# “At what cost?”: Qualitative accounts of parents of young Autistic people navigating the transition to adulthood in Aotearoa

A research report presented in fulfilment of the requirements for the degree of

Master of Science (Research)

in

Clinical Psychology

The University of Waikato, Hamilton, New Zealand

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2025

## Abstract

Neurodevelopmental disorders are paradoxically over diagnosed and underdiagnosed, with autism being one of the most underdiagnosed disorders under the neurodivergence umbrella. Autism spectrum disorder is a neurodevelopmental disorder impacting functioning in social, cognitive, and physical domains. Research suggests that Autistic people experience poorer health and quality of life outcomes, lower academic attainment, higher unemployment, and particularly struggle during the transition from secondary education to adulthood (Shochet et al., 2022). Although an established knowledge base exists in this area, research seldom observes this transition in Autistic people in Aotearoa. Two focus groups were conducted with five mothers of Autistic children (ages 17 to 30). Participants identified key changes to support successful transitions, including greater involvement of people with lived experience in autism services, improved societal education about autism, enhanced diagnostic accuracy, and increased access to ongoing, targeted support. Thematic analysis identified five themes (At what cost, the shortcomings of systemic education, the bio-psycho-social-systemic view of Autistic youth, the transition to adulthood, and the mental health system). The analysis examined predisposing and precipitating factors contributing to adult transition-related obstacles across social, systemic, economic, and family domains. Results from the current study illuminate how Aotearoa-specific factors are impacting Autistic people today. Examining these factors may support the navigation of diagnosis, contribute to ongoing support, and the wellbeing of Autistic young people transitioning into adulthood.



*Keywords:* Autism spectrum disorder, neurodiversity, underdiagnosis, mental health, education system, Aotearoa New Zealand, qualitative research, thematic analysis

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## Introduction

My name is Alex, and I am a clinical psychology student at The University of Waikato. I was diagnosed with autism when I was 18 by a psychiatrist, however I was not told until I sought an attention deficit hyperactivity disorder (ADHD) diagnosis in my 20's. My first attempt at receiving an autism diagnosis resulted in "insufficient childhood evidence of autism." My mother, a Plunket nurse who screened for autism in her role, was present in my session with the psychologist. When asked for my developmental history, she had noticed some quirks, yet nothing that jumped out at her. I behaved just like she did. Her answers to the questions were insufficient to have me diagnosed, as I wasn't deemed 'different' enough in childhood.

After working with dual disability clients during my post-graduate degree, I suspected I had ADHD, and was diagnosed within the year. My autism diagnosis followed shortly after. Working alongside my psychologist, I was able to learn about autism and ADHD, and how to manage my neurodivergent brain. Once I understood my deficits and had the support to cognitively learn what others find intuitive, I graduated with a postgraduate degree with first-class honours and was accepted into a clinical psychology training programme. I am thriving for the first time in my life, with the understanding of how my brain differs from a neurotypical brain. With support and determination, I have achieved a quality of life (QOL) that I never imagined.

My life experiences have influenced the current research, which seeks to shape the future of diagnosis and research into autism. I learned that the difficulties I faced in receiving diagnosis and support are common, and that the system we inhabit is deeply flawed. The flawed nature of our support system in New Zealand is a significant contributor to the lack of

educational attainment and poor QOL outcomes we see in Autistic[1] people today. These issues can be remedied through systemic and social change, alongside the hard work of Autistic people and their families. My primary focus is on young adult people who would be considered to have "high functioning" autism, to narrow the scope of this research. Those who can blend into society and operate mostly autonomously. I also want to illuminate the struggles they face and support outsiders to take steps towards supporting Autistic people to thrive. I put the Autistic experience at the forefront of this research, advocating for the allocation of additional support, understanding and resources.

[1] 'Autistic' is capitalised in this thesis to reflect identity-first language, signifying that autism is an intrinsic part of a person's identity, rather than as something separate from them.

## Literature review

### Autism spectrum disorder

Autism spectrum disorder (ASD) is quickly becoming one of the most diagnosed disorders in children and adults alongside ADHD (Dirix et al., 2022). It is common to hear "everyone has ADHD/autism these days" with a tone of disbelief and disagreement. This is likely a result of our historic failures as healthcare practitioners to identify cases of autism early and accurately. It is plausible that an autism neurotype has existed since pre-history and has become more prominent as our lives have become less communal and more specialised, leading to high life success in some people, and insufficiently met needs in others (Stace, 2011). Autism is a condition that expresses itself through a wide variety of differences across individuals. Some Autistic people require significant support to complete basic activities, and others excel in academic, musical or practical domains of life (Stace, 2011). As we transition to a more physically disconnected society, Autistic people receive fewer opportunities to develop their social skills and less support for their specific needs.

All Autistic people display some amount of the following impairments across their lifespan: Difficulty understanding and utilising verbal and non-verbal communication, difficulty developing and maintaining relationships, difficulty with cognitive flexibility and restrictive or repetitive behaviours (American Psychiatric Association, 2022). Autistic people can acquire language differently, often observing others and emulating tone, phrase, and accent (Eigsti et al., 2011). However, these emulations do not consider the nuanced context of communication. As communication requires effective use of tone, emotion, tempo, and volume to communicate subtle differences, Autistic people often miss some of these nuances. Imagine a deaf person learning to play piano. They can see the keys and learn the timing yet are unable to hear well enough to adjust their playing for optimal cohesion. Autistic people can misunderstand others, and their style of communication can put others on edge, similar to

people playing a piano in a duet. When the music does not sound right, others become uncomfortable and do not want to play anymore. Through practice and feedback, Autistic people can learn to engage in more dynamic and skilful conversation that draws people towards them.

Another aspect of autism is cognitive inflexibility and restrictive or repetitive behaviours, which can occur for several reasons. Firstly, Autistic people often have difficulty with executive functioning, which includes planning, managing tasks, focus, and memory (Bos et al., 2019). Altering routines or beliefs requires significant utilisation of cognitive resources, leading to avoidance of change. Once a routine or behaviour is established, the person can rely on it to help them regulate their emotions. Autistic people also show less reward circuit activation when looking at social objects, such as faces, compared with non-social objects, such as trains or maps. This can often lead to “special interests” where Autistic people dedicate much of their focus to objects or activities which activate this reward circuit (Bos et al., 2019). Autistic people therefore gravitate away from social situations and more towards activities for prolonged periods of time. Interruptions to focus, or changes to routine, can interrupt these reward pathways and cause Autistic people to feel frustrated or anxious. These experiences can have significant functional implications, as special interests and avoidance (of classwork and social situations) lead to disruptions in educational and occupational settings (Dudley et al., 2019; Stace, 2011; Wilson et al., 2023).

**Disorder vs neurotype**

The current ASD diagnostic criteria were released in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), replacing Asperger's Disorder (American Psychiatric Association, 2013). Asperger's Syndrome differed to commonly understood autism, being characterised by fewer social deficits, greater language acquisition, and the ability to integrate and participate in society, representing higher functioning (Stace,

2011). The creation of ASD merged the two into one continuous spectrum of functionality. The DSM is a collection of clinically observed and scientifically researched disorders that attribute a list of symptoms to a diagnostic label. Each edition of the DSM considers new progress in scientific knowledge to inform accurate diagnosis of the identified disorders. Diagnosis may only occur in the presence of distressing functional impairment, and people with ASD vary considerably in functionality, impairment, and distress.

Contemporary research considers autism to be a variation in neurological construction, and although considered a disorder within psychiatric literature, contemporary research is transitioning towards viewing autism as a normal neurological variation. This has led to autism being considered a natural difference in neurotype, and subsequently identified under the neurodivergence umbrella (Van Der Meer et al., 2023). People often imagine the autism spectrum across a rainbow, where one end is debilitated by autism, and the other end is 'high functioning'. However, this is a misconception. ASD can be thought of as an industrial gas stove top, where each part of a person's functioning is imagined as a single gas element. For example, the element representing a high sensitivity to sound may be turned up higher, whereas their low texture sensitivity may be turned down lower. Each Autistic person will need support to successfully navigate at least one of their needs, and many of these needs can be hard for others to identify.

**Diagnosis and treatment in Aotearoa**

Some cases of autism can be clear from birth and are often identified between the ages of 2 and 4 in males (Landa, 2008). The diagnostic process for autism in Aotearoa requires several working parts to succeed. Firstly, parents and caregivers need to correctly identify Autistic traits in the child. This is often missed, because parents are uninformed about autism characteristics, or are Autistic themselves and think their child's behaviour is 'normal' (Mason et al., 2021). Caregivers who do seek support require the resources to see a

professional, such as transportation, enough money to cover fees, and the ability to communicate effectively with the practitioner. An additional barrier to this is that doctors' offices do not reflect other environments the child may inhabit, such as school or home (Mason et al., 2021).

Often, a paediatrician may be uncertain and leave the family with no diagnosis due to a lack of substantial evidence (Mason et al., 2021). This discourages the family from ever seeking support again. Autistic children who receive support from a young age will often experience greater life satisfaction than their undiagnosed counterparts (Wilson et al., 2023). Those who miss a diagnosis experience lower life satisfaction and have a greater likelihood of comorbid diagnoses such as Borderline Personality Disorder (BPD), Obsessive Compulsive Disorder (OCD), ADHD, Major Depressive Disorder (MDD), Avoidant Restrictive Food Intake Disorder, burnout and anxiety disorders (Mazzone et al., 2012; Shochet et al., 2022).

A key exceptional example of successful early diagnosis and intervention is Temple Grandin, an Autistic woman born in 1947. She was severely Autistic and non-verbal as a young child and is now a successful academic who speaks publicly about autism, alongside her work with livestock within the meat production industry. Temple credits her success in life to an early diagnosis and unrelenting support, attention, and care from her parents. While having a strong edge of Autistic traits, she overcame a life of mutism and seclusion through hard work, early detection, and devoted support. She is a highly regarded academic and lives a fulfilling life that may have otherwise been lost. Her story exemplifies two things. The most severe cases of autism are easiest to identify, as paediatricians are most familiar with this presentation. And secondly, with the right education and support, families can overcome any obstacles autism creates. This is in stark contrast with the stories of those who are 'high functioning'. High functioning Autistic people are often misdiagnosed and seek a diagnosis

into their adulthood. These were the missed generations of Autistic children, who masked their difficulties successfully (Moyse & Porter, 2015).

