

Experiences of Pasifika fathers who care for children with Autism Spectrum Disorder (ASD)

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## ABSTRACT

This research explored the parenting experiences of Pasifika fathers' caring for a child diagnosed with autism spectrum disorder living in New Zealand. Although caregiving is a highly examined topic that focuses on the challenges and demands placed upon caregivers and the resources that help caregivers overcome the challenges and demands, Polynesian parents being a specific area of interest is not greatly researched. Objective and subject burdens can sometimes outweigh resources which lead to stress, depression, and financial burdens. Caregivers manage burdens through several emotional, cognitive, and action-based coping mechanisms, which include, daily routine and planning, seeking social support and getting educated and aware of autism spectrum disorder.

Despite being valuable and effective, most of the established models were developed from maternal data compared to paternal experiences which are relatively unaccounted for. The national documented strategies and guidelines, specifically the New Zealand Autism Spectrum Disorder Guidelines (2008), and the most recent New Zealand Carers Strategy Action Plan 2019-2023, make it appropriate to embark on qualitative research to reach a level of in-depth and thorough understanding of Pasifika fathers' experiences in New Zealand. Five Pasifika fathers were recruited to participate in this research through advertisements which were shared by two Pasifika focused support groups.

Data was collected through semi-structured interviews conducted via zoom. An interpretive phenomenological analysis was utilised to distinguish three superordinate theme categories: Support, coping mechanisms, and emotional aspects of parenting experiences. These superordinate themes consisted of seven emergent themes: 1) Experiences of support, 2) Support for Pasifika fathers', 3) Getting educated and aware, 4) Pasifika cultural norms, 5) Daily routine and planning, 6) Positive emotions, and 7) Negative emotions. Furthermore, a subtheme was also identified which was 'Reaction to diagnosis,' and was categorised under coping mechanisms, emergent theme three. Research results support previous literature which highlighted the concerns for caregivers with children with autism, in terms of unmet information requirements and insufficient respite services. Furthermore, results also conveyed the significance and applicability of current government and organisational schemes, and recommendations can be applied to Pasifika fathers caring for a child with autism.

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## **ATTESTATION OF AUTHORSHIP**

I declare that this submission is my own work and that, to the best of my belief and knowledge, it contains no material previously written or published by another individual (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:**

**Dated:** 17/02/2022

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The ethical approval (Reference number 21/210) for this study was approved by the AUT University Ethics Committee (AUTEK) on the 29<sup>th</sup> of July 2021 for three years until 29<sup>th</sup> July 2024 (See Appendix A).

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## **Introduction**

### **Background to Autism Spectrum Disorder**

Autism Spectrum Disorders (ASD) are a set of neurodevelopmental disorders that are defined as impairments affecting the individual's social functioning and communication, which are regularly accompanied by stereotyped and rhythmic patterns of behaviours and activities (Landa, 2008). Autism spectrum disorder typically develops throughout the early stages of an individual's childhood and is characterised using a spectrum with differences in severity and symptom presentation (American Psychiatric Association, 2013). This variation creates difficulties in providing resilient support systems for families caring for autistic children and, furthermore, explaining different reasons why parents or families have an increased risk in developing or experiencing depression and stress compared to parents and families who are not caring for an autistic child (Padden & James, 2017). Traditionally, parents with autistic children have the responsibility of care, which is automatically placed upon them as part of their parenting responsibility. Most research has focused on maternal experiences, which may not reflect the recent development within western countries of rising paternal care, which generally suggests that fathers are progressively taking more responsibility of care (Bianchi, 2000). There is a connection between caring for a child with disabilities and the challenges placed on families. Therefore, when these challenges are enduring, they constitute a high amount of financial and psychological stress and pressure. However, effective systemic provision and arrangements are seen as being protective against burden (Stuart & McGrew, 2009).

