

# Factors Predicting Stress in Parents Caring for Children with Autism Spectrum Disorder

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## Abstract

**Background:** Previous studies have suggested that parents caring for children with ASD experience increased psychological distress in comparison to caring for children with other developmental and physical disabilities. Studies have also indicated that comorbidity symptoms in children with ASD cause higher levels of parenting stress. However, there is a lack of research focusing on factors such as comorbid conditions, problem behaviours and core symptoms of ASD displayed by children and the impact it has on parenting stress.

**Aim:** Overall this study aims to examine the three factors listed: core ASD symptoms, problem behaviour, and comorbidities in an attempt to identify whether these contribute to the care-related stress of parents caring for a child with ASD. The study also analysed demographic variables of child and parent along with mental and physical aspects of the parent's stress.

**Method:** A total of 133 participants were recruited through the support of a New Zealand autism organisation. All participants were above 18 and identified themselves as parents caring for a child with autism spectrum disorder. Data was gathered through an online questionnaire regarding their child with autism and parental experience in raising them.

**Results:** Descriptive and regression analyses were conducted based on the data gathered. Regression analysis aided in identifying factors predicting stress in parents caring for children with autism. Variables such language impairment, comorbid conditions, social behaviours, emotional and social reciprocity showcased by the child along with parental relationship-status and lack of rewards for parent' were all analysed in this present study.

**Conclusion:** The present study identified that parents caring for children with ASD experienced increased stress due to factors such as comorbid conditions, presence of behavioural problems and core ASD symptoms.

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## Attestation of Authorship

*I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.*

*Signed:*

*Date:* 16/09/202

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## **Literature Review**

### **Autism and Historical Viewpoint.**

The term “autism” was first coined by Eugen Bleuler, to characterize a symptom present in individuals with severe cases of Schizophrenia (Bleuler, 1911/1950). According to Bleuler an individual’s infantile thoughts to avoid and replace reality with unrealistic fantasies is called “autistic thinking”. Therefore, autism represented an individual’s “inner life “which was inaccessible to outsiders. Followed by this discovery, Leo Kanner (1943) explained that autism is a profound emotional derangement. Kanner (1943), introduced characteristics of autism such as ‘delayed echolalia’ and the obsessive need for order and sameness’. Furthermore, Kanner (1943) stated that more often children with autistic symptoms are highly intelligent and indicate extraordinary memory.

Challenging Bleuler’s concept of ‘infantile thoughts’ many British child psychologist in the 1950’s formed new methods to validate child development and psychology. It was only from the 1960’s, that child psychologists formulated a new category to describe child development. There after child psychologists used the term autism to describe the lack of an unconscious symbolic life rather than Bleuler’s explanation of autism being excessive hallucinations and fantasies experienced by individuals. However, this approach as still steeped in Freudian theories. In contemporary times the the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) published by the American Psychiatric Association (APA, 2013) introduced specific criteria as a diagnosis of autism spectrum disorder which an individual must obtain in order to be clinically diagnosed with ASD.

Various treatments have been used for individuals with autism including electro-convulsion therapy which may have benefited some individuals diagnosed with autism (Luiselli et al., 2021). An intervention that is currently popular is early intensive behavioural intervention introduced by Lovaas (1987). This consists of behavioural learning programs using positive reinforcement to encourage desirable behaviours. Aversive punishments such shock therapy was also used on individuals with ASD in the 1990’s in an attempt to eliminate certain negative behaviours associated with ASD. However, this method has been disregarded due to ethical concerns.

### **DSM-5 and ASD**

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) there are five specific criteria's ranging from A to E that an individual must present in order to be diagnosed with autism spectrum disorder (American Psychiatric Association, 2013). Criterion A focuses on a history of deficits in social communication and inter-personal interactions over a range of contexts. Within Criterion A there are three sub- criteria, all of which must be met to be diagnosed with ASD, including: lack of social-emotional reciprocity (e.g., failure of response or initiation in social interactions), deficits in nonverbal communication in social interactions (e.g., lack of facial expressions, total lack of eye contact or body language), deficits in understanding, and developing or maintaining relationships (e.g., difficulties in sharing play or making friends). During the diagnosis severity of these criteria must also be specified.

Criterion B focuses on the presence of restricted or repetitive behaviour. There are four sub-criteria and an individual must present at least two of the following four: presence of stereotyped or repetitive motor movements (e.g., lining up toys or echolalia), need for sameness and adherence to routine (e.g., distress when coping with small changes), restricted or fixated interests (e.g., intense preoccupation with unusual items) and lastly, hyper and or hyperreactivity to sensory aspects in their environment (e.g., adverse response to loud noises). Similar to criterion A, the severity of sub-criteria in B must also be taken into account during the diagnosis.

Criterion C requires that all symptoms must be present in the onset of childhood for an individual to be diagnosed with ASD. However, the DSM-5 states that the symptoms may not be evident until an individual's capacity is challenged by social demands or it may be masked by learned strategies overtime (APA,2013).

Criterion D determines whether these symptoms cause clinically significant impairment in social, occupational or any other important functioning areas of an individual.

Lastly, Criterion E ascertains that these symptoms are not a result of intellectual disability disorder or global developmental delay. According to the DSM-5 intellectual disability and autism spectrum disorder may co-occur (APA,2013). Furthermore, in order to identify comorbidity between autism spectrum disorder and intellectual disability the social communication level presented by an individual must be below the level expected for general, normative, development.

The DSM-5 also states that an individual with an established diagnosis of autism disorder, Asperger's syndrome, or pervasive developmental disorder (not otherwise specified) should be given a clear diagnosis of ASD (APA,2013).

## **Epidemiology of ASD**

Dating back to the 1980's, about 1 in 1000 children exhibited ASD symptoms in the USA (Gilberg et al.,2007). However, in the 1990's the number of children diagnosed with ASD spiked rapidly. However, studies were not able to conclude whether this spike was a result of change in diagnostic criteria's or due to a legitimate increase in the prevalence of ASD (Newschaffer et al., 2007).

According to the latest New Zealand Health Survey, around 19,000 children between the ages of 2-14 were diagnosed with autism spectrum disorder ((Ministry of Health [MOH], 2020). Previous epidemiological research indicates a link to gender difference of people diagnose with ASD. According to Loomes et al. (2017) males are more likely to be diagnosed with ASD than females. However, studies have also challenged the notion that males are at a higher risk of developing ASD compared to females, concluding that this may be due to an inaccuracy in the method of diagnosis. Similarly, a study by Newschaffer et al. (2007) suggested an individual's ethnicity could play a part in the process of diagnosis regardless of the individual's gender. Furthermore, the study identified that there is a lack of association between socioeconomic status, gender and ASD diagnosis (Newschaffer et al.,2007).

Various studies have investigated the factors causing autism spectrum disorder. However, many have concluded that specific causation is not evident. A twin study conducted by Freitag et al. (2007) discovered that there is a component of genetic inheritability for ASD. Another study by Gardner et al. (2009) considered prenatal factors which may cause ASD. The study concluded that factors such as parental age and usage of medication during maternity are linked to ASD.

Another study by Moss et al. (2013), discovered that the weight of a mother during pregnancy had a possible link with delivering a baby with ASD symptoms. Moss et al. (2013) further explained that mothers who are obese or underweight during the period of pre-pregnancy have an increased chance of delivering a baby which may be display ASD symptoms in the onset of their childhood.

## ASD and Parental Stress

According to Hecke et al. (2012), parents caring for children with ASD are more likely to experience stress compared to parents of typically developing children. Various studies report that demanding deficits caused by ASD symptoms are linked to enhanced parenting worry as well as physical and mental stress when compared to parents with typically developing children (Abbeduto et al., 2004). Another study by Hayes and Watson (2013) indicated that parents caring for children with ASD experienced more stress than parents that of children with other disabilities such as Down Syndrome.

To better understand factors inducing stress among parents caring for a child with ASD Campbell et al. (2004) conducted a study focusing on social perceptions of children with autism. The study concluded that parents of children diagnosed with ASD face social stigma as people often compare and unfavourably judge both the child with ASD and the parent caring for that child. Another study by Samuel and Marsack (2017) reported that children with ASD are often judged as undesirable compared to typically developing children. Furthermore, different behaviours presented by children with ASD is often compared to typically developing children, which results in these parents feeling isolated or estranged.

Similarly, a study by Padden and James (2017) focusing on self-reported measures of stress, experienced symptoms of depression and anxiety were compared with physiological indicators (e.g., heart rate, ambulatory blood pressure, and cortisol levels) indicated that parents of children with ASD reported higher levels of distress, anxiety and depression in comparison to parents of typically developing children.

A New Zealand based study by Shepherd et al. (2020) focusing on the types and functions of support utilized by parents caring for a child with ASD explained that challenges faced by these parents can be alleviated by sources of support such as social media and informal social supports. Furthermore, support systems such as family and friends were found to be more significant in easing parenting stress more than formal supports such as district health boards, school teachers and therapists (Shepherd et al., 2020).

## **Parental Stress and Quality of Life (QoL)**

Parents caring for a child with ASD often experience higher levels of stress compared to parents caring for a typically developing child, resulting in lower quality of life. This notion was further supported in a study by Nisbet et al. (2016), which reported that factors such as the behavioural challenges presented by a child with ASD and the lack of social support and employment for parents caring for a child with ASD lead to lower quality of life experiences.

A study by Lavee et al. (1996) highlighted the association between increased negative effects and low positive affect in quality of life among parents caring for children with ASD. These experience also have shown to have a negative effect in the solidity of marriages (Deckard et al., 2016). Hecke et al. (2012) explained that caring for a child with ASD often leads to increased financial burden resulting in increased divorce rates and decreased overall well-being among parents caring for a child with ASD.

To better understand financial burdens experienced by parents caring for a child with ASD, Montes and Alterman (2008) calculated the annual household income and expenditure and compared it with families with and without a child diagnosed with ASD. Overall, the study found that families with an ASD child spent 14% more of their household income than parents caring for a typically developing child. Furthermore, Montes and Alterman acknowledged that individuals with ASD are often unable to live independently as adults. The study showcased that of the participants, 85% of the individuals with ASD were still supported by their parents, and 50% of the parents above the age of 55 still care for their child with ASD.