**Autistic masking**

Amongst the systemic issues of childhood diagnosis, there are societal factors that lead children to protect themselves from the judgment of others. 'Masking', or 'camouflaging' are terms used to explain the changes an Autistic person makes to their outward persona to 'fit in' with their peers. This begins in childhood when others invite them to play. Autistic people process social information cognitively rather than intuitively, which leaves them a few steps behind neurotypical children. School observations reveal Autistic children hanging back, or playing in the vicinity of, although not with other children (Moyse & Porter, 2015). Those who succeed in learning to play with children sit back and observe the social norms of their peers, spending time learning how their peers communicate and reciprocate. If the child can emulate that well enough, they can develop real social skills through ongoing invitations to play (practising social skills). If they continue to develop their skills, they can begin to develop long-term, effective relationships with others (Leedham et al., 2019).

The more the child is isolated, the fewer opportunities they have to practice their social skills, and they develop a mask that is ineffective for peer acceptance. This fallible mask hides many of the socially unacceptable behaviours yet does not make them desirable to be around (Belcher et al., 2023). Wearing this mask is resource intensive as each decision requires cognitive resources to analyse the interaction, then decide how to respond (Woods, 2017). In this way, Autistic masking can be likened to calculating algebraic equations every time they engage with a peer. Once they get home, the child can begin to remove their mask, however they are often afflicted with the stress and exhaustion of the day's hidden social curriculum (Moyse & Porter, 2015). This can lead to outbursts, tantrums, stimming,

avoidance/escape behaviours (such as movies or video games) or in extreme cases, suicidal ideation (Woods, 2017).

Many undiagnosed Autistic people develop MDD, BPD, anxiety disorders, OCD, drug addiction and burnout as a result of masking (Mazzone et al., 2012). Even those successful at masking develop burnout due to the cognitive load required to manage life responsibilities and pro-social skills (Belcher et al., 2023). Burnout in women is becoming more prevalent within academic settings. Women are being required to have children, work full-time and maintain a household in collaboration with their partners just to get by (Leedham et al., 2019). With the division of domestic tasks becoming more equal, and the pressures to survive becoming more pressing, the additional cognitive load associated with undiagnosed autism is leading to severe burnout in women.

Although burnout can affect everyone, autism adds an additional layer of cognitive load that was previously unacknowledged. With masking serving a primarily social function, Autistic women who mask are often impacted more than masking Autistic men (Leedham et al., 2019; Moyse & Porter, 2015). As women are expected to engage in greater pro-social behaviour and experience harsher treatment when they lack the necessary skills, Autistic women tend to have greater social skills than men and are misdiagnosed as a result. (Leedham et al., 2019; Moyse & Porter, 2015). Autistic women often live most of their lives without any autism specific support and suffer the consequences. This is likely contributing to the higher rates of personality disorders, anxiety disorders, OCD and eating disorders in Autistic women, and lower rates of employment (Belcher et al., 2023).

**The transition from school to the workplace.**

Employment rates for people diagnosed with ASD are disproportionately low, including those who have completed post-secondary school education (PSE) (Wehman et al., 2014). Researchers have identified a number of key factors that contribute to these statistics. Firstly,

people with autism experience difficulties in social interaction and communication, both of which are critical to success in the workplace. People who struggle with social communication, personal space, interpretation of facial expressions and reciprocal communication will often become ostracised by peers in the workplace or miss out on job positions due to their atypical style (Wehman et al., 2014). These deficits then begin to impact their feelings of self-efficacy, causing shifts in motivation and developing a more pessimistic outlook. Autistic people have been found to misinterpret more complex facial expressions in others (Adolphs et al., 2001). These deficits have been linked to a lower sense of personal autonomy, leading to greater rates of reliance on parents and decreased likelihood of venturing out to face challenges that support personal growth (Wehman et al., 2014).

**The transition for Autistic people into adulthood**

Identifying key factors contributing to the transition for Autistic people into adulthood in Aotearoa can become treacherous. Although a knowledge base exists, much of the research occurs in larger countries, which vary in social perceptions, prevalence statistics, assessment, and treatment procedures (Zaroff and Uhm, 2012). When examining this transition period, individual experiences can differ due to the opportunities available to them and the societal expectations thrust upon them. I therefore narrow my search towards Western countries, and the experiences and needs of those experiencing high-functioning autism (Asperger's Syndrome). With the deficiency aspect of autism being primarily socially constructed, it is imperative that the literature within this review encompasses similar social beliefs attributable to the Aotearoa context.

One thing is consistent internationally, Autistic people (diagnosed or undiagnosed) face lower rates of employment, education, QOL and social support compared to other disability groups. With this identified, ten predominantly westernised countries have autism- specific action plans enacted in policy to target the needs of Autistic people (Van Der Meer et al.,

2023). Aotearoa, being one of these countries, utilises The Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau (3rd Edition). This guideline, however, is enacted by a variety of fragmented organisations across the country, which differ in quality and philosophy of care (Van Der Meer et al., 2023).

Satisfaction ratings varied considerably when Autistic people were asked to rate their interactions with autism support service providers, with participants often feeling misunderstood and under-supported, with therapists rated positively, and the Accident Compensation Corporation (ACC) being rated negatively (Van Der Meer et al., 2023). This is further complicated by the fact that Autistic people require a variety of supports, which often cannot be completely accommodated by a monolithic autism support service.

As Autistic people have limited opportunities for mental health support, they typically either finance their appointments themselves, sit on a public health waiting list, or seek ACC support. This financial barrier creates significant inequity, and Autistic people who do not receive mental health support are likely to have lower QOL, be unemployed, experience low mood (Shochet et al., 2022), co-morbid mental health conditions and are more likely to experience physical health conditions connected to poorer wellbeing. Those who do not get diagnosed early in life are especially susceptible to poor wellbeing, poor self-worth, and poorer life outcomes (Dudley et al., 2019). With the public health sector overwhelmed and understaffed, Autistic people are facing increasingly limited access to support, harming their ability to participate and thrive within society.

Increased awareness of autism within the 90's led to an influx of childhood diagnoses. Despite early diagnosis being beneficial to QOL, the influx has led to a wave of Autistic adults needing support, which is overwhelming the current system (Dudley et al., 2019; Wilson et al., 2023). This bottleneck effect on the healthcare system has greatly increased waitlists and reduced potential access to adult support services. As our understanding of

autism and neurodivergence increases, further waves of children become bottlenecked in the system once they reach young adulthood (Dudley et al., 2019). Current timeframes to access an autism diagnostic assessment and associated support can be one year or more within the public system, and private sector wait-times continue to grow.

Qualitative research examining support for Autistic people indicates that Autistic people require significantly greater support than they currently receive when they leave school, partly due to the health sector's prioritisation of diagnosis and support in the early years of life (Marsack-Topolewski & Church, 2019; Wallas-Watkin et al., 2023; Wilson et al., 2023). In childhood, detection measures are being implemented within early childhood education (ECE) centres and public schools. Autistic children can receive free supported education through special education programmes within schools, or teacher aides. Autistic people's access to support varies considerably, with social status, household income, ethnicity, geographic location, and parental support all contributing to a child's ability to overcome obstacles encountered in autism (Dudley et al., 2019).

Public education is one of the main protective factors for Autistic children, as it will often support the child, regardless of the intersectional factors of their background. Autistic children can have many of their needs met at school, through one-on-one teacher aide support, connection with peers, school lunches, school counsellors and Ministry of Education-funded assessments. Research observes high support service utilisation of Autistic children before the age of 18 and a sharp decline in support service utilisation after the age of 18, which has been described as "falling off a cliff" (Dudley et al., 2019, p. 557; Nathenson & Zablotsky, 2017). As Autistic people age, their service utilisation decreases, despite receiving high levels of support across multiple services during school (Nathenson & Zablotsky, 2017). Autistic adults report unmet needs for services such as speech and language therapy, one-on-one support, occupational therapy, and social skills training (Turcotte et al.,

2016). High support service utilisation during school, with comparatively low service utilisation into adulthood, suggests prolonged need, yet insufficient resources available to Autistic adults. (Dudley et al., 2019).

Although exact reasons for low post-school usage are not known, a number of factors have been proposed. Firstly, access to specialised professional help is costly, and families often have limited disposable income. As described above, public health wait times can be enormous. Ethnic background has also been found to be a significant contributor toward unmet needs, with Caucasian people being diagnosed the most, and accessing the greatest amount of support in comparison to other ethnic minorities (Baoi et al., 2018; Liptak et al., 2008).

Children who are diagnosed early are likely to achieve the greatest QOL and receive the most support (Hastie & Stephens, 2019). Comparatively, adult diagnoses often carry long wait times and expensive appointments. An adult can be referred by a GP, but the referral can only be fulfilled by psychiatrists and clinical psychologists at an adult mental health service or private clinic (Autism NZ, n.d.). Waitlists for adult mental health services are notoriously long and are often addressed by level of risk. An adult not at risk to themselves or others will find themselves far down the list. Adult mental health services also have high thresholds for diagnosis, and people often find themselves receiving a diagnosis from a private clinic instead. People diagnosed as adults are the most likely to have diminished QOL from the years of being unsupported, and the ineffective coping strategies learned across their lifetime (Hastie & Stephens, 2019).

The purpose of this research is to explore narrative accounts of parents of Autistic people transitioning from childhood into adulthood to better understand the barriers encountered. The research question "*What are the factors contributing to the difficulty young Autistic people face when transitioning to adulthood*" was created to guide discussions.

Interviews were structured to obtain a stream of consciousness information, allowing narrative flows to occur. These flows allowed participants to explore ideas together and share stories, which provided rich, personal accounts of strengths and barriers they encountered along their journeys.

## Method

### Participants

Participants were selected if they were a parent of an Autistic child, who was between the ages of 15 and 30 years old. Alongside having an Autistic child, several were Autistic themselves, or believed that autism ran in their family. These participants were put on a short list, and then given the option of attending one of two focus group times, two months apart. Those who were able to attend these dates were selected to be part of the research. Two participants were unable to attend and were excluded from the research, leaving five total participants. All participants were mothers, yet no gender or age information was collected, as it was not relevant to the research question.