### **Pasifika Cultural Background**

There is limited research and qualitative reports which focus on the issues surrounding ASD among the Pasifika population. Each Pacific nation has their own set cultural customs, belief systems, values, and traditions, however, they also have similarities in values and beliefs. For example, in the Samoan culture, values that are ingrained in the individuals from a young age consist of respect (fa'aaloalo), family (aiga) and service (tautua). Furthermore, the Cook Island culture also consists of the Samoan values, but also focus on humility (tangata kauraro), generosity (ngakau aroa), and loyalty (kua atinga I toku oraanga). This provides a brief mental illustration for non-Polynesians of the Polynesians way of living. These important values are what shapes our thoughts, behaviours and influence our daily lives.

Pasifika culture has a great influence on an individual and their family's health beliefs, behaviours, and methods, and these differ from the western perspective, causing a decrease in understanding and relating. This being said, the Minnesota Department of Human Services (2004), suggested that an individual's behaviour is dependent of how they understand the cause of their sickness. Therefore,

indicating the differences of perspectives of sickness between Polynesians and non-Polynesians. Culture plays an important role in Pasifika life as it affects how we see, react, and understand physical and social phenomena. This is where we integrate our values and customs taught from our parents, and which have been passed on from their parents, to deal with life stressors.

The 1984 Fonofale health model was established by Samoan born Dr Fuimaono Karl Pulotu-Endemann (2009) to further clarify the important beliefs and values believed to be major contributing factors of Pasifika wellbeing (Chand, 2020). This Polynesian model benefits the people of the Pacific as it shines a different light on how people of westernised cultures or countries can comprehensively understand the factors that affect the Pasifika people's overall health, thereby, highlighting the differences in perspectives and approaches to health between holistic and westernised cultures.

The Fonofale health model is metaphorically explained as a Samoan fale (house) which signifies Pacific beliefs and values. The Fonofale model is grounded on aiga (family) with four pou (posts), physical, spiritual, mental, and other, which all hold up the roof of the fale, which is the culture aspect. The other pou in the model includes the individual's sexuality, age, gender, and socio-economic status and many more dimensions. The outer fale conveys that the context, time, and the environment also have an impact on the individual's health. All aspects of the Fonofale model intertwine and depend on each other to maintain a healthy wellbeing. For example, if an individual's spiritual pou is damaged, the three other pou along with the foundation and roof will also become damaged, which will have a negative impact on the individual.

The aim of this project is to explore the experiences of Pasifika fathers' who care for children on the autism spectrum in New Zealand. The limited frameworks of published research are not addressing the experiences of Pasifika parents, specifically Pasifika fathers caring for a child with ASD in New Zealand. Areas for interest consist of the positive or negative challenges experienced as a parent with a child with ASD, and the perceptions, attitudes, accessible support services and wellbeing. It is expected that through the exploration of these particular areas and awareness and deeper understanding of the Pasifika father's experiences in regard to the Pasifika parents' group will be achieved. These aims are fitting and appropriate in terms of a research context in which the parental experiences of Pasifika fathers are primarily described, and in which the advancement of effective intervention, community and clinical awareness, and acknowledgment are maintained as best practice. Furthermore, the New Zealand Autism Spectrum Guideline, is an evidence-based source of information that considers the Maori and Pacific perspectives on Autism, offers translations in different Polynesian languages (Samoan, Tongan, and Cook Island etc). Being able to provide a more comprehensive understanding of the experiences of Pasifika fathers as a parent would describe the

extent to which this evidence-based information is applicable to the population of Pasifika fathers caring for children with ASD.

Given the objective of the study is the lived experiences of Pasifika fathers, a qualitative methodology was chosen. Qualitative methodology is the most applicable approach in achieving a comprehensive interpretation of the Pasifika father's experiences of care in the New Zealand context. Particularly, this study design utilised interpretive phenomenological analysis (IPA), which is a methodological approach that focuses on the individuals lived experiences (phenomenological paradigm) and interpretive epistemologies (Smith et al, 2009). Although it is thought that the participants will have specialised knowledge and understanding, both participant and researcher roles are collaborative in the data collection process. The research participants discuss the questions asked by the researcher, who then analyses the information collected and organises it into main themes.

