It appeared that many participants reported that they became stuck in a state of brooding unwellness, thinking that appears to be founded on the reported erosion in support and health services. This emotional adhesion has structural, environmental, and within-person explanations. The structural elements of poor health capacity and ill-fitting service for autistic persons prior to the pandemic escalated into chronic proportions during the lockdowns and have marginally eased since, with services plagued by staffing and resource challenges and a continued lack of sensitivity for autistic persons' needs (The Royal Australian & New Zealand College of Psychiatrists, 2022). The environmental attack on movements and social connections has abated somewhat since the easing of epidemiological containment measures. However, anxiety remains high and autistic persons continue to observe illogically inadequate tentative self-restrictions of freedom of movement as infection continues to affect society.

Social isolation during lockdowns has been linked to declining mental health, even among non-autistic persons or those with no history of psychiatric issues. Cognitive concerns cited

included loneliness, weariness, tension, and difficulty concentrating (Kring et al., 2015, p. 221). The findings of this study suggest well-being in this community is low, and some autistic individuals may be stuck in a poor health modality, leading to ongoing health and mental health problems. Conversely, during these pandemic lockdowns, many felt they had an intense reflection and adaptability; this allowed individuals to improve their coping strategies, foster inner strength and resilience that they may not have had pre-pandemic.

This research revealed that specialised services that enable autism diagnosis have proven to be extra challenging to access in comparison to "just difficult" in pre-pandemic times (e.g. "*It is difficult to get medical supports, it was not that easy before lockdowns, but definitely has got worse"* (Participant two). For some, obtaining a diagnosis became impossible due to a lack of resources and significant barriers to accessing the already limited resources that do exist. Difficulties in obtaining mental health support for autistic individuals before the pandemic were indicated as quite difficult; during and after the pandemic this was exacerbated. With autistic persons questioning if the service deterioration was autism or pandemic related.

The systemic barriers in healthcare in New Zealand are ongoing from the historical exclusion of those with impairments (Stace & Sullivan, 2020). This discriminatory stance has created environmental obstacles and disabling attitudes. While barriers are slowly being dismantled, more needs to be done to create an inclusive healthcare system. These barriers are also reported in overseas research: finding that communication, attitudinal and knowledge barriers exist (Marjadi et al, 2023). Promoting and implementing accessibility, inclusivity, and awareness will align New Zealand's health system with the principles of the social model and fulfil the basic human rights of autistic people in New Zealand.

This research, which focused on social activity and connection resilience, involved the participants conveying their experiences and how they were impacted by the COVID-19

pandemic and its public safety measures and social changes. The participant's resilience has been tested by the cognitive battle of determining the root causes of adverse experiences, be it the pre-existing environment or pandemic-induced attacks on resilience (Kaye-Kauderer et al, 2021).

The cost of being in internal turmoil can impair other cognitive functioning, reducing the ability to solve this problem of unknown cause. The power of neurological differences in aiding and attacking resilience has historically been well studied: a range of work shows how the unique ways of autistic persons can provide some advantages in introspective analysis when they have developed metacognitive skills and self-awareness (Bem, 1967; Ghanouni et al., 2023). When this development is limited, the rumination can be entrapping and trauma-inducing.

However, it is not the sole responsibility of the autistic person to adjust or learn to cope with changes and pressures to activity ability, and society has a duty of consideration. The accounts of this research and reviewed literature show society's role of caring for the needs of autistic persons appears to be somewhat overlooked. This is a continuation of the historical patterns of "othering" despite positive signals such as political pressure to acknowledge the social model of disability (UPAIS, 1976).

5.4 Changes to Anxiety Levels

Anxiety is prevalent in people with autism when they are negotiating difficult or complex social and sensory situations (Hofmann & Bitran, 2007). Autistic people may experience extra difficulties, such as feeling misunderstood or less accepted by their non-autistic peers. Anxiety displays itself in autism in many different ways than it does in non-autistic individuals. Autistic people who are anxious may become nonverbal, increase stimming, reduce mobility, and refuse to participate in things they love (White et al, 2009). During the pandemic, many autistic

individuals in this research experienced increased anxiety. The disturbance of habits, social isolation, and uncertainty profoundly influenced their mental well-being. Many people struggled with the sudden changes, while others found respite from social stress yet suffered from a lack of social interaction (Oomen et al., 2021).