Participants were located across the North and South Islands of Aotearoa, and were primarily located in the Waikato, Auckland, and Canterbury regions. All participants had children who had been diagnosed with autism. Some participants had worked with or continued to work with neurodivergent people within their occupation. The first focus group consisted of three participants, with one parent who was also diagnosed as Autistic. The second group consisted of two people, both parents of young adult Autistic children. The first focus group spanned one hour and forty minutes, whereas the second focus group was split into two forty-minute sessions, with a fifteen-minute break in between.

### Procedure

Participants were recruited through online advertising, word of mouth and organisations that support Autistic adults. Participants who were interested in being a part of the research emailed me to express their interest, and were given an information sheet to read, sign and return. The information sheet (see Appendix) described the aim of the research and indicated that participants would receive a $50 Prezzy card in return for their participation. The information sheet also provided contact details for brief mental health intervention lines in

the event a participant became distressed. Potential participants were given the option to email me if they had any questions, although no questions were received.

Participants were asked to provide a short narrative discussing their experience of having an Autistic child, which provided preliminary information relating to exclusion criteria. Participants were asked to attend one of two online focus groups, spaced one month apart. Participants who were able to attend engaged in up to two-hour-long, semi-structured focus groups with up to two other participants and were asked to discuss their narrative accounts of their experiences as parents with an Autistic child. Participants were given the opportunity to discuss their experience without interruption. When conversation stalled, two prompting questions were prepared: "*What are some of the key barriers your child has encountered?*" and "*What are some of the key strengths of having an Autistic child?*" The aim of the focus group was to allow the participants to dictate the flow of conversation and draw themes from their uninterrupted stream of consciousness. Once a focus group had reached the time limit of two hours, the participants were thanked for their participation, and a $50 Prezzy card was posted to an address they provided.

**Reflexive thematic analysis**

Reflexive thematic analysis (reflexive TA) was used to identify themes that unified narratives shared within the focus groups. Thematic analysis is a qualitative analytic method used to group patterns within data into digestible, researcher generated 'themes', which communicate the essence of participant-generated shared narratives (Lochmiller, 2021). Some branches of thematic analysis are characterised by post-positivist research values which seek to produce objective knowledge through accurate descriptions and summaries of the data (Braun et al., 2023). However, themes are intrinsically interpretive, and attempt to describe experiential narratives that simply cannot be objective.

Reflexive TA values subjectivity, as it relies on researcher interpretation to effectively communicate results from the data. This analysis leans into subjectivity, viewing it as a valuable resource. Reflexive TA believes that subjectivity is inevitable, and that knowledge is always partial, perspectival, and contextually located (Braun et al., 2023). Positionality is stated so the reader can better understand researcher perspective and view the data through the researcher's subjective lens. Positionality requires reflexivity, which is a process the researcher must undertake to be reflective and critical of their own beliefs, values, expectations, and choices.

Despite its subjectivity, reflexive TA produces theoretically coherent and meaningful findings through prioritising meaningful patterns within the data. Themes are viewed as analytical outputs created by the researcher's engagement with the data (Braun & Clarke, 2024). Research quality is reinforced through robust literature usage, which bolsters the interpretive lens while the researcher engages with the data (Braun & Clarke, 2024). Scientific rigour is reconceptualised in reflexive TA, as it relies on procedural checks conducted by the researcher throughout the research (Braun & Clarke, 2024). This is done through reflexivity, transparency of analytical decisions and coherence between theoretical assumptions, analytic processes, and claims (Braun & Clarke, 2024). The key to its analytic strength lies within the intrinsic reflexivity and transparency of method (Braun & Clarke, 2024).

My positionality as an insider within this research made reflexive TA the right choice. My experience as a young person navigating the transition to adulthood strengthens my ability to connect with participants and share their stories in a validating and effective way. Not only was I able to connect with a community which values insider status, but I was also able to reflect on my own motivations and passion for the research. Participants were

approving and encouraging of this endeavour, emphasising the need for more insiders to conduct research focusing on the wellbeing of autistic youth.

**Data analysis**

Data was transcribed verbatim by Otter.ai and was then reviewed by me to correct any errors and anonymise all identifying information. Transcripts were then sent to the participants to confirm they were satisfied with the documented content. One participant asked for some personal information about her child to be removed from the transcript yet was happy for it to be used contextually. This information was removed and replaced with the notation "[This information has been removed at the request of the participant]". Once all participants had agreed that they were happy with the final results, I began to code specific themes throughout the conversations. This process began with reviewing video recordings and audio transcripts simultaneously. This allowed me to become intimately familiar with the content of the focus groups and begin to identify key areas of discussion.

As I reviewed the content, I began taking notes of key areas of discussion that appeared to enter the flow state described by Csikszentmihalyi (Dupuis et al., 2022). When a notable topic emerged (observed by their eagerness to share and their time spent on the topic), the relevant portion of the transcript would be copied and pasted into an Excel spreadsheet, and a label would be given to the excerpt in the column next to it. Once all focus groups had been combed through twice, I organised the spreadsheet by theme label. I then began reducing the excerpts into quotes that encapsulated the relevant theme. This made the spreadsheet less overwhelming to review. Once this was done, I began organising themes by similarity. For example, an excerpt identified as "healthcare" may be grouped with another excerpt labelled "mental health", under the new overarching theme "The healthcare system". This allowed me to condense the list of themes significantly. Theme categories were developed by analysing themes and creating a label that encapsulated each constituent theme. I aimed to have up to

seven overarching themes that constituted the greatest density of identified themes. If a theme did not fit within these seven categories, it was removed. Despite having seven overarching themes, only five were included in the results due to a lack of analytical relevance and to maintain a concise narrative flow.

## Results

Below are the results that emerged from participants' narratives surrounding their experience raising an Autistic child and attempts to encapsulate common barriers encountered by Autistic young people in Aotearoa. Reflexive thematic analysis was used to unify patterns of meaning across each of the focus groups. The five themes that emerged were:

1. *At what cost*, which explores the cost and consequences of tasks given to Autistic people.
2. *The shortcomings of systemic education*, which identifies how schools contribute to some of the disparities Autistic children face.
3. *The bio-psycho-social-systemic view of Autistic youth*, which identifies key factors precipitating the transition to adulthood.
4. *The transition to adulthood*, which discusses the subjective experiences of participants navigating the transition to adulthood and identifying the barriers they encountered.
5. *The mental health system*, which explores participant's experiences attempting to receive mental health support into adulthood.

### At what cost?

All participants acknowledged the costs activities had on their children. School was noted as a significant contributor to life stress with the effects of overstimulation, social pressures and learning needs as key culprits. "At what cost" refers to the consequences (such as tantrums and burnout) faced by Autistic people when they are required to engage in activities that drain them beyond their capacity (Hempseed & Bagshaw, 2022). This was known by participants as "spoon theory" describing the limited amount of energy (number of spoons) a person has each day. Activities either give or cost spoons, and people are

encouraged to identify which activities drain them and which nourish them. Running out of spoons reduces resilience and often precipitates meltdowns, isolation or burnout. One participant described her own experience as an undiagnosed Autistic person to exemplify how difficult 'normal' everyday tasks impacted her ability to function before her diagnosis:

> *"I made a list of like 15 different things that put me in a full meltdown every morning before even getting out the door to go to school. And it was an awful experience just growing up as an undiagnosed Autistic person."*

Her ability to reflect on her own experience influenced the adaptations she provided for her own child. She understood that meltdowns were often a result of being out of spoons, and she learned to triage daily tasks for her child to make sure her child had the capacity to complete the most important tasks of the day. This insight is often not reflected in the school environment, and one participant described her efforts to make other teachers aware of children lacking spoons:

> *"But I think the thing that I will often remind teachers about is, well, they just haven't got any spoons left."*

She explains that teachers will often operate on the assumption that children are just being difficult, and it requires a concerted effort to think about a child's behaviour as a lack of spoons:

> *"The question I always ask is, like, at what cost? Okay, we could get him into assembly, but at what cost, for what purpose? And yeah, and so looking at that and being like, okay, well, it actually wasn't the priority today."*

Through this new, insightful lens, she has been able to support children who had behavioural challenges at other schools and become more attentive and regulated students at

her school. This participant stressed the importance of supporting children to develop strategies that foster insight and autonomy over their own wellbeing:

> *"So, you need to be able to work with kids in a way that, first of all, they have got autonomy and choice around things that help them to understand what they need as a little person, rather than always doing exactly what they're told. But also, sometimes taking the lead when you can see that something is just not going to work for them."*

Participants identified that they were often the ones who had to step in and support the child to cope, making concerted efforts to accommodate the child prior to meltdowns. Most adults involved in the child's life expect the child to complete all tasks allocated to them, seldom considering the toll it may have. This can lead to meltdowns during school or meltdowns at home at the end of the day. Meltdown behaviour demonstrates their inability to regulate themselves, yet is often perceived as an act of defiance, rather than a cry for help. Participants shared their experiences of trying to calm or support a child who was out of spoons. One parent noted:

> *"I was getting beat, kicked, punched for hours every day in the afternoon, when he would come home, and I was in the way of that, because it was either me take the blow or him possibly injuring himself on a hard piece of furniture, and I would prefer to get punched than have my son smash his head on the table. And so, I would usually be in the vicinity to make sure that he could, you know, have me available, and also to make sure that he was safe, physically."*

Parents described feelings of helplessness when observing their child melting down after a hard day at school. As the meltdowns got worse, being available to intervene became

necessary, as they feared their child harming themselves. This produced significant stress on the family system, leading to some families needing to leave work to support their child. This can leave families in precarious situations, where they are unable to handle the additional stressors of their lives. One participant noted the difficulty she encountered when attempting to support her child, reflecting on how much work it took to end up where they are today:

> *"I think there are a lot of families that just don't have the wherewithal to do this. And I don't mean that they are not competent. I mean that they have got so much on their plates."*

Later, this participant reflected on how they were privileged enough to have the resources to manage and felt despair for families who were under-resourced and under-supported by others.