This introduction has outlined the study's objectives, the appropriate methodology and the study's context. A literature review will follow the introduction, describing the background information on ASD and parenting research with reference to the concepts of coping and stress. Research specifically relating to Pasifika fathers is also examined and critiqued. Furthermore, the perspective of Pasifika culture on ASD and mental health is provided in detail.

The following chapter provides a comprehensive description of the methodological approach of interpretive phenomenological analysis, data collection processes, and then ethical considerations. The results section will provide the demographic information of the participants, the structure of thematic structure of the analysis, followed by an in-depth description of every theme with supporting quotations from the interview transcripts. Lastly, a discussion of these results is conveyed in the context of the literature, and within the field of Pasifika caregiving in New Zealand, in conjunction with potential limitations, future recommendations for researchers, clinicians and the wider field.

## **Literature Review**

### **Diagnosis and prevalence**

This chapter critically evaluates the literature that informs this study. Autism Spectrum Disorder is classified alongside estimates of prevalence. Characteristics of diagnosis and resolution to diagnosis are studied and evaluated, before investigating the importance of parenting. Definitions of caregiving, parental coping, and stress are provided, and a critique of the literature offered. The impact of Polynesian culture, perspectives, beliefs, and values are explained and supported by previous research. Lastly, the research relating to Pasifika fathers and their parental role caring for a child with ASD will be described and critiqued. The limitations of the research literature and its gaps will be mentioned throughout, and the chapter finishes with the motivation for the current study.

## **Autism Spectrum Disorders**

### **Defining Autism Spectrum Disorders**

Autism is a complex neurodevelopmental condition that is characterised by persistent difficulties in social interaction skills and psychological functioning, and usually develops throughout the early stages of childhood (Lai et al., 2014; Lord et al., 2018). Autism is generally diagnosed within the first 24 months in a child's life and has a higher prevalence in males than females. The individuals' impairments in their development reflect different severity levels among the core symptoms. Autism spectrum disorder is considered one of the most disabling and puzzling childhood developmental disorders due to the atypical patterns' individuals have which negatively affect various areas of functioning (Phetrasuwan & Miles, 2009).

Gender differences are evident in the diagnosis of ASD as males are four times more likely to be diagnosed with ASD than females (American Psychiatric Association, 2013). In clinic samples females have a tendency to be more likely to show associated intellectual disability, thus signifying that females without accompanying intellectual impairments or language deficits may be camouflaging. This camouflaging may be because of reduced evidence of communication and social difficulties (American Psychiatric Association, 2013).

### **Autism Spectrum Disorder in the DSM-5**

The diagnostic criteria for ASD have developed throughout the evolution of diagnostic statistical manual (DSM), including the DSM III, IV, and V. The DSM-III established autism as its own distinct diagnosis, which was separate from schizophrenia and portrayed as a prevalent developmental disorder (American Psychiatric Association, 2013). The DSM-III established three essential factors of autism: an obvious lack of interest in people, severe deficiencies in communication, and maladaptive responses to their surroundings. These are signs that generally develop throughout the child's first 30 months of life (American Psychiatric Association, 2013).

The DSM-IV was the first DSM edition to establish autism as a 'spectrum', which consisted of five pervasive developmental disorders (PDDs): Autistic Disorder, Rett's Disorder, Asperger's Disorder, Pervasive Developmental Disorder not otherwise specified, and Childhood Disintegrative Disorder, (American Psychiatric Association, 2013). The DSM-V incorporates both social and language deficits into one measure, breaking down the three domains defined in the DSM-IV into two parts. For an individual to be diagnosed with ASD they are required to have deficits in both social interactions and communications and show repetitive and restrictive behaviours (American Psychiatric Association,

2013). However, with the DSM-5, the diagnostic criteria for ASD were reduced from three factors into two (social communications and restricted and repetitive behaviours) thus requiring children to meet an increased number of symptom criteria for diagnosis (American Psychiatric Association, 2000; 2013; Harris et al., 2021).