Studies have also discovered links between increased stress, lower QoL and education levels among mothers caring for a child with ASD. According to Zhou et al. (2019) mothers who attained university degrees experienced less stress compared to mothers with only primary school qualification. Furthermore, other factors such as comorbidities, core ASD symptoms and problem behaviours displayed by children with ASD have also shown to have a negative impact on their parents. These are further discussed below.

## Core ASD Symptoms

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) identifies specific ASD symptoms including: deficits in social-emotional reciprocity, communication and language deficits, lack of maintaining and understanding relationships, repetitive behaviours, atypical sensory reactivity and restricted interests (American Psychiatric Association, 2013).

A study by Brei (2014) reported that perceptions of ASD symptoms and its severity experienced by a child with ASD results in increased stress among mothers caring for that child. Furthermore, a direct link between the core ASD symptoms presented by a child and low QoL experience by their mother was discovered. For example, a mother who perceived their child's ASD symptoms as severe experienced an increased level of stress and low QoL.

Similarly, Lee et al. (2009) found that mothers of children with high functioning ASD showcased low QoL, increase anxiety and depression when compared to mothers caring for typically functioning children. A study by Giovagnoli et al. (2015) discovered that symptom severity in pre-school children diagnosed with ASD did not have a negative impact on the wellbeing of their parents. However, a study by Ben-Sasson et al. (2013) indicated a link between parenting stress and symptom severity of adolescents (aged 10-15) diagnosed with ASD. The study explained that mothers caring for adolescent children displaying severe symptoms of ASD experienced increased levels of parenting stress, anxiety and depression. Specifically, problem behaviours displayed by an adolescent with ASD symptoms was linked to increased stress in mothers caring for them.

## **ASD and Problem Behaviours**

According to Dominick et al. (2007) individuals with an ASD diagnosis often exhibit a variant of behavioural and emotional deficits known as “problem behaviours”. Behaviours of such may be expressed through tantrums, non-compliance, physical aggression and more (Zaidman et al., 2014). These behaviours are often difficult to alter and may interfere in the individual’s functioning on a day-to-day basis.

Many studies have identified a correlation between problem behaviours expressed by individuals with ASD and its negative impacts on their parent’s mental well-being. Problem behaviours have also been shown to impact stress levels among mothers more than fathers caring for a child with ASD (Hastings,2003). Furthermore, a study by Weiss et al. (2012), reported that fathers of a child displaying problem behaviours were linked to a decrease in psychological acceptance. Thus, negatively impacting their wellbeing by inducing anxiety and stress (Weiss et al., 2012).

Children diagnosed with ASD exhibit higher degrees of problem behaviours compared to children diagnosed with other developmental disorders (Estes et al., 2009). Another study by Eisenhower et al. (2005) explained that hyperactive behaviour displayed by a child with ASD was a major contributor to stress experienced by their parents. According to Eisenhower et al. (2005), disruptive hyperactive behaviour displayed by children with ASD induced stress in parents as it often led to external judgements or disapproval. Similarly aggressive behaviour displayed by a child with ASD was another factor contributing to increased stress level in parents of that child (Baker et al., 2002).

## **ASD and Comorbid Conditions.**

According to pre-existing studies and health records, ASD may co-occur with various physiological and genetic conditions. The presence of one or more co-occurring medical or psychiatric conditions can be identified as comorbidities or comorbid conditions (Bauman et al., 2010). Conditions that are commonly linked to ASD symptoms are as followed: sleep disorders, intellectual disabilities, gastrointestinal dysfunctions and more (Bauman et al., 2010). Furthermore, studies have also indicated that individuals diagnosed with ASD may also have psychological comorbid conditions such as attention deficit hyperactivity disorder (ADHD), anxiety, psychosis and depression (Jensen & Steinhausen, 2015).

According to a study by Jensen and Steinhausen (2015), ADHD is the most common comorbid condition experienced by children diagnosed with ASD. On average 50 – 70% of children diagnosed with ASD were also diagnosed with ADHD. Furthermore, a diagnosis of intellectual disabilities and ASD is also shown to be present among 12% of youth (Jensen & Steinhausen, 2015). A diagnosis of ASD and anxiety disorder has also been linked with factors such as repetitive behaviour as well as social and communication deficits (Zaboski et al, 2018).

A New Zealand based study by Bowden et al. (2020) reported that 68% of ASD diagnoses correlate with comorbid mental health related conditions such as problem behaviours, emotional distress and intellectual disability. Comorbid conditions among children with ASD also induce stress in parents caring for these children (Bowden et al., 2020). Furthermore, studies have indicated that mothers of children with ASD displaying two or more comorbidities experience low QoL, and are more susceptible to maternal depression (Zablotsky et al., 2013).

However, it is important to note that some studies have indicated difference in levels of parenting stress when comparing only ASD or ADHD alongside comorbid condition with ASD or ADHD diagnosis. An example of this is showcased in a study by Lani et al. (2021) in which no change in parental stress and QoL was indicated for parents caring for a child with only ASD or only ADHD. However, parents of children with ASD experience significant levels of stress along with depression and anxiety when their child displayed comorbidities such as temper tantrum, avoidant, or anxious behaviour.

## **Current Study**

As mentioned above, there are some studies focusing solely on parenting stress in relation to ASD core symptoms or problem behaviours (Lanyi et al., 2021). Similarly, there are a few studies examining parental stress with comorbidities and ASD diagnosis (Dykens et al., 2014). However, there is a lack of research focusing on all three variables as listed: ASD core symptoms, problem behaviours and comorbidities and its impact on parental stress.

This present study focuses solely on these three factors in an attempt to discover whether they have an impact on stress levels in parents caring for a child with ASD. Furthermore, the majority of the research conducted using these variables were based on overseas populations. Therefore, this study aims to contribute to the knowledge and identify the experiences of parental stress in caring for a child with autism from a New Zealand context. Additionally, New Zealand based research and discoveries could be beneficial in identifying gaps in currently available support for carers. Identifying key stress factors contributing to parental stress could encourage the need for better interventions and provide crucial information for practitioners and future researchers in the field of autism. More information on parental stress and factors of ASD could help parents educate themselves on coping skills as well as help them understand their child with autism better.

## **Methods**

The approval for all procedures used in this research project was granted by the Auckland University of Technology's Ethics Committee (AUTEC) (*re*: Appendix A). This study used Qualtrics to gather relevant data, through which participants were able to access an online questionnaire (*re*: Appendix C). A 'Participants information sheet' (*re*: Appendix B) was also readily available online explaining the criteria, purpose and implications of this research.

## **Participants**

In order to participate in this study there were specific eligibility criteria's including: participants must be living in New Zealand, are over the age of 18, and are parenting a child with autism spectrum disorder (ASD). Overall, 133 parents caring for children with ASD participated in this study; 129 of those participant's (97%) identified as female and four identified as male (3%). In regards to ethnicity, 107 participants (80.5%) identified as European, 18 participants (13.5%) as Māori, four participants (3%) Pasifika, with four participants (3%) identifying as Asian. The overall mean age of the participants was 40.9 years old ( $SD=6.76$ ) with the oldest participant being 58 and the youngest being 26 years of age. In relation to education 17 participants indicated that they had completed secondary level education, 54 participants had technical education or qualification, and 62 participants had a university degree. Furthermore, data regarding the relationship status of the participants indicated that 75 of the participants were married, 30 participants identified as being single, and 18 indicated that they were living together in a relationship.

The data also revealed that the mean age of children diagnosed with ASD was 9.2 years of age ( $SD = 3.53$ ). The ages of children varied between three to 19 years of age. Overall, there were 104 children identified as males and 29 as females. Lastly, the data indicated that the provider of diagnosis for ASD in these children varied, 82 of the children were diagnosed by a paediatrician, 28 were diagnosed by a psychologist, and six of them were diagnosed by a general practitioner. Of the overall number of participants seven children of these participant did not have a formal diagnosis. Sample details are provided in Table 1.

## **Ethical Consideration**

This present study upheld and respected the New Zealand Code of Ethics. Prior to participating in the study, all parents were given a Participant Information Sheet (Appendix) to read. Participants were given sufficient information on the study and informed that their participation is voluntary. They were also given reassurance in regards to protection of their privacy and anonymity when participating. If participating they were also given the right to opt out at any time before the completion and submission of their survey response. It is also important to consider that Autism New Zealand was the platform used to gain participants which may be considered as a conflict of interest.

**Table 1***The sociodemographic characteristics of parents (n=133) and their child with ASD.*

<b>Demographic Category</b>	<b>Frequency (N)</b>	<b>Percentage</b>
<b>Gender</b>		
Female	129	97
Male	4	3
<b>Ethnicity</b>		
European	107	80.5
Maori	18	13.5
Pasifika	4	3
Asian	4	3
<b>Education</b>		
Secondary	17	12.8
Technical	54	40.6
University	62	46.6
<b>Relationship status</b>		
Single	30	22.6
Married	85	63.9
Living together	18	13.5
<b>Child gender</b>		
Boy	104	78.2
Girl	29	21.8
<b>Number of other children</b>		
0	2	1.5
1	27	20.3
2	60	45.1
3	28	21.1
4	12	9
5	4	3

## **Instruments**

### **Autism Impact Measure (AIM)**

In this present study the Autism Impact Measure (AIM) was used to assess the severity of ASD symptoms of children from their parents' perspective. AIM was developed by Kanne et al. (2014) to measure treatment outcome in children with ASD. Previous studies using AIM have indicated acceptable validity and reliability whilst examining symptoms severity and its impact (Houghton et al., 2019).

The AIM questionnaire consists of 25 questions divided into four specific subscales that measure the impact of different behaviours experienced on a daily basis by children with ASD over a 2 weeks period prior to completing the questionnaire. It is presented in a Likert scale form ranging from 1 (not at all) to 5 (severely), and response are made by selecting the option best suited.

The first subscale aims to identify common behaviours found in ASD symptoms such as repetitive or orderly behaviour e.g., tendency to line objects. The second subscale covers questions based on atypical behaviours such as use of peculiar language or sounds when responding. The third subscale focuses on obvious language impairments and social reciprocity deficits, for example, use of odd tones and ability to make eye contact responses. Lastly, the fourth subscale identifies deficits in peer-interactions and emotional reciprocity such as temperament, social gestures and attention span.