Parents who supported their children to manage their spoons saw decreases in meltdowns and an increase in success towards important tasks. Participants felt that it was unrealistic to expect Autistic children to engage in all the activities expected of them, due to the cognitive load already required to navigate the social world. Participants instead recommended that major tasks be prioritised, and other tasks be put on hold until the child had enough spoons to manage. Participants also advocated for greater education and adaptation within schools, due to the significant impact schools had on their children's mental health.

**The shortcomings of systemic education**

School experiences make up a significant proportion of a child's life, yet they do not always provide the optimal level of care for their students. This is especially true with Autistic children who may require additional support and funding to enhance their ability to learn (Bond & Hebron, 2016). Autistic children are often misunderstood and require adults

with lived experience to adequately support their needs. One participant (a deputy principal), described how she manages autism at her school:

> *"I've sort of got that carer lived experience… I'm a deputy principal. We have a lot of kids that are directed to us from other schools. So, they've been kicked out of other schools because of things that you actually can accommodate."*

This participant shared her experience as a deputy principal who enrols students previously removed from schools due to "bad behaviour". She sees these children as misunderstood and under-supported, accepting enrolment and supporting unmet needs to enhance their ability to learn. She described having great success with these students and stated that no student will be expelled from her school while she is there. Her dedicated focus on supporting Autistic children stems from her own experience with an Autistic daughter. The participant goes on to explain that resources are often the primary issue, requiring costly supports for Autistic children, and insufficient funding for many schools:

> *"It's not easy, and there is no funding for supporting people…it's actually really difficult if you're a classroom teacher with 30 kids, and so it's about upskilling people in the knowledge base."*

She approaches this obstacle through educating staff, as alternative approaches to managing behaviours can alleviate some of the obstacles Autistic children face. However, schools that do not have autism-informed staff have limited opportunities for cost-effective adaptations and rely on funding to employ external supports. She explained that most schools will choose to spend their funding in other areas, which limits the number of Autistic students eligible for support, and the quality of support received:

> *"It's wrong that a school won't look to what they can do to support someone… schools are self-governing, and they can choose whatever they want to put*

*their priority into. So, if they want to put it into sports or technology, they can put their focus on that. And you can end up in a school where teachers don't have any understanding of any of this stuff."*

When children are unsupported, they can become overwhelmed and unable to manage their emotions, leading to outbursts or emotional shut-down behaviour. Uninformed teachers can incorrectly interpret this behaviour and punish these students, or ignore their needs and focus on other students. Students can become overwhelmed for a variety of reasons, and often their needs are superseded by the needs of the school and the Ministry of Education. The participant explained that layers of pressures impact the children, such as the pressures on the Ministry to achieve certain key performance indicators, and pressures on schools to achieve attendance and performance metrics:

*"From a systemic perspective, though, we have a Ministry of Education or a Government that is pushing for children to have full attendance. That's one of their main priorities. So, you have children that may do better with part-time school or adapted plans or whatever, that's not allowed through the Ministry of Education. So, you have a Ministry of Education expecting children to attend school full-time in an environment that is stressful for them and then punishing parents when they keep their kids home. But the Ministry is also not providing the right support for these kids."*

These systemic pressures leave the families of Autistic children beholden to the priorities of the overarching system and in conflict with the needs of the child in question. The resulting conflict leaves parents feeling helpless, the child unsupported, and the school rejecting parental cries for help. Parents were able to make successful adaptations in their homes, yet felt powerless to enhance their child's wellbeing in the school environment:

*"The other support that I couldn't provide simply wasn't there and I reached the extent to like, I can't control what is happening in the school environment. I did all the advocacy I could, and it amounted to absolutely nothing. The school started ignoring correspondence from me. To this day, I have dozens of unanswered emails from a year ago. They've never replied. The Board of Trustees have never replied. They've never taken responsibility for their failures. They've never engaged me in conversation. And so, when it got to a point where it's like, okay, this is a chunk of time, a large chunk of my child's day, that I have no say in, that he has no say in, and everything else we're dealing with, and everything else we have a good system around, but he's still having trouble."*

This participant described the futility in her attempts at bringing order into the child's life, as school difficulty remained a perpetuating factor in their daily struggles. She became resentful towards the school system, feeling disrespected and unsupported, resulting in the child changing schools or being home-schooled. Faced with the option of homeschooling, participants agreed that homeschooling their child would be unmanageable. One participant described their experience of moving schools as a last resort:

*"I had to decide after his crumbling mental health and wellbeing last year at a different school, I ended up keeping him home for three months while we waited on one of these directed enrolment things from the ministry. Which we got, and now he's at a wonderful school that I never expected [it to be] the school that it is for us…he would still have nothing if it weren't for that, and I would most likely be homeschooling him if it weren't for that support. And I'm exhausted at the thought of homeschooling him."*

This participant explained that the school's behaviour led to the crumbling of her son's mental health, and her only choice was to send him to another school in the hopes of a better experience. She felt lucky to find this school and noted the stark difference between his previous school and the one he was moved to.

These narratives exemplify the effect school attitudes and practices have on the mental wellbeing of students and families. Choosing the right school for an Autistic child is challenging and requires staff who are autism-informed and dedicated to increasing the wellbeing of their neurodivergent students. This is often the luck of the draw. However, when a good school is found, these teachers and a positive school culture can set the trajectory of an Autistic child's life. Without the right support, children can be left with insufficient skills to overcome challenges in their future.

**A bio-psycho-social-systemic view of Autistic youth**

Participants reflected on high school educational experiences, noting the intense load required to manage spoons across social, academic, and developmental domains within this transitional period. One participant shared her frustration with societal expectations of Autistic people, noting their increased sensitivity to bad experiences and their long-term impacts due to neurodivergent cognitive patterns:

> *"So, things that other people may think of as a bad experience and be able to move on from…. if you're neurodivergent, [you're] more likely to get stuck in those sorts of things and then feel invalidated. Because people are saying, well, come on, everyone experiences this, or whatever, I think, I think we're a long way off figuring all of this out."*

Dismissive comments like these can be incredibly invalidating and perpetuates the distress Autistic people feel. One participant described how her son experienced mental health issues and was unable to complete high school:

> *"School was not a happy place for him at all. He finished school after Year 12, and between Year 11 and Year 12 was some significant stuff, mental health stuff going on with him. He left school after Year 12, and he didn't get NCEA Level Two, but he got his NCEA Level One."*

Negative high school experiences can shape the way an individual views themselves or their peers. Autistic children are often bullied in high school, and they can begin to see other people as hostile, contributing to the development of social anxiety. This not only impacts their ability to finish school, it is also carried with them throughout their adulthood. In contrast, participants saw improvements in higher education environments that were more collegial:

> *"Being out of the school environment, he just, he just came home from tech and was like, Oh my gosh, people are actually nice, like, people are nice. And I'm like, yeah, not everyone's an asshole, you know."*

This participant described how the small-town culture that they lived in impacted her child in high school, noting that the hyper-masculine rugby boy culture made her son feel devalued, and he was shocked when we went to university, and people treated him nicely. His experience in school primed him to view the world as hostile and made him more sensitive to the judgment of others.

***Mental health***

The likelihood of a person developing a serious mental health condition is associated with the adverse experiences they encounter in their environments during childhood. Despite

parents' best efforts, school is a significant portion of a child's life, and often contributes to the difficulties Autistic individuals and their families face. The significant increase in pressure during high school precipitated a significant health event for one participant's daughter:

> *"My daughter, she became incredibly unwell when she was at high school, and she'd never been stood down, but she was stood down three times in four weeks, and the experience was revolting. It was so poorly handled by the school."*

Her daughter's mental health declined, and the school exacerbated the issues by punishing her for her distress. Their lack of support contributed to the presenting issues and exemplified how uninformed responses to Autistic youth can exacerbate an already difficult situation. This participant's daughter subsequently developed anorexia as a way of controlling an environment that felt out of control:

> *"My daughter developed anorexia… she made 50-odd suicide attempts, and it would have been incredibly easy for them to stick a BPD label on her, because she was so emotionally dysregulated all the time… [the doctors would say] oh, she needs to work on her emotional dysregulation. And I used to say, actually, she was emotionally regulated until she became anorexic."*

This participant described her daughter's experience through school and anorexia to exemplify how compounding distress can culminate in mental illness that severely impacts a person's ability to function. She explained that her daughter's world became so fragile and out of control that she began to bring order back into the world through control over her body. She described her frustration with doctors as they failed to treat her daughter with respect and accurately diagnose and treat her mental distress. A focus on dysregulated

emotions detracted from her experience with anorexia, the invalidating school environment, and the ongoing social rejection for being different. Not only was her daughter let down by her school, she was also let down when doctors failed to remedy the root cause of her distress.

Participants illustrated how Autistic children encounter challenges across biological, psychological, social, and systemic levels. Biologically heightened sensitivity meant that adverse experiences were felt more intensely and endured longer than their neurotypical counterparts. Repeated invalidation, peer culture, exclusionary environments and rigid norms contribute to the development of anxiety and distress. This became amplified by uninformed school responses, which punished distress and failed to implement autism-informed solutions. Viewed collectively, these interconnected bio-psycho-social-systemic factors shaped their experience of adolescence and created pathways towards mental health challenges as they approached adulthood.

**Transition to adulthood**

Participants described the stark difference between accessibility to supports in school and available support while transitioning into adulthood. Parents often become the primary support system for their child, collaborating with their child to help them achieve the steps required to transition to adulthood.