The mounting stressors in these aspects of individual and community daily life are significant factors for longer-term chronic health. The potential for psychological distress in an autistic adult in isolation and pandemic environments is in the substantial risk category due to thought processes and co-occurring health conditions experienced by autistic persons (Bal et al., 2021). The increased unpredictability due to the shifting infection vulnerabilities of the pandemic, such as the effects of safety measures, the changes to the environment and social protocols, have collectively created tension the mental health sector was unprepared for and slow to respond to. A robust participant reported common theme is the increase in aloneness and lack of support, a finding also shown by the autistic populations featured in overseas studies (Javed et al, 2021; Maljaars et al, 2023; Oomen et al, 2021; Pellcano et al, 2022).

It is now well documented that the pandemic significantly affected the most high-risk groups in society, such as those on low income, older persons and those who already have impairments (Liu et al., 2023). There is something to be said about the power of mutual suffering within a group context in that the empathy expenditure is lower due to everyone being in the same experiential place. During dark times, even with a fear of isolation, it is human nature to invest in mutually beneficial reparation through collaborating emotionally with others we are close to, with whom we can share our experiences, create coping solutions, and establish optimism and confidence in our capabilities and towards the future (Provenzi & Tronick., 2020). Having these experiential allies gives power to the shared story and can provide clearer signposts to the causes of suffering.

The internal emotional mirror is a symbolic device that highlights the denial of service, showing that when inward reflection of emotional states occurs it is possible to see that the reason for being this way was caused by unmet needs (Liamputtong, 2007). The compounding effects of having a need denied and an individual's metacognitive ability allow the realisation of the connections between the accumulated experiences of disablement-caused events and the building of a damning history of resulting sensations experienced (Ghanouni et al., 2023).

This knowing of the roots of pain and trauma gives rise to sensations of fear of these same triggers reoccurring. The autistic person reports both the world and their own thoughts as a connected sequence and can attribute the cause to the environment and their own environmentally affected state (Garcia et al., 2019). This attribution is held in place along with event replays within a cycle of rumination. Such cycles can act like a prison with realistic feelings affecting the deep thinker with self-recrimination, for example, resulting in further worrisome physical sensations such as elevated heart rate and trouble breathing (Kring et al., 2015). Calming oneself from such states can take time, with the residual exhaustion contributing to the baseline state by becoming a seemingly immutable record on which other later sensations are built, becoming a rigid state of feeling a certain way. These new sensations are appended on to the prior memories, with the resulting memory accumulation becoming a burden the individual may feel helpless to alter without external forces (Fenn & Byrne, 2013).

A useful strength of this research was in providing participants with an opportunity to speak aloud about their trauma. This seemed to have awakened a self-awareness of their negatively elevated baseline state of being, a state that was hidden from the mind's eye due to its everyday ordinariness. An example of this is of participants reporting the persistence of feeling unwell. At the same time, reports of health and other service accessibility friction could be implicated as attacking the participant's sense of well-being. It also points to their meta state being unchanging despite the somewhat easing of environmental pressures and the opportunity to

have an improved outlook. However, this is not entirely accurately reflective of present-time ability attacks or current environment opportunities but rather a bias from the conditional recall of prior accumulated sensations (Bem, 1967). This demonstrates that the post-pandemic environment lacked the stimuli magnitude to significantly influence the state towards a more favourable baseline. Such a bias is a valid human condition providing a picture of the accumulated severity of adverse environments, illustrating, in the case of this research, the role of the pandemic as a circumstantial amplifier. This adverse-experience-induced bias justifies the negative perception of subsequent service experiences while implying a lack of positive events to shift an individual's baseline favourably.

However, some reports of positive shifts show promise. Take being resourceful and kind to oneself through regular exercise, for example. Exercise provides a more excellent vitality baseline, and the excursion's positive neurochemistry's allow the individual to break into new metastates (Tse, 2020).