A study conducted by Mazurek et al. (2014) indicated that the AIM had good overall psychometric validation and internal consistency with a Cronbach's alpha score of 0.95. Furthermore, the AIM has also been utilized in New Zealand based studies (Shepherd et al, 2018;2020) to better understand the impact ASD symptoms have on the everyday functioning of children diagnosed with ASD.

## Strengths and Difficulties Questionnaire (SDQ)

Developed by Goodman (1997), the strengths and difficulties questionnaire consists of 25 items to measure displayed problem behaviours in children with ASD. These are split into five specific subscales such as: SDQEmotional, which identifies emotional symptoms, SDQConduct, covers behavioural problems such as fights with other children, SDQADHD, covers hyperactive behaviour or inattention (e.g., often fidgeting), SDQPeer focuses on relationship problems (e.g., prefers to playing alone) and lastly, SDQProsocial scale which focuses on behaviour such as helpfulness and acknowledging other people's feelings.

As opposed to the AIM questionnaire which required response based on the child's displayed behaviour from two weeks prior, the SDQ requests parents to respond based upon their child's behaviour over the last six months. There were three options of response that parents could choose from including "certainly true", "not true" and "somewhat true". In regards to the validity and reliability of the SDQ, previous studies have indicated that the SDQ has strong internal consistency and moderate discriminant validity (Muris et al.,2003).

## Comorbid Conditions

The study also aims to identify presence of comorbidities, focusing specifically on conditions such as anxiety, intellectual disability, gastro-intestinal complain, ADHD and sleep disruptions. To examine this, parents were asked two yes or no questions. One specific to the presence of comorbid condition's and the other to determine if those conditions were formally diagnosed. In this section a five-point Likert scale was also used to assess whether those comorbid conditions had an impact on the child's functioning and the range of its severity. To determine whether these comorbidities had an impact on the stress levels of parents another five-point likers scale question ranging from "not at all stressed" to "extremely stressed" was included. To further understand parenting stress in parents caring for children with ASD a parenting stress scale (PSS) was used.

## Parenting Stress Scale (PSS)

Overall, the purpose of this study is to examine factors predicting stress in parents caring for children with ASD. To measure levels of stress experienced by parents the PSS was utilised. Developed by Barry and Jones (1995), the scale consisting of 18 items was used to examine positive and negative elements of parenting using a five-point Likert scale format the response options ranged from “strongly agree to strongly disagree”.

This inventory categorises questions in two specific sections: positive and negative parenting experience. As shown in Appendix D4, the positive subscales focus on lacks of rewards experienced by parents, parental closeness with their child, parental satisfaction, feeling source of affection from their child and feeling of enjoyment when spending time with their child. The negative subscales as shown in Appendix 5 focus on aspects of time and energy consumed by their child with ASD, stress levels during those times, financial burden, lack of ability to balance life and responsibilities, experience of embarrassment leading to lack of control in life choices. Items on the PSS were summated in order to produce a total parenting stress score.

In regards to the reliability and validity of the PSS a study by Zelman et al (2018), indicated evidence in good test-retest validity withing the study. Barry and Jones (1995) also provided appropriate evidence for internal consistency whilst using the PSS in their study.

## **Procedure**

Through the support of Autism New Zealand, members were informed about the present study and survey via email. Parents of children with ASD interested were also informed that participation was voluntary. In this email a Qualtrics link was provided which included a participation information sheet (*re*: Appendix B) which included the procedure of this study, assurance on confidentiality, protection of privacy and participants ability to withdraw at any point during the survey. However, once submitted it would not be possible to exclude their response as it is anonymous. Lastly, participants were informed that by clicking submit after the completion of the survey participants would confirm their consent to participate and for the data to be used in this present study. The survey was accessible from the months of August to September 2021. An important event to acknowledge is that the time period of this data collection was during the COVID-19 pandemic lockdown level three and four which could have had an effect in the response as parents participating in this study may have experienced challenges during this period of time.

## Statistical Analysis

The data were extracted through Qualtrics then transferred into Microsoft Excel. In the process of conditioning any participants who did not respond to all items were removed. All conditioned data was then imported to Jamovi (v.2). The mean and standard deviation of all items were calculated. In order to ensure scale reliability Cronbach's alpha was also measured. This helps to identify if an item needed to be discarded as a result of impacting the overall reliability. Regression coefficients were used with 95% confidence interval (CI). Standardised regression Coefficients were interpreted as either poor (<0.50), moderate (0.51-0.75), good (0.76-0.90) or excellent (>0.91) (Koo & Li, 2016).

To indicate significant predictors of stressors in parents caring for children with autism, regression analyses were performed. The analysis included the parental factors such as: gender, sex, education, number of other children, and relationship status. Additionally, child-related variables such as child age, gender, the total number of comorbid conditions, subscales of the SDQ and subscales derived from the AIM were included. Note that comorbidities were encoded as dichotomous dummy variables.

# **Results**

## **Descriptive & Reliability Statistics**

Descriptive analysis of the data collected was analysed using Jamovi (v. 2). The means (*M*) and standard deviations (*SD*) of individual items and their total scores were calculated. In order to check the reliability of scales, Cronbach's alpha ( $\alpha_c$ ) was used to these items. All results can be seen in Appendix D.

### **Autism Impact Measure (AIM)**

The AIM included four subscales. The mean and standard deviation scores for the items across the scales are displayed in Appendix D1. Greater mean on an item indicates greater impact of than item on the daily functioning of the child.

Appendix D2 showcases all four AIM subscales followed by the mean and standard deviation. Greater mean scores indicate a more severe impact on a child's functioning in that dimension. In this case, for example, the results show that restricted or ritualised behaviours have more of an impact, followed by deficits in social and emotional reciprocity communication and language difficulties, and atypical behaviours respectively. Cronbach alpha values for all AIM subscales are above 0.7, indicating good internal consistency within the subscales. Overall indication that it is suitable for this present study.

### **Strengths and Difficulties Questionnaire (SDQ)**

Unlike the AIM, Cronbach's alpha was not needed to be utilized for SDQ as there were only three response options. The overall mean for 132 responses was 50.6, and the standard deviation was 4.46.

### Parenting Stress Scale (PSS)

Appendix 3 displays the mean and standard deviation scores for the 18 items in the PSS. Appendix D4 and Appendix D5 display the mean and standard deviation scores of parenting stressors and lack of rewards. In this case, greater means show that a parent is experiencing increased levels of stress as a result of raising a child with ASD. The overall Cronbach's alpha value is well above 0.7, indicating good internal consistency and suitability of this scale and its items for this present study.

## **Regression Analyses**

Regression analyses was used to identify the impact of predictor variable on parental stress. To indicate the extent to which the regression model fits the observer data a goodness-of-fit measure was obtained. Between the first and second steps of each regression analysis model comparisons were added. A significant change in  $R^2$  verifies that a variable or set of variables had an effect on the dependent variable (Schneider, 2010).

Standardised regression coefficients were used with 95% confidence intervals (CI) and a p-value of 0.05 was used to indicate statistical significance.

**Table 2**

*Model fit for the regression analysis of Stress levels in Parents when comparing predictors.*

Model	R	R <sup>2</sup>	F	df1	df2	p
1	0.763	0.582	8.34	18	108	< .001

Table 3

*Results from the regression model*

Predictor	Estimate	SE	95% Confidence Interval		t	p	Stand. Estimate
			Lower	Upper			
Intercept <sup>a</sup>	27.3643	19.114	65.248	10.520	1.432	0.155	
Sex:							
Male – Female	20.1738	6.445	7.400	32.947	3.130	0.002	1.3822
Age	0.0987	0.161	-0.220	0.417	0.615	0.540	0.0463
Child_Gender:							
Girl – Boy	-0.4718	2.617	-5.658	4.715	0.180	0.857	0.0323
AIM_Restricted.	0.2961	0.211	-0.122	0.714	1.404	0.163	0.1279
AIM_Language	0.8398	0.312	0.222	1.458	2.692	0.008	0.3187
AIM_Odd	-0.3808	0.276	-0.928	0.166	1.380	0.171	0.1018
AIM_Social	0.4144	0.302	-0.184	1.013	1.372	0.173	0.1612
SDQ_Emootional	-0.7803	0.674	-2.116	0.556	1.158	0.250	0.1185
SDQ_Conduct	3.6398	0.656	2.339	4.941	5.546	< .001	0.4493
SDQ_Peer	-1.5623	0.697	-2.943	-0.181	2.242	0.027	0.2128
SDQ_Prosocial_R	0.7372	0.783	-0.815	2.290	0.941	0.349	0.0924
Anxiety:							
Yes – No	13.7290	3.741	6.314	21.144	3.670	< .001	0.9406
SDQ_ADHD	0.7306	0.740	-0.736	2.198	0.987	0.326	0.0884
IDD:							
Yes – No	0645	3.019	17.048	-5.081	3.665	< .001	0.7581
Gastric:							
Yes – No	0.6115	2.077	-3.505	4.728	0.294	0.769	0.0419
Sleep:							
Yes – No	2.4548	2.452	-2.404	7.314	1.001	0.319	0.1682
Diagnostic_Age	1.2391	0.371	0.503	1.975	3.336	0.001	0.3107

<sup>a</sup> Represents reference level

## **Results**

The overall regression analyses resulted in ( $p < .001$ ) and  $F$ -values for Model 1 ( $F = 8.34$ ) indicating that the findings are statistically significant. The  $\Delta R^2$  value of 0.581. Factors such as parent gender, language deficits, conducts, anxious behaviour, comorbid intellectual development disorders and child diagnostic age all indicated high significance in contributing to parental stress. As seen in Table 2 conduct which often relates to behaviour displayed by a child with ASD significantly impacted parental stress ( $p = 0.002$ ), language deficits ( $p = 0.008$ ) also increased parental stress ( $p=0.008$ ). The results also indicated that parents experienced parenting stress when their child displayed anxious behaviour as apposed to when the child showcased prosocial behaviour. Comorbid development disorders also induced parenting stress among parents caring for children with ASD in this present study.

The results also indicated that parents were positive impacted when their child exhibited social behaviour and show caused good emotional capacity. Children with ASD who showcased good prosocial behaviour also positively impacted parenting stress.