***Internal barriers***

Fulfilling the role of the support person can be complex and require consistent and creative solutions to achieve their child's goal. This participant has been deliberate in breaking down goals into achievable steps for her son:

> *"We've been really deliberate in working with him around well, what are the steps you need to get to? Where do you want to go? For example, he wants to*

*be a reptile keeper in Australia. And we said, well, you need your full license before you go to Aussie… He's like, I want to do it now. And so, we've just been working with him around some of those steps, even things like, you know, you've got to double bus to get from our place to [University] in Hamilton, so learning some of those things."*

She explained that he struggled to acknowledge the steps needed to achieve his goal and required support to manage each step. Autistic people often hyperfocus on an activity of interest, yet neglect the steps required to reach that interest (Dupuis et al., 2022). Intense interest is often motivating for Autistic people, and can lead to great achievements. However, the unmotivating, anxiety-provoking steps required to achieve goals can often cause great distress and avoidance (Rodgers & Ofield, 2018). This participant explained that one of the greatest barriers for her son was his lack of a driver's license, which limited his opportunities to get work experience:

*"I mean, there's sort of things too, like he hasn't got his license yet, but he's getting close. He just, he's had one attempt, and failed, but not terribly, and I think he'll get it next time."*

She continued to explain that his initial failure to obtain his license became very demotivating, leading to increased anxiety when driving. This initial setback could have led to prolonged avoidance due to fear of failing again, yet she knew that ongoing support and consistent encouragement would facilitate his continuing pathway forward. This participant shared a similar story, explaining that one of her son's difficulties was his black-and-white thinking:

*"The driving is a really good example. He was terrified that he was going to hurt someone… One day, he came home absolutely terrified. He had got in a*

*car crash, nothing serious, he didn't even leave a mark on the other car, but the woman was pregnant… you see, he's a black-and-white thinker, he would have thought, if you have an accident, catastrophe, people die, there's blood, as opposed to, sometimes shit can happen… so he didn't get back in the car for weeks."*

His predisposition towards rigid thinking made him overreact to a minor car accident, leaving him fearful of his potential to cause disasters on the road. This led to weeks of avoidance of getting back in the car and exemplifies how Autistic people can often become stuck in seemingly insignificant thinking patterns that become barriers in their progress. These fears and anxieties are real and serve to keep the individual safe, although they often come at the cost of progression.

***External barriers***

Overcoming these barriers requires support people to help them navigate these challenges effectively. However, participants discussed how the general public will often invalidate these challenges, resorting to frustration or punishment towards an Autistic person struggling. One participant described a negative workplace experience, which speaks to the difficulties of transitioning to the employment expectations of adulthood while managing autism:

*"So, yeah, and he had a couple of instances where he went for a job, just like being a trolley boy… and had gone for a trial run, and the guy shouted at him… I just, I really, I don't want him to be in those sorts of situations… and you know, he's 21 now, and he's got nothing on his CV, so he probably doesn't even get considered… And, you know, the job market is tricky! Even for people that have got stuff on their CVs."*

Despite having a supportive parent, this participant's son's first experience of entering the workplace was negative and invalidating, punishing his attempts at exposing himself to the job market. Along with the general public, workplace employers can also lack understanding of autism (Sosnowy et al., 2018). One participant stated her frustration with employers and their lack of support for neurodivergent ways of working:

> *"Um, whether for autism-related reasons or other mental health-related reasons, all of those people are doing their job generally in ways that have zero, not at all been informed by the Autistic experience, yeah? And it's harmful, it's traumatic."*

Lack of understanding in society and empathy towards Autistic people can lead to them becoming unable to fulfil their dreams, which can lead to the degradation of their mental health. One participant felt that the solution could be simple, educating society to offer widespread understanding, which is affirming and offers support to those with difficulties:

> *"It's being in environments that are appropriately affirming, that offer support when it's needed, and that are with people who you can relate to, that's supportive, that's helpful."*

An Autistic person's quirks, anxiety, and negative self-perception can lead to them being unfairly rejected, however with the right understanding, difficulties can be easily managed and should not prevent the Autistic person from doing a job well.

***Support opportunities***

Limited pathways are available to support Autistic people, which leaves many of them unsupported through this transition period. One participant shared her experience with her son being supported into work:

> *"There were a number of years of challenges getting him into work… [there were] a couple of agencies that helped with it, but he fell under the Ministry for getting [support]… and we also had some support from family connections to give him some unpaid work so he could start building up a CV. And he did some volunteer work, much to his disgust, but nevertheless, it all added to the CV… He's independent now…it's more around the advocacy. And I think that if you understand, you know, how does the health system work? How does the support [system work], how does the Ministry work? How does this work? How does that work? And I will go and find the information I need, and I will push and push and push."*

She explains that despite their struggles, her and her husband's hard work to understand available systems, and their tireless advocacy allowed their son access to career pathways. This experience demonstrates that advocacy and support systems can be effective in providing Autistic people with ways to enter the workforce and thrive.

Systemic supports are scarce, and families often need to get creative to achieve similar outcomes. One participant explained that she has taken an alternative approach with her son, so he can develop life skills:

> *"[Our neighbours are] quite elderly and frail, so he's just been helping with that, doing, helping with the shopping for them and gardening for them, and odd jobs for them, and that sort of thing, while we try and find his niche."*

When services are not available, parents have found opportunities to build their child's CV through unofficial work experience. Once the child has built up their CV, they can begin to receive compounding support that increases their desirability as a candidate:

*"So, MSD funded [an internship], and he was given to [a lab] to become a med lab scientist… So, he has expectations about what he should be doing there… so he thinks that, because he did this degree, he should get this work. It's his right. But the world doesn't work like that… and if they don't think you're capable, then they get to say no. He hasn't been able to retain a scientist role in the med lab science space. He has what's called a technician role, which he considers beneath him, and he lobbies hard there… and they're very sweet, they actually gave him a secondment into a scientist role."*

This participant shared her son's experience of being given an opportunity within a supportive workplace. She praised them for giving him opportunities and support, despite his quirks. When employers utilise support and empathy, Autistic people can learn to overcome the functional barriers they face, refine their interpersonal skills, and redefine their identity to be that of potential, rather than the socially constructed, disordered individual.

Advocacy for Autistic people in the workplace must come from within, and each employed Autistic person opens the gate for several others to be given opportunities in the future. The participant continued to describe the experience of her son, who was given opportunities because his employer took time to get to know him and learn about his strengths:

*"They like him, and because, I think they value him, he gets very good feedback on his reviews, I think that they got to know him really well… he's taken on a small level of advocacy for himself, where he is choosing to go to a group which meets within the hospital to make things easier for people with special needs, and it's a very wide range [of disabilities]. And actually, it's been good for him to see people with other needs being addressed so that he doesn't feel special. There are lots of other diversities, and that's hopefully*

*given him some insights into the fact that feeling sorry for himself is not very useful."*

Because of this experience, both he and his employer reap the benefits of his employment, and he has been given opportunities to advocate for others with support needs. This participant's experience demonstrates the power of empathy and advocacy for Autistic people in the workplace. Those who are given support can become assets to an organisation, yet sufficient support remains scarce. Those who were lucky enough to receive adequate support have opportunities to alter the system, although those who remain unsupported often become stuck in a state of limbo, between the trauma of their past and the terror of their future.

Parents identified that their child encountered internal and external barriers during the transition to adulthood, which required parents to fulfil support roles that had previously been helped by support services in school. Although their support was successful, parents described the difficulty they experienced in helping their child navigate their challenges. Taking this role not only created additional financial and stress burdens, it also made parents feel despair when they saw their child defeated after trying to progress.

**The mental health system**

This theme reflects participants' experiences navigating systems that were disjointed, unresponsive, or misaligned with the needs of Autistic young people and their families. Many parents described exhaustion from advocating across silos and the long-term emotional and financial cost of systemic neglect. Those who have been given insufficient opportunities will often become stuck within the cogs of the mental health system, unable to effectively transition into adulthood.

One participant was appalled at the treatment of her daughter within the public health system. She explained that the mental health system lacked an holistic approach, which resulted in segmented and ineffective treatment:

> *"I think my understanding of the mental health system has increased exponentially in the last five years; my daughter developed anorexia… She's had multiple inpatient stays in the psychiatric ward under the Mental Health Act, and she's had three stays under the eating disorders ward, despite the fact that they won't help her with anything therapeutic. She was declined from the eating disorder service because she's Autistic, and they didn't work with people who are Autistic… you die of anorexia, it's got the highest mortality rate, and she's never been in the eating disorder service, despite being considered severe."*

Despite being acutely unwell, this participant's daughter was unable to receive adequate support for her eating disorder, and her autism remains untreated. These experiences left her in an acutely unwell state and amplified the distress she experienced.

When Autistic people become acutely unwell, and the system fails to support them again, they can become helpless and believe that there is no way to overcome the challenges they face, potentially developing into suicidal ideation. The participant continued to describe her daughter's negative experience navigating the health system with autism and co-occurring mental health issues:

> *"She wanted an admission because she didn't feel safe at home, because everything was a potential weapon for her to harm herself now, just remembering she's had a lot of stays under the Mental Health Act, which were totally against her will, which involved the police dragging her away and all*

*of that sort of stuff… I didn't find out until she made a suicide attempt, and she was treated appallingly in the hospital after that, and I had to fight tooth and nail to get her help… Both places that she's been, they actually weren't fit for purpose, and they've been just awful, awful experiences. I found the health system incredibly difficult to navigate for her."*

During a crisis, she expected her daughter to receive supportive, caring and mana-enhancing interventions, yet felt that the experience was traumatic, unsuitable, and far too complex. Their first experience with the health system left them feeling confused and in despair:

*"I don't trust anyone in the health system because of what my daughter experienced. I mean, they made very poor decisions and lied to me when she was an inpatient and all the rest of it, I just, I have no trust. I don't trust anyone… I found that my knowledge of ADHD and autism far exceeded any of the psychologists that were working with her, and I found that so difficult to understand how these people can diagnose things, but not really understand people."*

The mental health system did not provide the aid it purports to, which resulted in this participant losing trust in the entire health system. Participants felt that the mental health system relied on its own expertise too much, neglecting to consider the importance of lived experience and family consultation in treatment planning:

*"It's not about somebody with a certain credential waltzing in and saying, I have the magic wand, I'm going to fix everything…it's been getting the information from relevant sources, as in, people who have some aspect of lived experience."*

Parents found that people with lived experience working with autism were able to provide the greatest level of support, beyond that of professionals. Parents were often involved in the Autistic community through peer support groups, organisations that support Autistic people, or through their career pathway. Their integration into the Autistic community often felt like the antidote for the distress experienced while navigating the public health system. While being cast aside to wait, they were able to implement strategies they learned from others whom they identified as credible:

> *"The best advice I was ever given was from somebody who happened to be in a role that was, you know, other people might have seen them as credible because of their role, but I saw them as credible because of their experience with Autistic people."*

Participants felt that credibility relied on someone who had experienced life with or as an Autistic person. A person's credibility relied on their worldview and their ability to support families in navigating the unique intricacies of autism through lived experience. Parents, therefore, sought out professionals who had lived experience to feel safe and supported throughout their journey.