The ASD diagnostic criteria consists of five parts: with the first two parts of the diagnostic criteria including severity level, continuous deficits in social communications and social interactions consisting of various behaviours or conditions. The other part of the criteria consisting of a severity level is the constrained, repetitive patterns of behaviours, hobbies, or activities. The last three criteria in the DSM for ASD include: individual's symptoms need to be present during the early years of development, symptoms cause clinically substantial deficiency in social, occupational, and/or in other essential areas of current functioning, and finally, that these impairments are not better explained by another intellectual disability (American Psychiatric Association, 2013). Previous research has compared children who met the DSM-IV rather than the DSM-5 criteria and have reported that the children who did not meet the diagnostic criteria for the DSM-5 had an increase cognitive or adaptive skills and low acute core symptoms or were diagnosed with pervasive developmental disorder (otherwise not specified) through the DSM-IV (Gibbs et al., 2012; Jashar et al., 2016; Harris et al., 2021). However, previous literature has suggested a possibility of disproportionately affecting children that are less probable to meet the stricter DSM-5 criteria compared to older children (Gibbs et al., 2012; Harstad et al., 2015; Harris et al., 2021).

### **Autism Spectrum Disorder Prevalence**

In New Zealand, there is inadequate data on the prevalence, incidence, age at diagnosis, and management of ASD (Eggleston et al., 2019; Thabrew & Eggleston, 2018). Publications of the Ministry of Health (MoH) still estimate ASD prevalence percentages based on older United Kingdom studies from 2006, which suggests that the prevalence of ASD in New Zealand affects 1% (1 in 100) of New Zealanders (Ministries of Health Education, 2016). Generalising the prevalence percentage to the total New Zealand population of 5 million suggest that there is 50,000 people diagnosed with ASD in New Zealand (Ministries of Health and Education, 2013). However, the MoH ASD prevalence numbers can be considered outdated, and with diagnostic changes these percentage figures may have increased and are still increasing. The 2019 New Zealand Health Survey (NZHS) reported families receiving a diagnosis of ASD for their children ages 2-14 years, which may be evidence of the prevalence statistics increasing to 1.6% (MoH, 2019a).

Bowden et al. (2020) studied 9555 unique participants aged 0-24 years with ASD. Their study identified an estimate of 10,000 children and young people with ASD in New Zealand and further highlighted that the most prevalent comorbid ASD conditions were intellectual disability, emotional

problems, and disruptive behaviours. In a comparison between New Zealand European (NZE) and Maori and Pasifika populations, ASD was found to be more prevalent in males and in New Zealand European than Maori and Pasifika populations. A study by Eggleston et al., (2019); Simpson et al., (2018) had similar findings. However, Elsasbogh et al., (2012) argued the uncertainty of prevalence rates not strongly signifying true ethnic differences. Whereas Bowden et al. (2020) further suggested there were low prevalence rates of ASD among Maori and the Pasifika populations, thus, conveying consistency among completed studies.

### **Diagnosis and Resolution**

For a father, the resolution of diagnosis involves coming to terms and acknowledging the ASD diagnosis for what it is and the implications that comes with it. A diagnosis of any health disorder, specifically autism, is a traumatic and distressing event in a parent's life. The process of a father (or mother) coming to terms with their child's ASD diagnosis, along with the acceptance and the feeling of resolution with a show of respect, can be discouraging and an overwhelming challenge. A parent's acceptance and resolution of their child's ASD diagnosis begins when the parents core representations of the child, and of the self as a parent before receiving the diagnosis, are conducted through, and shared with post-diagnostic core representations of the self and the child (Milshtein et al., 2010).