Comparing all comorbidity factors displayed anxious behaviour and intellectual disability disorder had the most negative impact on parenting stress. Lastly, factors such as lack of sleep, gastric and child gender did not indicate any statistical significance.

## Discussion

This study examined three specific characteristics present in children diagnosed with ASD in an attempt to better understand what factors contribute to parenting stress in parents of those children. The three specific characteristics examined were comorbid conditions, displayed problem behaviours and core ASD symptoms. The findings implement the need for more resources to minimise the impacts those characteristics have on the parent's stress levels. The results indicated that factors such as intellectual disability, lack of appropriate conduct and difficulties in communicating and anxious behaviour displayed by children with ASD had the most impact on parental stress. These were followed by deficits in emotional and social reciprocity, peer relationships and atypical behaviour, which had lesser impact on parental stress. This finding is similar to that of the study conducted by Shepherd et al. (2018). Shepherd et al. (2018) reported that deficits in communication and social reciprocity had higher impacts, followed by odd or atypical behaviour having lesser impact on the day-to-day functioning of a child with ASD. Thus, this could be the result of increased stress among parents caring for a child with ASD.

### Factors Contributing to Parental Stress

Parents caring for a child with ASD are highly likely to experience psychological distress compared to parents caring for children with typically developing children (Woodman et al., 2015). This present study aimed to investigate factors predicting parenting stress among parents caring for children with autism.

Studies have identified that parents experience increased distress as the child with ASD ages. This is a result of worry around the lack of support for their aging children. As parental age increases so does the parents worry for the future guardianship and who will care for their child as parental age increases (Rezendes and Scarpa 2011). This finding helps support the result in this study which show cases that child diagnostic age impacted parental stress. A possible explanation for this could be that parents face increased stress when trying to access support for older children with ASD (Sawyer et al., 2010).

The demands of caring for a child with ASD may cause difficulties in managing personal and parental responsibilities. Other parental stressors include stress caused by feelings of guilt in mothers who worry about not being able to care for their other typically functioning kids properly due to the additional demands of caring for a child with ASD

(Papadopoulos, 2021).

Results from this study indicated that displays of prosocial behaviours by children with ASD contributed to reduced parenting stress. This is similar to the study by Huang et al. (2014) which discovered that problem behaviours tended to drain parents of their mental energy while prosocial behaviours were displayed by their child with ASD enhanced their mental wellbeing. An explanation for this could be that often parents feel isolated due to problem behaviours displayed by children with ASD. However, prosocial behaviour could provide an opportunity for affiliation with others and gain support (Huang et al., 2014).

Lastly, when looking at comorbid conditions and language deficits displayed by children with ASD, the greater language impairment displayed by their children indicated lower parental stress. Also, increases in comorbid conditions results in decreased parental stress. Similarly, a study by Beurkens et al. (2013) found that the lack of communication between a child with ASD and their parent negatively impacted their mental health. Furthermore, children with comorbid conditions experience greater language difficulties, behaviour problems and sleep disturbances, all of which impact the overall wellbeing of the parent (Martin et al., 2019).

## Limitations and Future Research

There are a number of limitations present in this study. Firstly, the sample used in this study only included New Zealand residents. The majority of the studies referenced above to compare results with this present study were derived from overseas research hence, it may not be a fair representation as cultural differences need to be considered when comparing findings.

It is also important to acknowledge the disproportion in the representation of ethnicity among participants as the majority were European, with only a small number representing Maori, Asian, and Pasifika populations. Thus, the sample used in this study cannot be a representative for all ethnicities and cultures in New Zealand (Bowden et al., 2020). Participants gathered in this study are also members of the Autism New Zealand community, indicating that they have predisposed knowledge and possible support from this service. Thus, the results from this study does not account for children with ASD and or their carer who may not have any access to formal or informal support for ASD.

The very nature of this data requires that parent's self-report their experience in raising their child with ASD. A limitation in this case is that often self-reported measures can attribute to self-selection bias such as social desirability bias, response bias, lack of honesty, and recall bias (Smith et al.,2009).

Future research could focus on expanding the sample size to include a wider population of individuals, including various ethnicity, age range and gender. In this case the majority of the participants in this study were mothers, thus the responses may not match a father's perspective. Future research could emphasize paternal experiences in both fathers and mothers to gain both perspectives.

Lastly, data of the present study was collected during the level 3 lockdown due to COVID-19. Thus, it is important to acknowledge that parents participating in this study may have been experiencing distress while trying to manage the restrictions of the lockdown and caring for a child with ASD. A study by Yilmaz (2021) identified that during the period of COVID-19 lockdowns parents of children caring for a child with ASD experienced increased stress and anxiety. Therefore, it is important to acknowledge that the results may have been influenced by the impacts of COVID-19 restrictions.

## **Conclusion**

Overall, the study identified the existence of specific factors of ASD which impact parental stress in parents caring for children with ASD. Core ASD symptoms, such as lack of communication, problems behaviours such as lack of conduct and comorbid conditions such as anxious behaviour and displayed intellectual disability all played a part in inducing parental stress in parents caring for a child with ASD. Overall, this study has added to the body of knowledge as well as introducing specific factors which affect health related quality of life such as increased stress in parents caring for children with ASD. Drawing upon comparisons from previous studies, this study indicates great reliability and validity supporting similar findings from overseas based research. Limitations of this study have also been mentioned above along with recommendations for future research.

## Reference List

- Algarvio, S., Leal, I., & Maroco, J. (2018). Parental Stress Scale: Validation study with a Portuguese population of parents of children from 3 to 10 years old. *Journal of Child Health Care*, 22(4), 563-576.
- Altieri, M. J., & Von Kluge, S. (2009). Searching for acceptance: Challenges encountered while raising a child with autism. *Journal of Intellectual & Developmental Disability*, 34(2), 142-152. <https://doi.org/10.1080/13668250902845202>
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.).
- Baker, B. L., Blacher, J., Crnic, K. A., & Edelbrock, C. (2002). Behavior problems and parenting stress in families of three-year-old children with and without developmental delays. *American journal on mental retardation*, 107(6), 433-444.
- Baron-Cohen, S. (2020). *The Pattern Seekers: How Autism Drives Human Invention*. Basic Books.
- Batool, S. S., & Khurshid, S. (2015). Factors associated with stress among parents of children with autism. *Journal of the College of Physicians and Surgeons Pakistan*, 25(10), 752-756.
- Bauman, M. L. (2010). Medical comorbidities in autism: challenges to diagnosis and treatment. *Neurotherapeutics*, 7(3), 320-327.
- Belardinelli, C., Raza, M., & Taneli, T. (2016). Comorbid behavioral problems and psychiatric disorders in autism spectrum disorders. *Journal of Childhood & Developmental Disorders*, 2(11), 2472-1786.
- Ben-Sasson, A., Soto, T. W., Martínez-Pedraza, F., & Carter, A. S. (2013). Early sensory over-responsivity in toddlers with autism spectrum disorders as a predictor of family impairment and parenting stress. *Journal of Child Psychology and Psychiatry*, 54(8), 846- 853.
- Beurkens, N. M., Hobson, J. A., & Hobson, R. P. (2013). Autism severity and qualities of parent– child relations. *Journal of autism and developmental disorders*, 43(1), 168-178.
- Bleuler, E. (1950). Dementia praecox or the group of schizophrenias. (Original work published 2006)
- Bowden, N., Thabrew, H., Kokaua, J., Audas, R., Milne, B., Smiler, K., ... & Gibb, S. (2020). Autism spectrum disorder/Takiwātanga: An Integrated Data Infrastructure-based approach to autism spectrum disorder research in New Zealand. *Autism*, 24(8), 2213-2227.

- Brei, N. (2014). Parenting Stress in Parents of Children with Autism Spectrum Symptomatology
- Campbell, J. M., Ferguson, J. E., Herzinger, C. V., Jackson, J. N., & Marino, C. A. (2004). Combined descriptive and explanatory information improves peers' perceptions of autism. *Research in developmental disabilities, 25*(4), 321-339.
- Chan, K. K. S., & Leung, D. C. K. (2020). The impact of child autistic symptoms on parental marital relationship: Parenting and coparenting processes as mediating mechanisms. *Autism Research, 13*(9), 1516-1526.
- Chiarotti, F., & Venerosi, A. (2020). Epidemiology of Autism Spectrum Disorders: A Review of Worldwide Prevalence Estimates Since 2014. *Brain Sciences, 10*(5), 274. <https://doi.org/10.3390/brainsci10050274>
- Di Renzo, M., Guerriero, V., Petrillo, M., & Bianchi di Castelbianco, F. (2021). What is Parental Stress Connected to in Families of Children with Autism Spectrum Disorder? Implications for Parents' Interventions. *Journal of Family Issues, 0192513X211030735*.
- Dominick, K. C., Davis, N. O., Lainhart, J., Tager-Flusberg, H., & Folstein, S. (2007). Atypical behaviors in children with autism and children with a history of language impairment. *Research in developmental disabilities, 28*(2), 145-162.
- Eisenhower, A. S., Baker, B. L., & Blacher, J. (2005). Preschool children with intellectual disability: syndrome specificity, behaviour problems, and maternal well-being. *Journal of intellectual disability research, 49*(9), 657-671.
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X. H., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism, 13*(4), 375-387.
- Freitag, C. M. (2007). The genetics of autistic disorders and its clinical relevance: a review of the literature. *Molecular psychiatry, 12*(1), 2-22.
- Gentles, S. J., Nicholas, D. B., Jack, S. M., McKibbin, K. A., & Szatmari, P. (2019). Parent engagement in autism-related care: a qualitative grounded theory study. *Health Psychology and Behavioral Medicine, 7*(1), 1-18.
- Gillberg, C., & Wing, L. (1999). Autism: not an extremely rare disorder. *Acta Psychiatrica Scandinavica, 99*(6), 399-406.
- Giovagnoli, G., Postorino, V., Fatta, L. M., Sanges, V., De Peppo, L., Vassena, L., ... & Mazzone, L. (2015). Behavioral and emotional profile and parental stress in preschool children with autism