***Taking back control***

Participants expressed how simple and practical solutions were often more effective than formal clinical interventions. One participant shared their experience of this point:

> *"The most helpful thing that I ever did was introduce a visual schedule in my house. Do you know how much it cost me? Probably $5 in supplies and a few hours of my time… [When creating the visual schedule, I'd ask my son], "Do any of these pictures look good"? Because I know when there's buy-in from somebody that they're more likely to use something. And rather than me just*

*being like, I'm going to make this in your absence while you're at school, it was something we did together."*

Utilising cost-effective and child-focused strategies, this participant was able to make positive changes to her son's routine at home. She explained that it was imperative to create this change in conjunction with her son, as his 'buy-in' was a key factor in encouraging him to become a part of the new strategy:

*"As soon as I started implementing strategies that cost pretty much $0, that was the turning point in realising that support doesn't actually look like what people think it is."*

She continued, reiterating her success with implementing home-based strategies to overcome some of the obstacles her son faced. Parents felt disappointed with systemic aids and learned to implement lived experience strategies at home. This frustrated families, as the systems claiming to provide support for their children often failed them, and in some cases, made their children's lives worse.

When a system fails to help, parents feel despair and helplessness, reaching for peer support to try to overcome the obstacles facing them. Although parents saw great success implementing strategies at home, a well-functioning system that adequately serves Autistic communities would increase treatment efficacy and lower the risk of implementing unscientific or ineffective strategies at home. This means that the system is responsible for learning from its mistakes and integrating strategies that align with Autistic people. Without them, Autistic people are at greater risk of unnecessary service usage and the development of acute health concerns.

The mental health system often fails to provide support that is effective and autism-informed as participants felt that their child's symptoms became worse when engaging with

mental health professionals. Participants also felt that the health professionals responsible for their children were often improperly equipped to effectively support their children. Overall, parents felt that some of the most effective solutions were simple and could be implemented at home.

# Discussion

Research from around the world suggests that successfully transitioning to adulthood as an Autistic person requires support from early in childhood and for this support to continue into adulthood, especially during key transitional periods of life (Dudley et al., 2019). The purpose of this study was to explore the narrative experiences of families with Autistic children navigating the transition to adulthood. Literature on autism has identified several potential reasons for a lower QOL and success in Autistic adults (Dudley et al., 2019) and this research aimed to obtain qualitative accounts of Aotearoa-specific issues to inform changes that can overcome these disparities.

Participants were parents of Autistic children (aged 17 – 30) who engaged in two separate focus groups to build upon each other's narratives and allow the flow of conversation to identify key areas of strength or difficulty. Thematic analysis was used to analyse the data from these focus groups, and five overarching themes were identified: "At what cost?", "The shortcomings of systemic education", "A bio-psycho-social-systemic view of autism", "Transition to adulthood" and "The mental health system".

## Theme 1: At what cost

The theme "At what cost" describes the Autistic experience as a game of resource management. Spoon theory captures the common narrative that Autistic children have limited amounts of energy and attention available each day to complete the tasks required of them. Parents discussed how Autistic people are required to manage a finite number of spoons each day, and seldom become effective at managing without adequate support (McGuinness, 2021). A common narrative between parents was the necessary management of the tasks their child partook in each day. Supporting their child to manage their spoons required constant

cost-benefit analyses, considering the importance of the task and whether undertaking it was worth the risk of exhausting their child of all their spoons.

Parents all understood the cost of running out of spoons, as their children would often meltdown after returning from school. A child of one participant in this study would begin to punch and kick her for hours in an attempt to decompress and re-regulate himself after a day at school. School was found to drain their children significantly, and these parents tried to communicate with schools to reduce the toll it had on their children. Some parents experienced positive support from their child's school, but described this as "lucky", indicating that it was out of the ordinary. In fact, all parents described often feeling let down by schools and their lack of receptivity to change. Parents began to consider the cost of their child running out of spoons, and also the cost it had on their family if they did not move their child to a more supportive school. Managing spoons effectively became a daily part of life as their Autistic children navigated the expectations of a neurotypical world.

The meltdowns observed by parents at the end of the school day can be explained by the "hidden curriculum" (that we are not taught directly and are assumed to know), which involves all of the additional learning Autistic children engage in to navigate the social environment. These energy-depleting factors that are seldom considered include ongoing and complex social interactions, unstructured periods such as playtime, overstimulated sensory stimuli, unspoken social rules and social ostracism (Moyse and Porter, 2015). Autistic children are heavily drained by the cognitive effort required to manage the day, and research suggests that the hidden curriculum impacts their ability to learn, retrieve information, their processing speed, and their ability to achieve academically.

The anxiety, social isolation, fear of failure, and exhaustion culminate when they feel safe at home, where they can remove their social mask and begin to meltdown (Moyse & Porter, 2015). Increased energy consumption is a fact of life for Autistic people.

Consequently, spoon theory provides a strategy for Autistic people to manage their energy expenditure and reduce the likelihood of burning out (McGuinness, 2021). Spoon theory re-frames the structure of the day by replacing hours with the quantity of achievable tasks (Harper, 2025).

Adequate support from parents and teachers is imperative as failure to do so may result in poor academic performance, burnout and mental health disorders (McGuinness, 2021). The consequences of not learning to manage spoons effectively are directly linked to the difficulty faced when transitioning to adulthood. A child who is unable to manage their spoons is at risk of reduced academic performance, leading to poorer PSE outcomes (Van Bergeijk et al., 2008). PSE children who do not learn to manage are also more susceptible to burnout during adulthood, which can be debilitating (Arnold et al., 2023). This is why having family and school support in childhood is essential when trying to uplift the lifetime outcomes for Autistic people.

**Theme 2: The shortcomings of systemic education**

The theme "The shortcomings of systemic education" explores the impact the education system in Aotearoa has on Autistic people. Parents felt that schools prioritised reaching a wide variety of students and focusing on specialised areas of interest, such as technology and sport, at the cost of sufficient resourcing for Autistic children needing support. Parents felt that funding should instead focus on providing professional development for teachers that supported them to understand the needs of Autistic children and how to manage challenging behaviours effectively.

A common narrative between focus groups was the significant difficulties their children experienced when teachers had insufficient insight into autism informed education. One participant described the arduous process of advocating for her child's needs to be met. She explained that her child's mental health began to crumble as a result of his school

environment, and her attempts to advocate for her child were left unresolved. She was forced to change schools and felt lucky to find the school he currently attends. She noted a stark difference in his academic ability and his mental health when attending a school that was attentive to his needs.

Literature suggests that children who receive insufficient pedagogical adaptation suitable for their needs are at significant risk of academic failure (Bond & Hebron, 2016). The literature also suggests that the solution to this problem requires a multifaceted approach. The Autistic child within education is impacted by several ecological forces discussed by Bronfenbrenner's (2005) model for interconnected factors impacting a person across time. These factors are: The chronosystem (the impact of time), the microsystem (the impact of family, classroom, peers, teachers, and resource provision), the mesosystem (The interaction between microsystem factors and how they impact the child), the exo-system (the impact of the school system, local external agencies, and local authorities) and the macro-system (political philosophy, cultural values, social conditions) (Bond & Hebron, 2016).

Effective change requires society to acknowledge the presence of autism in children and make the necessary adjustments for greater social acceptance and acknowledgment of differing needs. Teachers should also be given sufficient professional development to understand and adapt to the needs of their students. The school system itself must allocate sufficient resources to provide adaptive care for Autistic students needing pedagogical adjustment (Bond & Hebron, 2016). The current adaptations made are often reliant on teachers or principals having lived experience supporting an Autistic person close to them. This motivates them to enhance the wellbeing of other Autistic children under their care. Schools that do not have lived experience are often unaware of the value of supporting Autistic children.

On a purely financial level, providing Autistic children with additional support allows them to develop effective skills to overcome challenges across their lifetime, both increasing their wellbeing and economic productivity (Van Bergeijk et al., 2008). Those who are unsupported are more likely to require social assistance into adulthood, and often experience significant QOL impairment, increasing their likelihood of need for mental and physical health care (Wehman et al., 2014). Implementing mandatory and structured support systems within schools enhances the lives of Autistic children, their families, and their communities.

**Theme 3: The bio-psycho-social-systemic view of autism**

The theme "The bio-psycho-social-systemic view of autism" attempts to view an Autistic person's experience through a wider lens, organising a multitude of stressors on Autistic people to understand how their negative life experiences result in lower QOL and successful PSE. Parents shared similar narratives of their children having heightened sensitivities to social rejection, greater academic difficulty, and periods of mental distress across their lives.

Parents noted that these difficulties commonly occur during high school. Despite the link between this difficulty and high school, the school itself only serves as a portion of the cause. Research suggests that this stage of life often bombards Autistic people with stimuli that can overwhelm their capacity (Wehman et al., 2014). Similar to Bronfenbrenner's (2005) ecological forces, it is the culmination of different negative forces acting upon the individual, alongside their interactions with one another. For example, a child begins high school, and they struggle to make friends and feel lonely (Moyse & Porter, 2015). High school is more academically challenging than their previous schooling, and they begin to struggle with their class work. They then feel alone at lunch time, which makes them withdraw further, become bullied for their isolation, and struggle to determine whether people they engage with are friend or a foe. They come home, exhausted from the hidden curriculum and the academic

curriculum. As a result of their new stress, they have difficulty sleeping and struggle with their academic work more. They begin to think they 'suck' at school and 'suck' at being a human.

This is a common theme experienced by Autistic children. Small yet persistent experiences snowball to increase the distress the individual feels, their functioning in social and academic domains becomes impaired, and they feel unable to achieve. This can manifest in several ways, with parents describing their children leaving high school early and struggling to find work or further education. Some parents supported their children through mental health services, finding that the support structures available to their child continued to fail them. The disparities we see in outcomes for Autistic people are significant, and do not have a single solution. These are a result of many micro factors impacting the individual, and the lack of autism-informed and accessible support for families in need (Wehman et al., 2014).