5.5 Summary

The research found that the lived experiences of the group of autistic persons in New Zealand became adversely affected by the COVID-19 pandemic and adverse effects have persisted since. This is comparable to reports from other countries about this sector of populations and their lived experience. It has been found that much of the causation for ill effects lies in the way societies treat autistic persons by not accommodating their needs. This is most apparent in the services directly in contact with autistic communities such as the health, education, justice and retail sectors. This and studies like it, can contribute to societies' knowledge of the damaging lapses in making a place for some members. With this, perhaps a stimulus to act can occur that will result in better outcomes for autistic persons.

Chapter Six: Conclusion

6.1 Introduction

This study is about a group of persons with unique neurology sharing an account of their experiences during and due to the COVID-19 pandemic. This study examined how this uniqueness presents and the friction that society poses to this group that prevents them from achieving an equivalent quality of life to the general population. Their reported experiences during and after the pandemic illustrate the powers and pitfalls of neurologic differences in social domains of service consumption, community, the social environment, and the sense of self.

6.2 Summary of Key Findings

Many of the autistic individuals in this research were confronted with a lack of targeted specific emotional support during the lockdown, with some obtaining no emotional support at a time when it would be most needed. The increased demand in the mental health sector in New Zealand led to many autistic individuals losing some of their therapeutic support and access to mental health care due to the services being over-subscribed. A substantial funding boost that occurred in 2019 has not seen a change in access to specialist chronic mental health services (Sutherland, 2023). Similar to a statement made in research by Kulshrestha and Shahid (2021), this research found that general practitioners cannot refer patients to counsellors or other mental health supports due to the service's unavailability. According to Longhurst (2022), people with impairments encounter more mental health issues and considerable disparities in access to adequate care than their non-impaired peers.

Awareness of autism and co-occurring conditions, even at the clinical level, can be limited, especially when looking into the combination of autism and catatonia, as shown in this

research. Catatonia is a neuropsychological disorder that occurs alongside autism and occurs to varying degrees; identifying this co-occurring condition is essential, as it affects self-care and mobility and, at some levels, can be life-threatening. Identification of this in autism can be difficult due to a minimal field of knowledge on catatonia in autism, but also the symptoms of both can overlap (Vaquerizo-Serrano et al., 2021). New Zealand mental healthcare has faced many challenges over the years and continues to struggle. The COVID-19 pandemic severely impacted both healthcare capacity and accessibility.

Inaccessible website content delivery styles or a lack of video captioning might limit participation with one participant indicating that this presented barriers to their ways of sensing. Addressing these challenges is critical as the online and physical cultures merge. The social model of disability encourages us to acknowledge that disability is created by society, and understanding this helps to create a more accessible and equity-driven digital culture. Advocacy, policy reforms, and technological advances are essential for fostering a more inclusive digital culture. As is the education of the private industry to build better digital experiences for everyone.

Anxiety presented a challenge to an already difficult social burden autistic persons face when interacting within society. The heightened tension of prior events casting a shadow across future events to create a perception of these being uncomfortable or frightening further abates the will of autistic persons to interact. Anxiety around the ever-changing rules and social interactions was apparent for most participants, as well as the anxiety of the unknown.

The advice of autistic persons to their peers in this research contains the wisdom of those able to see both within and outside their world. This reflective power could be a result of unique insight and it could also be that the world holds up a harsh, marginalising mirror, leading them to become accustomed to seeing themselves through the unkind actions of society. This researcher believes it to be a bit of both, with the pandemic playing the role of a circumstantial

amplifier that has both honed that self-reflection, yet made the mirror more brutal and unyielding to the needs of the autistic community. The advice shows a deep self-awareness and empathy for those in similar situations, obtained by taking the time and effort to think about themselves and others.