- spectrum disorder. *Research in developmental disabilities*, 45, 411-421.
- Goodman, R. (1997). The Strengths and Difficulties Questionnaire: a research note. *Journal of child psychology and psychiatry*, 38(5), 581-586.
- Goodman, R. (2001). Psychometric properties of the strengths and difficulties questionnaire. *Journal of the American Academy of Child & Adolescent Psychiatry*, 40(11), 1337-1345.
- Guerriero, V., De Campora, G., Gnazzo, A., Vegni, E., & Zavattini, G. C. (2017). Parents facing their child's disease: Insights from attachment theory. *Advances in Psychology Research*, 126, 137-158.
- Harding, L., Murray, K., Shakespeare-Finch, J., & Frey, R. (2020). Understanding the Parental Stress Scale With a Foster Carer Cohort. *Family Relations*, 69(4), 865-879.
- Hartley, S. L., Barker, E. T., Baker, J. K., Seltzer, M. M., & Greenberg, J. S. (2012). Marital satisfaction and life circumstances of grown children with autism across 7 years. *Journal of Family Psychology*, 26(5), 688.
- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of autism and developmental disorders*, 43(3), 629-642.
- Houghton, R., Monz, B., Law, K., Loss, G., Le Scouiller, S., de Vries, F., & Willgoss, T. (2019). Psychometric validation of the autism impact measure (AIM). *Journal of autism and developmental disorders*, 49(6), 2559-2570.
- Huang, C. Y., Yen, H. C., Tseng, M. H., Tung, L. C., Chen, Y. D., & Chen, K. L. (2014). Impacts of autistic behaviors, emotional and behavioral problems on parenting stress in caregivers of children with autism. *Journal of Autism and Developmental Disorders*, 44(6), 1383-1390.
- Jensen, C. M., & Steinhausen, H. C. (2015). Comorbid mental disorders in children and adolescents with attention-deficit/hyperactivity disorder in a large nationwide study. *ADHD Attention Deficit and Hyperactivity Disorders*, 7(1), 27-38.
- Johnson, N., Frenn, M., Feetham, S., & Simpson, P. (2011). Autism spectrum disorder: parenting stress, family functioning and health-related quality of life. *Families, systems, & health*, 29(3), 232.
- Joshi, G., Faraone, S. V., Wozniak, J., Tarko, L., Fried, R., Galdo, M., ... & Biederman, J. (2017). Symptom profile of ADHD in youth with high-functioning autism spectrum disorder: a comparative study in psychiatrically referred populations. *Journal of Attention Disorders*, 21(10), 846-855.

- Kanne, S. M., Mazurek, M. O., Sikora, D., Bellando, J., Branum-Martin, L., Handen, B., ... & Warren, Z. (2014). The Autism Impact Measure (AIM): initial development of a new tool for treatment outcome measurement. *Journal of autism and developmental disorders*, 44(1), 168-179.
- Lanyi, J., Mannion, A., Chen, J. L., & Leader, G. (2021). Relationship between Comorbid Psychopathology in Children and Adolescents with Autism Spectrum Disorder and Parental Well-being. *Developmental Neurorehabilitation*, 1-11.
- Lavee, Y., Sharlin, S., & Katz, R. (1996). The effect of parenting stress on marital quality: An integrated mother-father model. *Journal of family issues*, 17(1), 114-135.
- Lee, G. K., Lopata, C., Volker, M. A., Thomeer, M. L., Nida, R. E., Toomey, J. A., ... & Smerbeck, A. M. (2009). Health-related quality of life of parents of children with high-functioning autism spectrum disorders. *Focus on autism and other developmental disabilities*, 24(4), 227-239.
- Lindor, E., Sivaratnam, C., May, T., Stefanac, N., Howells, K., & Rinehart, N. (2019). Problem behavior in autism spectrum disorder: considering core symptom severity and accompanying sleep disturbance. *Frontiers in psychiatry*, 10, 487.
- Lins, L., & Carvalho, F. M. (2016). SF-36 total score as a single measure of health-related quality of life: Scoping review. *SAGE open medicine*, 4, 2050312116671725.
- Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, 56(6), 466-474.
- Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of consulting and clinical psychology*, 55(1), 3.
- Luiselli, J. K., Bird, F., & Wachtel, L. E. (2021). Electroconvulsive Therapy (ECT) for Autism Spectrum Disorder Associated with Catatonia and Self.
- Marsack, C. N., & Samuel, P. S. (2017). Mediating effects of social support on quality of life for parents of adults with autism. *Journal of Autism and Developmental Disorders*, 47(8), 2378- 2389.
- Martin, C. A., Papadopoulos, N., Chellew, T., Rinehart, N. J., & Sciberras, E. (2019). Associations between parenting stress, parent mental health and child sleep problems for children with ADHD and ASD: Systematic review. *Research in developmental disabilities*, 93, 103463.
- Ministry of Health. (2020). *Indicator: Autism Spectrum Disorder (diagnosed, includes Aspergers Syndrome) (2-14 years)*. [https://minhealthnz.shinyapps.io/nz-health-survey-2019-20-annual-data-explorer/\\_w\\_d8280bc8/#!/explore-indicators](https://minhealthnz.shinyapps.io/nz-health-survey-2019-20-annual-data-explorer/_w_d8280bc8/#!/explore-indicators)

- Miranda, A., Mira, A., Berenguer, C., Rosello, B., & Baixauli, I. (2019). Parenting stress in mothers of children with autism without intellectual disability. Mediation of behavioral problems and coping strategies. *Frontiers in psychology, 10*, 464.
- Miranda, A., Tárraga, R., Fernández, M. I., Colomer, C., & Pastor, G. (2015). Parenting stress in families of children with autism spectrum disorder and ADHD. *Exceptional Children, 82*(1), 81-95.
- Montes, G., & Halterman, J. S. (2008). Association of childhood autism spectrum disorders and loss of family income. *Pediatrics, 121*(4), e821-e826.
- Muris, P., Meesters, C., & van den Berg, F. (2003). The strengths and difficulties questionnaire (SDQ). *European child & adolescent psychiatry, 12*(1), 1-8.
- Newschaffer, C. J., Croen, L. A., Daniels, J., Giarelli, E., Grether, J. K., Levy, S. E., ... & Windham, G. C. (2007). The epidemiology of autism spectrum disorders. *Annu. Rev. Public Health, 28*, 235-258.
- Oakley, B. F., Tillmann, J., Ahmad, J., Crawley, D., San José Cáceres, A., Holt, R., ... & Loth, E. (2021). How do core autism traits and associated symptoms relate to quality of life? Findings from the Longitudinal European Autism Project. *Autism, 25*(2), 389-404.
- Padden, C., & James, J. E. (2017). Stress among parents of children with and without autism spectrum disorder: a comparison involving physiological indicators and parent self-reports. *Journal of developmental and Physical disabilities, 29*(4), 567-586.
- Polyak, A., Kubina, R. M., & Girirajan, S. (2015). Comorbidity of intellectual disability confounds ascertainment of autism: implications for genetic diagnosis. *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics, 168*(7), 600-608.
- Rezendes, D. L., & Scarpa, A. (2011). Associations between parental anxiety/depression and child behavior problems related to autism spectrum disorders: The roles of parenting stress and parenting self-efficacy. *Autism Research and Treatment, 2011*.
- Rimland, B. (1964). *Infantile autism: The syndrome and its implications for a neural theory of behavior*. Appleton-Century-Crofts.
- Rivard, M., Terroux, A., Parent-Boursier, C., & Mercier, C. (2014). Determinants of stress in parents of children with autism spectrum disorders. *Journal of autism and developmental disorders, 44*(7), 1609-1620.

- Robinson, M., & Neece, C. L. (2015). Marital satisfaction, parental stress, and child behavior problems among parents of young children with developmental delays. *Journal of Mental Health Research in Intellectual Disabilities*, 8(1), 23-46.
- Rowland, D. (2020). The neurophysiological cause of autism. *Journal of Neurology & Neurophysiology*, 11(5), 1-4.
- Sawyer, M. G., Bittman, M., La Greca, A. M., Crettenden, A. D., Harchak, T. F., & Martin, J. (2010). Time demands of caring for children with autism: What are the implications for maternal mental health? *Journal of Autism and Developmental Disorders*, 40(5), 620-628.
- Schneider, A., Hommel, G., & Blettner, M. (2010). Linear regression analysis: part 14 of a series on evaluation of scientific publications. *Deutsches Ärzteblatt International*, 107(44), 776.
- Shepherd, D., Goedeke, S., Landon, J., & Meads, J. (2020). The types and functions of social supports used by parents caring for a child with autism spectrum disorder. *Journal of autism and developmental disorders*, 1-16.
- Siu, Q. K., Yi, H., Chan, R. C., Chio, F. H., Chan, D. F., & Mak, W. W. (2019). The role of child problem behaviors in autism spectrum symptoms and parenting stress: A primary school- based study. *Journal of Autism and Developmental Disorders*, 49(3), 857-870.
- Smith, L. E., Seltzer, M. M., Tager-Flusberg, H., Greenberg, J. S., & Carter, A. S. (2008). A comparative analysis of well-being and coping among mothers of toddlers and mothers of adolescents with ASD. *Journal of autism and developmental disorders*, 38(5), 876-889.
- Totsika, V., Hastings, R. P., Emerson, E., Berridge, D. M., & Lancaster, G. A. (2015). Prosocial skills in young children with autism, and their mothers' psychological well-being: Longitudinal relationships. *Research in Autism Spectrum Disorders*, 13, 25-31.
- Valicenti-McDermott, M., Lawson, K., Hottinger, K., Seijo, R., Schechtman, M., Shulman, L., & Shinnar, S. (2015). Parental stress in families of children with autism and other developmental disabilities. *Journal of child neurology*, 30(13), 1728-1735.
- Vasilopoulou, E., & Nisbet, J. (2016). The quality of life of parents of children with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, 23, 36-49.
- Volkmar, F. R., Paul, R., Rogers, S. J., & Pelphrey, K. A. (Eds.). (2014). *Handbook of autism and pervasive developmental disorders, diagnosis, development, and brain mechanisms* (Vol. 1). John Wiley & Sons.
- Weiss, J. A., Cappadocia, M. C., MacMullin, J. A., Vecili, M., & Lunsy, Y. (2012). The impact of child problem behaviors of children with ASD on parent mental health: The mediating role of acceptance and empowerment. *Autism*, 16(3), 261-274.