**Theme 4: Managing the transition to adulthood**

The theme "Transition to adulthood" views the narrative accounts of participants to inform some of the key obstacles encountered during this transitional period in Aotearoa. Parents commonly identified mental health difficulties, finishing school early, societal attitudes and lack of ongoing support PSE, as key barriers to the successful transition to adulthood. The literature suggests that one of the primary barriers to a successful transition to adulthood is the feeling of "falling off a cliff" when childhood support systems end (Dudley et al., 2019).

The term "falling off a cliff" refers to the sudden withdrawal of resources and support once the child leaves school. The vast majority of available supports for Autistic people are available and accessible during childhood. When a child is identified as having a need, a professional actively supports them to build the skills necessary to overcome the obstacles

ahead of them. It has been identified that Autistic people struggle to transition into work and community life as a result of being underprepared for the transition (Carter et al., 2013). Parental narratives and the literature make it clear that the transition to adulthood is not a developmental milestone intrinsic to autism, but instead the consequence of systemic ruptures that occur at the end of school. Institutional scaffolding ceases rapidly, and the responsibility of continued support is thrust upon the parents (Dudley et al., 2019). The Autistic young adult's success is then dependent on parental capacity to provide individualised and effective support within this transitional period (Westbrook et al., 2012).

Participants felt significant stress within their role as a primary support person during the transition to adulthood. The primary stressors were financial and temporal and contributed to the degradation of their mental health. Much of their emotional distress occurred as a result of the treatment their child received while navigating the adult world. One participant described her son's experience applying for a job, where he was yelled at during an interview. Parents felt that these experiences were damaging to their child and increased their anxiety and drive to push themselves out of their comfort zone. Parents felt stuck in these situations, noticing a delicate balance between overstepping their boundaries by advocating on behalf of their children and providing background support that supported them to manage these setbacks. Parents felt that negative societal attitudes precipitated these events and asked for significant positive shifts in the future.

These experiences can precipitate or perpetuate mental distress for both the Autistic individual and their family (Marsack-Topolewski & Church, 2019). Existing vulnerabilities, unresolved mental health events, perceived failure, and the recent loss of school routine can trigger a significant mental health event and plunge the individual into further chaos (Van Bergeijk et al., 2008). Mental health distress can cause significant issues in two major ways, first, by impacting the Autistic person's ability to venture into adulthood, and second,

because distress becomes compounded when the individual gets stuck. The young adult impacted by significant mental distress increases their vulnerability to negative emotion and subsequently decreases their capacity to complete further study or thrive in the workplace (Wallace-Watkin et al., 2023). This is why effective and timely mental health support is critical during the transition to adulthood.

### Theme 5: The mental health system

The theme "The mental health system" speaks to participant experiences navigating the mental health system in Aotearoa. One participant shared her daughter's experience of hospitalisation during an episode of acute suicidal ideation and severe anorexia. She felt that this experience was traumatic for both her and her daughter and has concluded that she is unable to trust the health system to provide adequate care for her family. Parents noted that systemic failures often manifested in significant wait times, lack of insight into the Autistic experience, and failure to provide actionable strategies to manage symptomology.

Parents described how they initially longed for mental health intervention, but quickly became frustrated with the quality of care received. Parents began to seek out alternative forms of support, such as peer support and low-cost strategies they could implement at home. Parents concluded that much work must be done in order to increase mental health system efficacy. Peer support and community were noted as essential to overcoming mental health concerns, and participants often involved themselves in the community to both receive and provide support for other families struggling with mental health concerns.

## Implications

Living with autism in Aotearoa can be very complex and relies on the luck of the draw to receive the support necessary to overcome the internal and external obstacles set in front of the Autistic person and their family. The challenges that participants' children face transitioning to adulthood can often be difficult for their parents to observe and their PSE

achievement often falls short of their expected potential (Wehman et al., 2014). While parents may blame themselves and mental health professionals may blame mental health, the observed phenomenon is complex and requires micro, meso and exo systems to be addressed (Bronfenbrenner, 2005).

The findings of this study, in conjunction with the wider autism literature provides a more comprehensive understanding of the challenges experienced by Autistic young people transitioning to adulthood from school. The process begins in childhood, by struggling to have their needs met, and often learning insufficient skills to manage their increased sensitivity (Theme 1) (Shochet et al., 2022). Despite parents' best efforts, their child was often subjected to exhaustion when their spoons were not managed outside of the home.

When at school, the system often fails to provide them with the necessary academic and interpersonal help required to fulfil each of their developmental milestones (Theme 2). They begin to lose confidence in themselves and develop negative cognitions, which influence their self-efficacy and lead to further academic and interpersonal issues (Wehman et al., 2014). Parents have to make difficult decisions to move their children to schools that may meet their needs more effectively (Theme 2).

Parents feel helpless, schools appear careless, and this becomes the snowball that ultimately strikes when the transition to adulthood approaches (Theme 3). These precipitating factors lead to the Autistic person feeling incapable and reduce their resilience to stress (Theme 3). Some may leave school prematurely as a result, and parents scramble to support their child into alternative opportunities (Theme 3).

Despite being one of the primary stressors, schooling provides significant benefits to the individual's life (Westbrook et al., 2012).Some participants described school as a time when their child was at their best, as the routine of school attendance, cognitive stimulation, exposure outside of their comfort zone, and teacher oversight all contributed to their child

developing resilience (Shochet et al., 2022). Once they leave school, the routine that provided psychological safety is gone, reducing their psychological stability, and the supports they may have received are no longer obtainable (Dudley et al., 2019). They are required to decide their life trajectory yet were not taught the skills to break goals down into steps to make them achievable. If a goal is attempted and fails, this increases the likelihood of avoidance in the future (Rodgers & Ofield, 2018).

Participants' children continued to live with their parents into adulthood, often due to unemployment or mental health concerns. This is often the result of obstacles paralysing the individual and contributing to transitional difficulty (Shochet et al., 2022). They can become stuck in avoidance and fall into a hole of mental distress (Theme 5). The resources they once had while attending school are no longer available, nor are the teachers who historically referred them for support.

In addition to this, referral to mental health or support services can be costly and time-consuming (Theme 4). Many mental health wait lists are over a year long, and the individual's distress can worsen significantly in that time. Some participants described the wait being so long that once seen, the snowball had grown so complex that the clinician was forced to address the acute nature of the mental distress, as opposed to the underlying causes (Theme 5). Once the acute distress is managed, parents described their child being discharged, and the cycle begins again.

Autistic people are often unaware of their neurodivergence and believe that their suffering is a result of anxiety and depression (Shochet et al., 2022). It is common for them to live with this belief until they are diagnosed in middle to late adulthood (Belcher et al., 2023). One participant stated, "I wish I had known sooner… it was an awful experience growing up as an undiagnosed Autistic person" (Theme 1).

***Summary of key findings***

What is clear is that Autistic people require significant support to achieve greater outcomes when transitioning to adulthood. Participants felt that this required changes to the education system, the mental health system, society, and the lived experience of those in roles responsible for Autistic wellbeing. This research indicates that there is much room for change if we want to see fewer disparities between Autistic and neurotypical youth, transitioning to adulthood.

**Applications**

The implementation of school-based programmes that teach resilience and goal management may be effective in alleviating many of the internal obstacles faced. Longitudinal studies on resilience programmes in schools have demonstrated greater affect regulation, school connectedness and emotional wellbeing in Autistic children attending these programmes. This programme was based upon CBT strategies which promote stress management, cognitive re-structuring, problem-solving strategies and interpersonal effectiveness (Shochet et al., 2022). Programmes such as these can be implemented in intermediate or secondary schools to teach children skills to manage future obstacles more effectively.

Although Shochet's (2022) study primarily focused on Autistic children, schools in Aotearoa may be more inclined to provide these programmes if they were taught to all students. Taking this approach would not only increase the likelihood of school implementation, it would also allow undiagnosed Autistic people to benefit from these lessons. Providing structured lessons within the curriculum provides equitable opportunities for students to learn skills that may not be modelled to them within schools or their homes. Many of the struggles faced by Autistic people exist due to insufficient skills to navigate the complexities of the social and systemic world (Moyse & Porter, 2015), and implemented, structured, and evidence-based school programmes can bolster students' abilities to navigate

the intrinsic obstacles ahead of them as they approach the transition to adulthood (Wehman et al., 2014).

In addition to school-based interventions, transitional-focused programmes support young adults to manage the obstacles encountered when leaving school and entering the workplace or further education. These programmes, which have been shown to be effective overseas, support Autistic people to break down their goals into achievable steps while providing resources for goal completion. A coach provides support by stepping the individual through the required steps to prepare themselves for the workplace or PSE (Wehman et al., 2014). Similar programmes may be adapted to suit the New Zealand environment with sufficient governmental funding. Additionally, each of these roles should be filled by people who have lived experience of the Autistic experience, as this was identified by participants as a crucial element in service provision.

**Limitations**

This study involved two small focus groups of parents of Autistic children who attended a 1–2-hour focus group to share their families' accounts of living with autism. Participants were recruited based on their motivation to share their stories. As a result, the sample may be more representative of families who have been impacted most significantly by systemic barriers, resulting in greater frustration and a desire to support change. Therefore, the experiences within these narratives may be skewed and not entirely representative of the Autistic experience in Aotearoa. The nature of qualitative research also limits the generalisability of knowledge. Therefore, a mixed-methods study may provide greater clarity into the Autistic experience when transitioning to adulthood. In addition to this is the intrinsic subjectivity of this research, as I have also been impacted by the transition to adulthood as an Autistic person, and my interpretation of events may be skewed towards an experience more similar to my own.

As the current research was conducted online, future research may be more appropriately held in person, where greater levels of connection and manaakitanga can be established. Finally, participants attended on behalf of their children. This decision was based on reducing the risk of harm for participating in this research. Sharing adverse or traumatic experiences in the presence of strangers could be re-traumatising or triggering. Future research with available resources to support the mental wellbeing of children and their families would likely benefit from speaking to the Autistic child alongside a representative from their family. This may provide added depth to their narratives and identify core issues important to the individual.