The role of reflection in making sense of the world is about the level of self-awareness of an individual being held up against their sense of the world. This is a means to see sameness and differences, parallels and tangents of a person's internal base compared to their environment. It is also the ability to perceive the interface where the person stops, and the world begins. This distinctive edge allows them to know that they are apart from the world, an entity with an identity separate from the environment. This inner and outer sight distinguishes personal abilities as being apart from social impediments, with the viewer having a perspective of exterior forces like those described in the social model of disability. This distinction can be mapped as inner or personal inability forces instead of subjected to disabling external social, systemic and environmental forces. This acts as a taking back of power, even if purely symbolic, even if just in cognitive space, to mitigate the attacks of indifference and ignorance. Self-enabling the hope that the factors that erode against their potential can be deferred and that an autistic person can do more than what society believes possible.

However, the autistic community's voices remain muted by the overwhelming power of the dominant non-autistic culture with those tasks of providing services to autistic persons unable or unwilling to translate for unique sensory input and manifestations. Be it capacity deficit or intolerance, the result is that the autistic person has been without a clear and true voice.

6.3 Limitations

While holding up a mirror to the quality and pitfalls of this research, this section also answers the two remaining research questions: What needs to happen to improve health outcomes for

autistic adults in New Zealand? How can marginalisation in the autistic adult population be reduced following adverse events?

The main limitation of this research was the small sample size. A small sample size may prevent the research from representing the entire population being studied. Although there are no definitive rules for sample size in qualitative research, the sample size is not clearly established until data collection has been completed, when it appears that no new data is to be found. This data saturation may in some cases never be achieved according to Braun and Clarke (2021), due to every participant contributing new data (Ayton et al., 2023). Then the researcher, by using a thematic analysis framework, also contributes data via their experiences and review of prior literature, providing these as lens variations into the participant's lived experiences (Braun and Clarke, 2006).

The hope is that this research has given a voice to various perspectives to allow a deeper understanding of the challenges faced by the autistic adult community in times of disaster/disease events and that the research will enable a greater preparedness for such events in the future. Further study with a larger sample size may allow these themes and data to be further explored for robustness.

The approach of phenomenology helps to focus on experience, hearing out the voices of those who lived through the experience of the pandemic, and how it affected their world. The reliance on a potentially traumatically altered memory due to the events of the COVID-19 pandemic may colour participants' comparison with life before the pandemic. This implies a magnitude colouration whereby the recall potentially has an added increase or decrease that, in turn, makes the pandemic effects seem better or worse in memory and subsequent retelling (Norris & Maras, 2022). This limitation relies on accepting the argument in this research that the pandemic did have a significant effect on participants. It also relies on the acceptance that the

neurological schemas of autism in this and prior research have provided considerable evidence of being unprotected from escalation of sensation into trauma, an intensity of trauma that may not exist to the same level of intensity outside of the autistic population (Liamputtong, 2007).

The solution to this tension is to have a larger body of research into the daily lives of autistic persons, which is a window into how everyday events are experienced alongside the more infrequent significant events such as births, deaths, moving house, starting a new job and so on. The most straightforward longitudinal study designs could provide a valuable pool of data that better describes autistic daily life in New Zealand. This longitudinal study proposition can bloom into a recommendation via two pathways: one, including a neurotype identifier in currently running research, or two, designing a new study in conjunction with the autism support community that can highlight individuals and service anecdotes. While most costly, the second proposition has more significant potential to capture an encompassing view into the living culture and mindscape of autistic persons in New Zealand with the ability to gather vital community connection data from three viewpoints of the communication paradigm, with the researcher providing the third viewpoint.

The risk of abuse and potential confounding of a participant's agency was avoided by those taking part in this research, achieved in the interview method being as comfortable as possible and the presence of any report-assisting support persons being closely scrutinised with suspended belief until confirming reputations. Another confounding potential is that the narratives will be discontinuous; part of this is the hierarchy of the researcher questions, and prompts will have a varied level of sensation weighting from one participant to the next. Also, it is natural for humans to self-select memory weighting depending on the sensorium at the time of memory resynthesis and disclosure (Bem, 1969).