- Weitlauf, A. S., Gotham, K. O., Vehorn, A. C., & Warren, Z. E. (2014). Brief report: DSM-5 "levels of support:" A comment on discrepant conceptualizations of severity in ASD. *Journal of autism and developmental disorders*, 44(2), 471-476.
- White, M. K., McCausland, K. L., Sanchorawala, V., Guthrie, S. D., & Bayliss, M. S. (2017). Psychometric validation of the SF-36 Health Survey in light chain amyloidosis: results from community-based and clinic-based samples. *Patient related outcome measures*, 8, 157.
- Whiteley, P., Rodgers, J., Savery, D., & Shattock, P. (1999). A gluten-free diet as an intervention for autism and associated spectrum disorders: preliminary findings. *autism*, 3(1), 45-65.
- Wing, L. (1981). Asperger's syndrome: a clinical account. *Psychological medicine*, 11(1), 115-129.
- Woodman, A. C., Mawdsley, H. P., & Hauser-Cram, P. (2015). Parenting stress and child behavior problems within families of children with developmental disabilities: Transactional relations across 15 years. *Research in developmental disabilities*, 36, 264-276.
- Yao, S., Zhang, C., Zhu, X., Jing, X., McWhinnie, C. M., & Abela, J. R. (2009). Measuring adolescent psychopathology: psychometric properties of the self-report strengths and difficulties questionnaire in a sample of Chinese adolescents. *Journal of Adolescent Health*, 45(1), 55-62.
- Yılmaz, B., Azak, M., & Şahin, N. (2021). Mental health of parents of children with autism spectrum disorder during COVID-19 pandemic: A systematic review. *World Journal of Psychiatry*, 11(7), 388.
- Yu, C. H. (2010). Reliability of self-report data.
- Zaboski, B. A., & Storch, E. A. (2018). Comorbid autism spectrum disorder and anxiety disorders: a brief review. *Future neurology*, 13(1), 31-37.
- Zaidman-Zait, A., Mirenda, P., Duku, E., Szatmari, P., Georgiades, S., Volden, J., ... & Pathways in ASD Study Team. (2014). Examination of bidirectional relationships between parent stress and two types of problem behavior in children with autism spectrum disorder. *Journal of autism and developmental disorders*, 44(8), 1908-1917.
- Zelman, J. J., & Ferro, M. A. (2018). The parental stress scale: psychometric properties in families of children with chronic health conditions. *Family Relations*, 67(2), 240-252.
- Zhou, W., Liu, D., Xiong, X., & Xu, H. (2019). Emotional problems in mothers of autistic children and their correlation with socioeconomic status and parent of children's core symptoms. *Medicine*, 98(32).



## Appendices

### Appendix A: Ethics Approval

The logo for Auckland University of Technology (AUT) features the letters 'AUT' in a bold, white, sans-serif font against a black rectangular background.

TE WĀNANGA ARONUI  
O TĀMAKI MAKĀU RAU

#### **Auckland University of Technology Ethics Committee (AUTEK)**

Auckland University of Technology  
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9 July 2021

Daniel Shepherd  
Faculty of Culture and Society

Dear Daniel

Re Ethics Application: **21/211 Factors predicting parenting stress in parents caring for children with autism.**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEK).

Your ethics application has been approved for three years until 23 July 2024.

#### **Non-Standard Conditions of Approval**

1. Amendment of the Information Sheet before the survey as follows:
  - a. Inclusion of the AUT logo;
  - b. Update the withdrawal statements so that they advise participants that they can withdraw from the survey at any point until their responses have been submitted but that once this has occurred their data cannot be identified or withdrawn;
  - c. Inclusion of the AUTEK approval details, wording for which can be found in the Information Sheet template on the Research Ethics website at <http://aut.ac.nz/researchethics>.

Non-standard conditions must be completed before commencing your study. Non-standard conditions do not need to be submitted to or reviewed by AUTEK before commencing your study.

#### **Standard Conditions of Approval**

1. The research is to be undertaken in accordance with the [Auckland University of Technology Code of Conduct for Research](#) and as approved by AUTEK in this application.
2. A progress report is due annually on the anniversary of the approval date, using the EA2 form.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using the EA3 form.
4. Any amendments to the project must be approved by AUTEK prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTEK Secretariat as a matter of priority.
6. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEK Secretariat as a matter of priority.
7. It is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard and that all the dates on the documents are updated.

AUTEC grants ethical approval only. You are responsible for obtaining management approval for access for your research from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

Please quote the application number and title on all future correspondence related to this project.

For any enquiries please contact [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz). The forms mentioned above are available online through <http://www.aut.ac.nz/research/researchethics>

(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat

**Auckland University of Technology Ethics Committee**

Cc: kfr6417@autuni.ac.nz

## Appendix B: Participant Information Sheet

# Participant Information Sheet



### **Date Information Sheet Produced:**

27/05/2021

### **Project Title**

Factors predicting stress in parents caring for children with Autism Spectrum Disorder.

### **An Invitation**

Dear participant,

My name is Nirmatha Arunthavam and this study is the dissertation component of my Honours Degree in Psychology at Auckland University of Technology.

We would like to invite you to be involved in our research exploring the factors that may predict parenting stress in parents who are caring for a child with Autism Spectrum Disorder.

Participation in this research is completely voluntary and anonymous. You are under no obligation to complete the questionnaire and will be able to withdraw at any stage without question.

### **What is the purpose of this research?**

Our research aims to document your experiences for someone you care for who has an Autistic Spectrum Disorder and better understand stress factors that may be experienced. Specifically, it aims to explore factors which may predict stress when caring for a child with ASD.

### **How was I chosen for this invitation?**

Autism New Zealand have given their support to the study and agreed to post invitations to its members. As an individual receiving support from ANZ, or benefitting from their advocacy, you are invited to partake in the study.

### **What will happen in this research?**

You will be invited to fill out an online questionnaire about your experiences caring for a person with an Autism Spectrum Disorder. The answers from this questionnaire will be used to investigate factors that may impact the well-being of parents caring for children with ASD. Specifically, in predicting stress factors when caring for a child with ASD.

### **What are the benefits?**

By undertaking this study, we hope to inform and improve future policies and interventions aimed at understanding, assisting and supporting caregivers of persons with Autism Spectrum Disorder. The findings of this study will be shared with Autism New Zealand and will be made available on their website.

### **How will my privacy be protected?**

Your responses are confidential, and your privacy and anonymity are protected as it is not possible to identify you through your responses. The data will be combined with all other participants' data and then presented as averages, percentages and proportions. Your anonymity is therefore completely assured at all times throughout the project.

### **What are the costs of participating in this research?**

The only cost in participating in this research is 15-25 minutes of your time to fill out the questionnaire.

However, sensitive topics may be encountered in some parts of the questionnaire. There is a possibility that some questions may result in negative feelings that have not been previously addressed.

### **How do I agree to participate in this research?**

By completing the questionnaire below, you are expressing your consent to participate in this study. You are under no obligation to do so as your participation in this study is completely voluntary. You are also free to

withdraw at any stage during the completion of the survey. Please feel free to keep this page for your own record.

### **Will I receive feedback on the results of this research?**

Findings of the current study will be available online. Feel free to visit <http://www.autismnz.org.nz> to obtain a copy of the report after the completion of this research. Additionally, you can email the project supervisor (see below) to enquire as to the study's progress.

### **What do I do if I have concerns about this research?**

You can report any of your concerns regarding the nature of this project to the Project Supervisor Dr Daniel Shepherd ([daniel.shepherd@aut.ac.nz](mailto:daniel.shepherd@aut.ac.nz))

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEK, [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz).

### **Whom do you contact for further information about this research?**

#### **Researcher Contact Details:**

Nirmatha Arunthavam

[jcb9938@autuni.ac.nz](mailto:jcb9938@autuni.ac.nz)

#### **Project Supervisor Contact Details:**

Dr Daniel Shepherd

[daniel.shepherd@aut.ac.nz](mailto:daniel.shepherd@aut.ac.nz)

Tel.: +64 9 921 9999 extn: 7238

## Appendix C: Participant Questionnaire

### Intro

Hello, Kia ora, Kia orana, Fakaalofalahiatu, Talofa lava, Gudetruolgeta, Talohani, Malo e lelei, Talofa, Ni sabulavinaka, Bonjour, Guten Tag, Nǎhǎo.

## Parenting a child on the spectrum: What are you experiencing and how are you doing?

If you are the parent of a person on the spectrum then we invite you to participate in this research investigating your parenting experience.

This survey is designed to be easy to complete and should take no more than 20 minutes of your time.

By completing the questionnaire, you are expressing your consent to participate in this study.

Thank you for participating.

Daniel Shepherd  
Auckland University of Technology

### PIS

This research has received ethical consent from the Auckland University of Technology's Ethics Committee (AUTEK).

This survey takes between 15 - 20 minutes to complete, and is in four parts:

- 1) A bit about you
- 2) A bit about your child

3) What are you experiencing as part of your ASD parenting odyssey?

4) How are you coping with caring for an ASD child?

## **Participant Information Sheet**

**Date Information Sheet Produced:** 27/05/2021

**Project Title:** Contributing factors to parenting stress in parents of children diagnosed with autism spectrum disorder in New Zealand

**An Invitation:** Dear participant, This study is the dissertation component of an Honours Degree in Psychology at Auckland University of Technology. We would like to invite you to be involved in our research exploring the factors that may predict parenting stress in parents who are caring for a child with Autism Spectrum Disorder. Participation in this research is completely voluntary and anonymous. You are under no obligation to complete the questionnaire and will be able to withdraw at any stage without question.

**What is the purpose of this research?** Our research aims to document your experiences for someone you care for who has an Autistic Spectrum Disorder and better understand stress factors that may be experienced. Specifically, it aims to explore factors which may predict stress when caring for a child with ASD.

**How was I chosen for this invitation?** Autism New Zealand have given their support to the study and agreed to advertise invitations to its members. As an individual receiving support from ANZ, or benefitting from their advocacy, you are invited to partake in the study.