Research that attempts to expand upon the current research could conduct a study that implements a culturally adapted transitional programme for Autistic people, with the aim of supporting youth in Aotearoa to navigate the challenges of the transition to adulthood successfully. Researchers may be able to identify key areas of need more effectively when working with individuals during this period.

## Conclusion

My pathway toward conducting this research began after my own struggle transitioning to adulthood. Through hard work, luck, and unrelenting support, I learned to overcome many of the barriers ahead of me. Being able to overcome these struggles puts me in a position of power, and I feel obligated to utilise my personal experience and my psychological knowledge to give back to the Autistic community. As I spoke to Autistic adults and their parents, I began to realise that we all shared common struggles in young adulthood and wanted to understand the cause.

During the focus groups, I quickly learned that most Autistic people would encounter bullying, difficulties in school, and challenges in managing their mental health. Their pathway through this, and likelihood of overcoming it, however, was often contingent on luck in environmental circumstances such as family relationships, socioeconomic status, and the social environment. For me, I was lucky enough to have a special interest in psychology and became unwell enough in my adolescence to receive wrap-around support within community mental health. This weekly attention to my wellbeing, alongside my career pathway, oriented my life towards understanding and overcoming mental health challenges.

I was lucky, however, my escape was simply not enough. The current research suggests significant systemic and social change is needed to positively alter Autistic young peoples' trajectories. Enacting these changes will be difficult, yet there are still opportunities available to us. Participants made it clear that their greatest support people were those with lived experience. It was the connection and shared understanding of the Autistic struggle that propelled them forward. Through this research, it is now clear to me that the most pragmatic solution to this wicked problem is the connection between the Autistic community (Braun, 2017).

Readers who seek to aid in the wellbeing of Autistic people can support others through connection and providing actionable solutions that families can manage at home. When one Autistic person overcomes an obstacle, that experience can be shared so that another may also conquer that obstacle. We must create macro-level change from the bottom up. Making change within the education or mental health system requires Autistic people working in these roles to make small, positive changes for people within their care. For societal perceptions to change, Autistic voices must be heard within the social and systemic discourse. When we are open about our differences and encourage greater acceptance, we can slowly shift societal perceptions to improve the wellbeing of future generations of Autistic people transitioning to adulthood.

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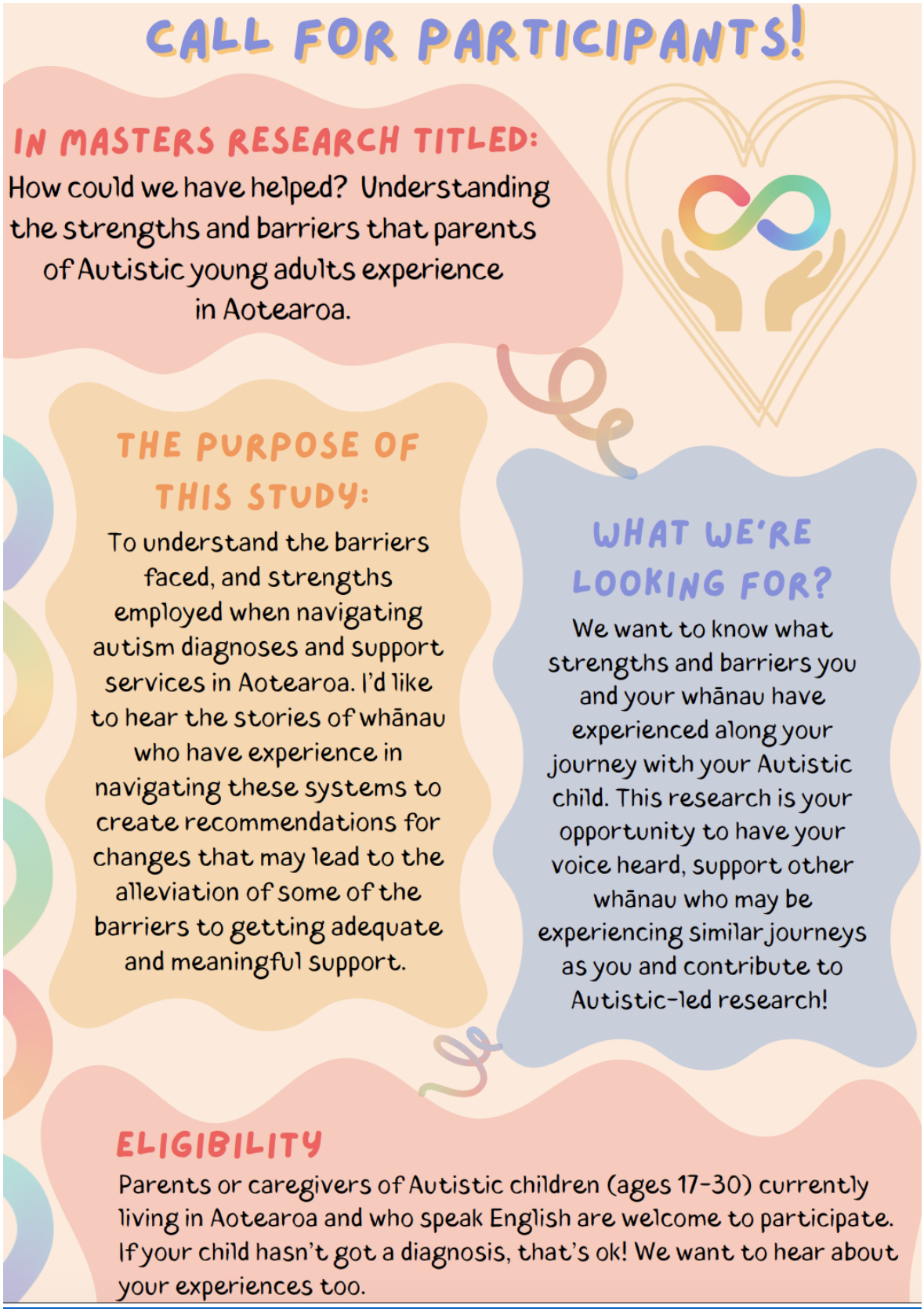
## Appendix

*Information sheet*



## WHO AM I?

My name is Alex and I was diagnosed with ASD when I was 18 and ADHD when I was 22. I only recently found out I am Autistic, despite being diagnosed 7 years ago. I have been studying Psychology for 7 years and am currently studying to be a Clinical Psychologist at Waikato University in Hamilton. I love building computers, playing Catan and collecting things. I have become passionate about supporting other Autistic people to thrive and do what they love. Throughout my neurodivergent journey, I experienced many challenges and was lucky enough to receive support and guidance to overcome them. I hope to use my experience and knowledge of this space to support Autistic people along their journey.

## WHERE DO WE START?

Email me to express your interest (find my contact details on the right) and I'll email you the next steps along with a consent form. In first part of the study, you'll be asked to share your experiences via an online questionnaire requiring you to write no more than 1000 words in total. You'll also be sent a short questionnaire about participating in a 1-2 hour Zoom focus group with two other whānau as another opportunity to have your voice heard. If you're not chosen to participate in the Zoom focus group, you may be placed on a waitlist in case a whānau can't participate on the day. You'll be informed by email if you have been put on the waitlist or not.

## CONTACT INFO...

My email is:
AD124@students.waikato.ac.nz

My Supervisor is Dr Ririwai Fox, University of Waikato. Dr Fox can be contacted at:
Ririwai.fox@waikato.ac.nz

This research has been approved by the Human Research Ethics Committee of The University of Waikato. Any questions about the ethical conduct of this research may be sent to the Secretary of the Committee, email humanethics@waikato.ac.nz

## THE ZOOM FOCUS GROUP...

This will take place online via the meeting platform, Zoom. The focus groups are separated into two groups of three whānau in each. Group one is for whānau with diagnosed Autistic children and group two is for whānau with non-diagnosed/suspected Autistic children. These focus groups will take place between the 18th-22nd November 2024. Whānau will be chosen based on their motivation and availability to participate. The groups will be an opportunity for you to share more in-depth about the barriers and strengths you've experienced when: seeking a diagnosis, accessing support, finding age-appropriate services, etc. You may also find connecting with other whānau in similar situations to be valuable.

You'll be sent a compendium of Autism support services as a koha for submitting a written document of your experience
Whānau who participate in the Zoom focus group will receive a $50 Prezzy card as a koha for sharing your experiences.

## CARING FOR YOUR STORIES...

Your written submission and your contributions in the Zoom focus group will be used within the write-up of this research. The Zoom sessions will be recorded and transcribed to make sure that my memory of your stories is correct. All your stories will be kept safe on the university server for five years, before they are destroyed by my supervisor.
All identifying information will be removed from my data, and you will be asked to choose a fake name for any potential quotes in the research. You may withdraw your consent at any time during the Zoom session and withdraw any of your stories up until 6 months after you've shared your experiences. You can do this by emailing me with a request to remove your experiences from the research. Only your words will be included in the research and photos or videos of you will not be published in any way.

## YOUR RIGHTS!

You don't need to participate if you don't want to, however by agreeing to participate, you have the right to:

·Decline to answer any question.

·Ask to leave the session, or have your camera turned off.

·Withdraw from the study any time up until 6 months after submitting the written document or participating in the Zoom focus group. (video/audio can not be withdrawn!)

·Ask questions about the research, researcher, supervisor, or university at any time during your participation.

·Ask for a copy of the transcript relating to your stories up until 6 months after participating in the Zoom focus group.

·Be given access to a summary of the project findings or be sent the finished study once it has been graded.

·Ask to be removed from the waitlist before the Zoom focus group begins.

## SUPPORT

If you are feeling unsafe or need to speak to someone about your mental health, the following services are free, brief mental health support lines which can be reached at any time:

·Need to talk? Free call or text **1737** any time for support from a trained counsellor.

·Lifeline – **0800 543 354 (0800 LIFELINE)** or free text **4357 (HELP).**

·Youthline – **0800 376 633**, free text **234** or email **talk@youthline.co.nz** or online chat.

·Samaritans – **0800 726 666**

·Suicide Crisis Helpline – **0508 828 865 (0508 TAUTOKO)**

·Healthline – **0800 611 116**