The one-sided confounding potential of this research was primarily mitigated by including the extra-personal window of peer-to-peer advice and strengthening in accuracy via the participants' ability to edit transcripts if they so wished. The use of supervision by mentors and the autism reference group provided another validity cushion. There, however, remains a residual tension that questions the real-life accuracy of the structural impression of the members of the autistic community who participated in this study being relied on as the sole source of experiential data. Having a counterpoint with its bias and sense of self, such as sampling the frontline service people, would give contrast and reaffirmation. With its duality of structural connection viewpoint, the second longitudinal proposition would be obtained by sampling both the individual and the autism community-facing service enterprises, a strategy that would eliminate any residual doubt in structural data.

In academic terms, the availability of literature on the pandemic and its effects has developed throughout this study. It will continue to increase due to the current proximity to the pandemic and the need to find solutions to problems that arose or intensified. As such, further research is required to examine subsequent findings so that future communities are better prepared for future large-scale events. The chance of new information changing the meaning and validity of research is the academic risk faced by most who dare to conduct science. It is, therefore, reasonable to encourage being wrong in the face of new knowledge, and any research that can change meanings should be encouraged.

6.4 Recommendations

Work should be done to establish social environments that encourage and support autistic people. These accommodations, acceptance, and understanding will help improve autistic people's quality of life. Such adaptions as using non-fluorescent lighting, quieter spaces, building spaces that have a more natural flow from one area to the next, and using calming or

natural colours in the design and allowing space to retreat were needed. This advocacy for inclusive education, accessible venues, and job opportunities is consistent with the social model of disability and urges us to see autism as a variance that increases our understanding of human diversity to build a more caring and inclusive society, including health environments that are accessible.

There is a noted gap in knowledge across health professions when addressing the needs of autistic individuals; all healthcare professionals must be trained in recognising autistic traits in adults and understanding their needs to start filling this gap in care while also providing guidance and training on the management of co-occurring conditions that affect daily life for autistic adults.

In adverse event occurrences such as the COVID-19 pandemic, the autistic population would benefit from a specialised disaster plan to assist in coping and adjusting to any changes that occur. Establishing an emergency "pop-up" care facility alongside testing or vaccination tents. Which could provide clearer information formats, and care for autistic persons and others with impairments is one example of a possible course of action that specialised disaster relief plan could implement, a more comprehensive plan would be obtained in wider consultation with the autistic community and service providers.

Improving access and availability to mental health care in New Zealand is key. Increasing funding to the education and health sectors with the stipend that the number of qualified psychologists, psychiatrists, and counsellors into the public system is increased to meet the service demand for mild to severe levels of mental illness.

This research recommends that further autistic-led research is needed in New Zealand, in particular, regarding autistic adults and their experiences of life and how they experience major

life-changing events, but also autistic persons as they age and what changes and challenges occur.

6.5 Summary

In this chapter, the research questions were reiterated and tested against the research results and found to have been answered affirmatively that there have been effects as a result of and since the COVID-19 pandemic in Aotearoa New Zealand. These effects have been summarised as hurting the anxiety levels, stress, and overall health experience of participants. However, positive social benefits from isolation occurred due to a reprieve from the cognitively burdensome physical presence. Others orchestrated their growth via social adaption, resulting in better social experiences occurring more often since the pandemic. Further research and consulta tion with the autistic adult community and increased access to mental health support are recommended to establish a healthier life-course for autistic persons.

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Appendices

Appendix A

Ethics Approval Letter

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

16/06/2023

Dear: Natasha Bramwell

Re: Ethics Application - OM3 23/18 - Continuing Pandemic-Induced Effects on the Autistic Adult Community in Aotearoa New Zealand

Thank you for the above application that was considered by the Massey University Human Ethics Committee:

Ohu Matatika 3 at their meeting held on **Thursday, 13 April 2023**

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.

Yours sincerely

Professor Craig Johnson
Chair, Human Ethics Chairs' Committee and Director (Research Ethics) Research Ethics Office, Research and Enterprise Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand T 06 951 6841; 06 95106840 E humanethics@massey.ac.nz; animalethics@massey.ac.nz; gtc@massey.ac.nz

Appendix B

Participant Consent Form

Continuing Pandemic-induced Effects on the Autistic Adult Community in Aotearoa New Zealand.