**What will happen in this research?** You will be invited to fill out an online questionnaire about your experiences caring for a person with an Autism Spectrum Disorder. The answers from this questionnaire will be used to investigate factors that may impact the well-being of parents caring for children with ASD. Specifically, in predicting stress factors when caring for a child with ASD.

**What are the benefits?** By undertaking this study, we hope to inform and improve future policies and interventions aimed at understanding, assisting and supporting caregivers of persons with Autism Spectrum Disorder. The findings of this study will be shared with Autism New Zealand

and will be made available on their website.

**How will my privacy be protected?** Your responses are confidential, and your privacy and anonymity are protected as it is not possible to identify you through your responses. The data will be combined with all other participants' data and then presented as averages, percentages and proportions. Your anonymity is therefore completely assured at all times throughout the project.

**What are the costs of participating in this research?** The only cost in participating in this research is 15-25 minutes of your time to fill out the questionnaire. However, sensitive topics may be encountered in some parts of the questionnaire. There is a possibility that some questions may result in negative feelings that have not been previously addressed.

**How do I agree to participate in this research?** By completing the questionnaire below, you are expressing your consent to participate in this study. You are under no obligation to do so as your participation in this study is completely voluntary. You are also free to withdraw at any stage during the completion of the survey. Please feel free to keep this page for your own record.

**Will I receive feedback on the results of this research?** Findings of the current study will be available online. Feel free to visit <http://www.autismnz.org.nz> to obtain a copy of the report after the completion of this research. Additionally, you can email the project supervisor (see below) to enquire as to the study's progress.

**What do I do if I have concerns about this research?** You can report any of your concerns regarding the nature of this project to the Project Supervisor Dr Daniel Shepherd (daniel.shepherd@aut.ac.nz)

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTECH, ethics@aut.ac.nz.

**Whom do you contact for further information about this research?** Researcher Contact Details: Marc Nazareth kfr6417@autuni.ac.nz

**Project Supervisor Contact Details:** Daniel Shepherd daniel.shepherd@aut.ac.nz Tel.: +64 9 921 9999 extn: 7238

Parent

## Part One, please tell us a bit about yourself...

**What sex are you?**

Male

Female

Another Gender  
(Please State):

**What is your age in years?**

**Which ethnic group do you feel you most identify with?**

European

Maori

Pasifika

Asian

Middle Eastern/Latin American/African

Other (please specify):

**What is the highest level of education you have completed?**

Primary School

Secondary School

Technical College or other professional training

University Degree

Other (please specify):

**Are you currently (tick all that apply):**

Single / a solo parent

Married

Previously divorced

Not married but living in a relationship

In a relationship but living independently

**Child**

## **Tell us about your child...**

**How old is your child with ASD (years old)?**

**What sex is your child's (please tick)?**

Male

Female

**How many other children (under 18 years of age) are currently in your care?**

**How old was your child when YOU first noticed their ASD-like behaviours?**

**Who first formally diagnosed your child with ASD?**

My Doctor/ General Practitioner (GP)

Pediatrician

Psychologist

My child has never received a formal diagnosis

Other (please specify):

**How old was your child when they received a formal diagnosis?**

AIM\_1

**Tell us about your child's Autism**

Please rate the impact that the following behaviours had on the daily functioning of the person with ASD in the past 2 weeks:

**On a five point scale, how much do these behaviours interfere with your child's everyday functioning? (Note: Select "1" if the behaviour is absent)**

	Not at all 1	Rarely 2	Moderately 3	Frequently 4	Severely 5
Shown fascination with parts of objects or toys rather than the whole object/toy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lined things up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Had certain rituals or routines that have to be followed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shown strong attachments to unusual toys or objects?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Experienced problems with repetitive behaviours or restricted interests?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Avoided certain sounds, textures, or smells to an unusual extent?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shown a preoccupation with one subject or area of interest?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Resisted changes in routines?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**AIM\_2**

## **Tell us about your child's Autism**

**Please rate the impact that the following behaviours had on the daily functioning of the person with ASD in the past 2 weeks:**

**On a five point scale, how much do these behaviours interfere with your child's everyday functioning? (Note: Select "1" if the behaviour is absent)**

	Not at all 1	Rarely 2	Moderately 3	Frequently 4	Severely 5
Had speech problems or been hard to understand?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Experienced problems in communicating with others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Had problems with pronouns (such as using "you" for "I")?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not engaging in reciprocal conversation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Used a private or made-up language?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**AIM\_3**

## **Tell us about your child's Autism**

**Please rate the impact that the following behaviours had on the daily functioning of the person with ASD in the past 2 weeks:**

**On a five point scale, how much do these behaviours interfere with your child's everyday functioning? (Note: Select "1" if the behaviour is absent)**

	<b>Not at all</b> 1	<b>Rarely</b> 2	<b>Moderately</b> 3	<b>Frequently</b> 4	<b>Severely</b> 5
Responded oddly or inappropriately to others?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Experienced problems in social interactions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Used odd or unusual pitch, volume, or tone when talking?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Had repetitive movements with his/her whole body (such as rocking or spinning)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shown repetitive hand or finger movements (such as finger flicking or hand flapping)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**AIM\_4**

## **Tell us about your child's Autism**

**Please rate the impact that the following behaviours had on the daily functioning of the person with ASD in the past 2 weeks:**

On a five point scale, how much do the ABSENCE of these behaviors interfere with your child's everyday functioning?? (Note: Select "1" if the behaviour is absent)

	Not at all 1	Rarely 2	Moderately 3	Frequently 4	Severely 5
Used a number of different facial expressions (such as surprise, interest)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Used gestures to communicate (such as nodding, waving goodbye, shrugging)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Used a social smile to greet people or respond to them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brought/shown things to others just to share his/her interest (not just for help)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comforted others when they were upset?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Made eye contact with others?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shared enjoyment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### Checklist\_1

**Tell us about your child's everyday behaviour**

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of your child's behaviour over the last six months.

	<b>Not True</b>	<b>Somewhat True</b>		<b>Certainly True</b>
Considerate of other people's feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Restless, overactive, cannot stay still for long	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Often complains of headaches, stomach-aches, or sickness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shares readily with other children, for example toys, treats, tablets	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Often has temper tantrums or hot tempers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comforted others when they were upset?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Rather solitary, prefers to play alone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Checklist\_2

## **Tell us about your child's everyday behaviour**

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of your child's behaviour **over the last six months.**

	Not True	Somewhat True	Certainly True
Many worries, often seems worried	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Restless, overactive, cannot stay still for long	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helpful if someone is hurt, upset or feeling ill	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Constantly fidgeting or squirming	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Has at least one good friend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Often fights with other children or bullies them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### Checklist\_3

**Tell us about your child's everyday behaviour**

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of your child's behaviour **over the last six months.**

	Not True	Somewhat True	Certainly True
Easily distracted, concentration wanders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nervous or clingy in new situations, easily loses confidence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Kind to younger children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Often lies or cheats	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Picked on or bullied by other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Often volunteers to help others (parents, teachers, children)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thinks things out before acting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

#### Checklist\_4

**Tell us about your child's everyday behaviour**

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of your child's behaviour **over the last six months.**

	Not True	Somewhat True	Certainly True
Steals from home, school or elsewhere	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gets along better with adults than with other children	<input type="radio"/>	<input type="radio"/>	
Many fears, easily scared	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Good attention span, sees chores, homework, tasks through to the end	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Generally liked by other children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Generally well behaved, usually does what adults request	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Parenting\_1

### How do you cope parenting a child with autism?

The following statements describe feelings and perceptions about the experience of being a parent of a child with ASD. Think of each of the items in terms of how your relationship with your child or children typically is.

Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.:

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree
I am happy in my role as a parent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is little or nothing I wouldn't do for my child if it was necessary.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caring for my child sometimes takes more time and energy than I have to give.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I sometimes worry whether I am doing enough for my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel close to my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I enjoy spending time with my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child is an important source of affection for me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parenting this child gives me a more certain and optimistic view for the future.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The major source of stress in my life is my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Parenting\_2

### How do you cope parenting a child with autism?

The following statements describe feelings and perceptions about the experience of being a parent of a child with ASD. Think of each of the items in terms of how your relationship with your child or children typically is.

Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.:

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree
Parenting this child leaves little time and flexibility in my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parenting this child has been a financial burden.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is difficult to balance different responsibilities because of my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The behaviour of my child is often embarrassing or stressful to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I had it to do over again, I might decide not to have children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel overwhelmed by the responsibility of being a parent.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parenting this child has meant having too few choices and too little control over my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied as a parent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I find my child enjoyable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Anxiety

Does your child experience anxiety?

Yes

No

Has your child's anxiety been formally diagnosed and acknowledged?

Yes

No

How much does your child's anxiety interfere with their everyday functioning?

Very mildly

Mildly

Moderately

Severely

Very Severely

How much does your child's anxiety contribute to your levels of parenting stress?

Not at all                  Slightly                  Moderately                  Quite a bit                  Extremely

## **ADHD**

Does your child experience ADHD?

Yes

No

Has your child's ADHD been formally diagnosed and acknowledged?

Yes

No

How much does your child's ADHD interfere with their everyday functioning?

Very mildly                  Mildly                  Moderately                  Severely                  Very Severely

How much does your child's ADHD contribute to your levels of parenting stress?

Not at all                  Slightly                  Moderately                  Quite a bit                  Extremely

## **Disability**

Does your child experience intellectual disability?

Yes

No

Has your child's intellectual disability been formally diagnosed and acknowledged?

Yes

No

How much does your child's intellectual disability interfere with their everyday functioning?

Very mildly

Mildly

Moderately

Severely

Very Severely

How much does your child's intellectual disability contribute to your levels of parenting stress?

Not at all

Slightly

Moderately

Quite a bit

Extremely

## **Gastro**

Does your child experience gastrointestinal (gut / tummy) problems?

Yes

No

Has your child's gastrointestinal problems been formally diagnosed and acknowledged?

Yes

No

How much does your child's gastrointestinal problems interfere with their everyday functioning?

Very mildly

Mildly

Moderately

Severely

Very Severely

How much does your child's gastrointestinal problems contribute to your levels of parenting stress?

Not at all

Slightly

Moderately

Quite a bit

Extremely

## **Sleep**

Does your child experience sleep difficulties?

Yes

No

Has your child's sleep difficulties been formally diagnosed and acknowledged?

Yes

No

How much does your child's sleep difficulties interfere with their everyday functioning?

Very mildly

Mildly

Moderately

Severely

Very Severely

How much does your child's sleep difficulties contribute to your levels of parenting stress?

Not at all

Slightly

Moderately

Quite a bit

Extremely

## Health\_1

**Finally, as a parent of a child with autism we'd like to hear what you think about your health and wellbeing.**

**We would like to know about how your health has been over the two weeks. Please answer the following questions by selecting the answer which you think most nearly applies to you.**

**In general, would you say your health is:**

Excellent

Very Good

Good

Fair

Poor

**Compared to one year ago, how would you rate your health in general now?**

Much better now than one year ago

Somewhat better now than one year ago

About the same as one year ago

Somewhat worse now than one year ago

Much worse now than one year ago

## Health\_2

**We would like to know about how your health has been over the past two weeks. Please answer the following questions by selecting the answer which you think most nearly applies to you.**

**The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lifting or carrying groceries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Climbing several flights of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Climbing one flight of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### **Health\_3**

**We would like to know about how your health has been over the past two weeks. Please answer the following questions by selecting the answer which you think most nearly applies to you.**

**The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Bending, kneeling, or stooping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking more than a kilometer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking several 100 meters	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking 100 meters	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bathing or dressing yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

#### **Health\_4**

**We would like to know about how your health has been over the past two weeks. Please answer the following questions by selecting the answer which you think most nearly applies to you.**

**During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

	Yes	No
Cut down on the amount of time you spent on work or other activities	<input type="radio"/>	<input type="radio"/>
Accomplished less than you would like	<input type="radio"/>	<input type="radio"/>
Were limited in the kind of work or other activities	<input type="radio"/>	<input type="radio"/>
Had difficulty performing the work or other activities (for example, it took extra effort)	<input type="radio"/>	<input type="radio"/>

**How much bodily pain have you had during the past 4 weeks?**

None                  Very Mild                  Moderately                  Quite a bit                  Extremely

**During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**

Not at all      A little bit      Moderately      Quite a bit      Extremely

### Health\_5

**We would like to know about how your health has been over the past two weeks. Please answer the following questions by selecting the answer which you think most nearly applies to you.**

**During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

	Yes	No
Cut down on the amount of time you spent on work or other activities	<input type="radio"/>	
Accomplished less than you would like	<input type="radio"/>	<input type="radio"/>
Did work or other activities less carefully than usual	<input type="radio"/>	<input type="radio"/>

**During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?**

Not at all      Slightly      Moderately      Quite a bit      Extremely

**During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?**

All of the time      Most of the time      Some of the time      A little of the time      None of the time

### Health\_6

**We would like to know about how your health has been over the past two weeks. Please answer the following questions by selecting the answer which you think most nearly applies to you.**

**These questions are about how you feel and how things have been with you during the past two weeks. For each question, please give the one answer that comes closest to the way you have been feeling.**

**How much of the time during the past 4 weeks**

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Did you feel full of life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been a very nervous person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt so down in the dumps that nothing could cheer you up?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt calm and peaceful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have a lot of energy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt downhearted and sad?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel worn out?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been a happy person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel sleepy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Health\_7**

**We would like to know about how your health has been over the past two weeks. Please answer the following questions by selecting the answer which you think most nearly applies to you.**

**How TRUE or FALSE is each of the following statements for you?**

	Definitely True	Mostly true	Don't Know	Mostly False	Definitely False
I seem to get sick a little easier than other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am as healthy as anybody I know	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I expect my health to get worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My health is excellent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Finish!**

**This is the end! Thank you for sharing your experiences with us. These results are important to us and the ASD community. We would be grateful if you could pass on this link to other parents of children with ASD so we can obtain the results that best reflect the overall experience of New Zealand parents.**

**If you have any further comments relating to the support you receive as a parent of a child with ASD, or about this survey in general, then we'd be interested to hear them:**



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## Appendix D: Tables

### Appendix D1

*Means (M), standard deviations (SD), and Cronbach's alpha ( $\alpha_c$ ) values if an item is deleted for the items present in the AIM subscales*

<u>Item</u>	<u>M</u>	<u>SD</u>	<u>Cronbach's alpha (<math>\alpha_c</math>) if item deleted</u>
<b>Restricted/Ritualised Behaviours</b>			
AIM_R1: Fascination with Parts	2.59	1.28	0.799
AIM_R2: Lined-Up Objects	2.44	1.37	0.812
AIM_R3: Rituals or Routines	3.66	1.05	0.794
AIM_R4: Attached to Certain Objects	3.08	1.41	0.800
AIM_R5: Repetitive Behaviours	3.53	1.03	0.800
AIM_R6: Avoidance of Textures/Smells/Sounds	3.55	1.08	0.788
AIM_R7: Restricted Interests	3.75	1.08	0.793
AIM_R8: Resistant to Changes	3.61	1.01	0.800
<b>Communication/Language</b>			
AIM_C1: Speech Difficulties	2.77	1.50	0.849
AIM_C2: Communication Problems	3.44	1.15	0.855
AIM_C3: Difficulties with Pronouns	2.55	1.54	0.842
AIM_C4: Engagement in Reciprocal Conversation	3.48	1.13	0.884
AIM_C5: Usage of Made-Up Language	1.95	1.32	0.891
<b>Social-Emotional Reciprocity</b>			
AIM_S1: Range of Facial Expressions	2.87	1.083	0.794
AIM_S2: Gesture Usage	2.33	0.894	0.800
AIM_S3: Appropriate Smiling	2.79	1.148	0.808
AIM_S4: Shared Interests	3.23	1.353	0.774
AIM_S5: Comforts Others	3.37	1.334	0.770
AIM_S6: Makes Eye Contact	3.38	1.071	0.815
AIM_S7: Shared Enjoyment	3.42	1.089	0.817
<b>Odd/Atypical Behaviours</b>			
AIM_O1: Odd Approaches	2.66	1.14	0.697
AIM_O2: Social Interaction Problems	2.67	1.16	0.698

AIM_O3: Odd Tone/Pitch	2.31	1.16	0.747
AIM_O4: Repetitive Movements	2.68	1.00	0.695
AIM_O5: Hand Flapping	2.74	1.01	0.698

## Appendix D2

Means (*M*), standard deviations (*SD*), and Cronbach's alpha values if an item is deleted for the totaled subscales of the AIM

<u>Scale</u>	<u>M</u>	<u>SD</u>	<u>Cronbach's alpha (<math>\alpha_c</math>) if item deleted</u>
AIM: Restricted/Ritualised Behaviours	3.27	0.779	0.819
AIM: Communication/Language	2.84	1.11	0.890
AIM: Social/Emotional Reciprocity	3.06	0.798	0.822
AIM: Odd/Atypical Behaviours	2.61	0.776	0.751

## Appendix D3

Means (*M*), standard deviations (*SD*), and Cronbach's alpha values if an item is deleted for all the items present in the PSS, along with scale reliability results

<u>Item</u>	<u>M</u>	<u>SD</u>	<u>Cronbach's alpha (<math>\alpha_c</math>) if item deleted</u>
PSS_1: Happy as Parent	2.32	1.178	0.931
PSS_2: Would Do Everything for Child	1.34	0.752	0.939
PSS_3: Time and Energy	4.18	1.212	0.933
PSS_4: Doing Enough for Child	4.43	0.945	0.936
PSS_5: Close to Child	1.94	1.149	0.934

PSS_6: Enjoy Time with Child	1.99	0.827	0.933
PSS_7: Child Is Source of Affection	2.38	1.173	0.937
PSS_8: Optimistic Future View	3.11	1.185	0.931
PSS_9: Child Is Major Stressor	3.49	1.249	0.932
PSS_10: Little Flexibility	3.98	1.070	0.934
PSS_11: Financial Burden	3.01	1.250	0.938
PSS_12: Difficulty Balancing Responsibilities	3.82	1.201	0.931
PSS_13: Embarrassing Behaviours	3.50	1.372	0.932
PSS_14: Not Have Children Again	2.11	1.266	0.934
PSS_15: Overwhelmed by Parenting	3.38	1.454	0.931
PSS_16: Few Choices and Control	3.18	1.395	0.931
PSS_17: Satisfied as Parent	2.49	1.026	0.930
PSS_18: Children Enjoyable	1.94	0.943	0.933
<b><u>PSS Total Score</u></b>	<b><u>M</u></b>	<b><u>SD</u></b>	<b><u>Cronbach's alpha (<math>\alpha_c</math>)</u></b>
	2.92	0.807	0.937

#### Appendix D4

*Means (M), standard deviations (SD), and Cronbach's alpha values if an item is deleted for the Lack of Reward items present in the PSS, along with scale reliability results*

<b><u>Item</u></b>	<b><u>M</u></b>	<b><u>SD</u></b>	<b><u>Cronbach's alpha (<math>\alpha_c</math>) if item deleted</u></b>
PSS_5: Close to Child	1.92	1.146	0.861
PSS_6: Enjoy Time with Child	1.99	0.821	0.858
PSS_7: Child Is	2.36	1.176	0.884

## Appendix D5

Means (*M*), standard deviations (*SD*), and Cronbach's alpha values if an item is deleted for the Parenting Stressor items present in the PSS, along with scale reliability results

<u>Item</u>	<u><i>M</i></u>	<u><i>SD</i></u>	<u>Cronbach's alpha (<math>\alpha_c</math>) if item deleted</u>
PSS_3: Time and Energy	4.18	1.212	0.933
PSS_9: Child is Major Stressor	3.49	1.249	0.932
PSS_10: Little Flexibility	3.98	1.070	0.934
PSS_11: Financial Burden	3.01	1.250	0.938
PSS_12: Difficulty Balancing Responsibilities	3.82	1.201	0.931
PSS_13: Embarrassing Behaviours	3.50	1.372	0.932
PSS_16: Few Choices and Control	3.18	1.395	0.931
<b><u>PSS: Parenting Stressors Total Score</u></b>	<b><u><i>M</i></u></b>	<b><u><i>SD</i></u></b>	<b><u>Cronbach's alpha (<math>\alpha_c</math>)</u></b>
	3.59	0.992	0.900