PARTICIPANT CONSENT FROM - INDIVIDUAL

Please read and tick the following boxes if you are satisfied with the information provided and happy to partake in the study:

□ I have been given a full explanation of this project and have had the opportunity to ask questions.

□ I understand what is required of me if I agree to participate in the research.

□ I understand that participation is voluntary, and I may withdraw at any time without penalty.

Withdrawal of participation will also include withdrawing any information I have provided, should

this remain practically achievable.

□ I understand that any information or opinions I provide will be kept confidential to the researcher

and that any published or reported results will not identify the participants. I understand that a thesis is a public document and will be available through the Massey Library

□ I understand that all data collected for the study will be kept in locked and secure facilities and/or

in password-protected electronic form and will be destroyed after 7 years.

□ I understand the concerns associated with taking part and how they will be managed.

□ I understand that I can contact the researcher [redacted] or supervisors Dr G.A.Good@massey.ac.nz or C.Egwuba@massey.ac.nz for further information.

□ I would like to review the transcript of my interview before publication

□ I would like to receive a summary of the project results.

□ By signing below, I agree to participate in this image or audio-recorded interview for this research project.

Delcaration:

Name: …… Signed:…….. Date: ……..

Email/Postal Address: …….. (for return of transcript and report of findings)

Appendix C

Interview Schedule

Continuing Pandemic-induced Effects on the Autistic Adult Community in Aotearoa New Zealand.

Interview Schedule

This interview schedule has been designed based on a literature review and discussions with supervisors and a reference group.

Before commencing, ensure consent has been given to participate and to record the interview

Researcher Introduction:

1. Hi, my name is Natasha. We have communicated by email/phone/message previously. Before we start, please confirm that you consent to participate in this research about your day-to-day experiences around the COVID-19 pandemic. The information you provide will be anonymised so that the information you give will not be related to you.

2. Before we get into the main questions, Tell me about yourself …

    a. what activities do you enjoy

    b. are you social?

    c. Do you have a formal diagnosis?

    d. Any other diagnoses?

3. What was the Pandemic lockdown like for you and your experiences day to day?

a. Who did you live with?

b. What changed for you?

c. How did you feel?

d. Anything further to add?

4. What was your experience with accessing appropriate support during lockdown?

a. Emotional

b. Practical

c. Social

5. How are your day-to-day experiences now? Are your needs being met?

a. What is better?

b. Would you say anything is worse now?

what is the access to these supports like now?

a. Emotional

b. Practical

c. Social

6. Have your community networks continued to support you appropriately?

7. Do you go out shopping/socialising more or less than before the Pandemic?

8. How do you feel your health is now?

9. Many people have experienced anxiety around the pandemic. Did you or do you experience anxiety due to the pandemic? If so, could you rate your anxiety from 1 for low anxiety to 5 for high anxiety.

a. Have you received help for your anxiety?

b. When did you get help? And what was your experience getting help?

11. What advice would you give others with autism in New Zealand today in coping with the post-pandemic society?

12. Do you have anything else you would like to add?

Now I have a few questions to ask to help with demographic data, if that is ok with you.

10. How old are you?
11. How do you identify (gender)?
12. What is your Ethnicity?
13. Where are you from?
14. Highest Level of Education?

Please feel free to make answers as detailed as possible; if more room is needed to answer questions please do so.

Appendix D

Poster

PARTICIPANTS NEEDED

Call for Autistic adults to participate

in a research study

on day-to-day functioning since COVID-19 lockdowns.

INTERVIEW BASED RESEA

REQUIREMENTS:

Age 18 and over and Clinically diagnosed or self-diagnosed

If you would like more information, click on the QR Code

IF YOU WISH TO PARTICIPATE, CONTACT THE RESEARCHERS

Natasha Bramwell (PRINCIPAL RESEARCHER)

[redacted]

Dr Gretchen Good, Senior Lecturer Disability and Rehabilitation, School of Health Sciences at Massey University

G.A.Good@massey.ac.nz

Dr Charle Egwuba, Public Health and Health Promotion Lecturer at the School of Health Sciences

C.Egwuba@massey.ac.nz