According to Pianta and Marvin (1992a), parents who have achieved resolution with respect to their child's diagnosis generally acknowledge the hardships associated with receiving the diagnosis along with understanding and recognising the positive changes in their feelings in response to the diagnosis over time. Participants from Pianta's study described their initial reactions as heart-breaking, numb, and lost. However, after the establishment of acceptance, participants described positive feelings such as living a purposeful life with a greater sense of gratitude. Moreover, parents who are unresolved with respect to their child's diagnosis usually convey cognitive biases concerning their child's capabilities and struggles (Milshtein et al., 2010). Common feelings parents experience with the diagnosis are uncertainty, disbelief, and fear of the unknown (Lilley, 2011; Lutz, et al., 2012; Mulligan et al., 2012; Taylor & Warren, 2012). The level of the negative experiences parents may encounter is influenced by diagnostic and environmental factors, and consist of social assistance, symptom severity, and other additional demands (Stuart & McGrew, 2009).

The Reaction to Diagnosis Interview (RDI) initiated by Pianta and Marvin (1992) is a 15-minute open-ended parent interview established to gain an insight on the reactions, feelings, and experiences towards their child's diagnosis. During the RDI parents were asked to recall the time when they started noticing abnormalities in their child's development ("When did you first recognise your child's developmental abnormalities?"); how they felt at the time, and if their emotions have changed since discovering their child's diagnosis. The parents are also questioned about their experience when

receiving the diagnosis and if they had any thoughts about what may have caused their child's disorder.

A model established by Taylor and Warren (2011) focuses on recognising what, when and how to communicate a diagnosis of autism. This study was a retrospective study which reported that three-quarters of mothers (78.7%) supplied retrospective details of clinically depressive symptoms within the week after their child's ASD diagnosis, along with 37.3% still reporting continuous significant depressive symptoms a year-and-a-half later (Taylor and Warren, 2011). The study's limitation was the sample size, as it was not culturally diverse which prevents the results being generalised to various cultural backgrounds, which then provides difficulties when attempting to generalise to the Pacific populations. Therefore, these studies possess inadequate information about depression across racial and familial backgrounds. Another limitation was the parental nature of non-maternal respondents, including fathers, and grandparents, which resulted in the analysis being limited to the data obtained from the maternal mothers. The researchers could not specify if these encounters could be relevant to the fathers' experiences.

### **Impact of Culture on ASD**

Culture is important to the Pasifika population. The family structure is where individuals begin learning and developing thought patterns and perspectives about mental health, disability, and other aspects in general. Therefore, family has a direct influence on the decisions determining ASD diagnosis and treatments (Ennis-Cole et al., 2013), thereby being influenced by the family's cultural background. Family are Pasifika children's first teachers, they learn from their family members, such as parents, grandparents, and siblings. This early learning guides the way Pacific Islanders understand, interpret and experience ASD and mental health in a family setting. Previous research (Kwok and Wong, 2000; Ilias et al., 2016) has indicated that cultural context can influence the stress parents with autistic children experience. Furthermore, parental beliefs and attitudes about ASD can be positive, for example, this is a challenge for parents to better themselves as an individual and as a parent. In the current study, you will see that the participants became a better person and even better fathers. Moreover, parental beliefs and attitudes can also be negative, a common example relating to the Pasifika mindset is, the child is defective, and the impairment must be resolved rather than accepting the child for who they are (Papadopoulos 2021). Health and sickness are considered cultural aspects due to the influence cultural groups have. Such groups can include family and religious groups, which impact and shape how we understand, experience and cope with disability (Mandell & Novak, 2005). Furthermore, regarding the Pasifika health worldview perspective, behaviours we do in terms of where we seek treatment and how we evaluate treatments are influenced by culture and traditional practices (Ministry of Health, 2020). For instance, some Samoan families still rely on traditional

healers and practices (Wai et al., 2010). The Pasifika family dynamic in terms of duty of care is respected in most Pasifika cultures, where the responsibility for the disabled or, in general terms, the sick does not only fall on the immediate family but also the extended family. This is what it is meant when the Pasifika people say “It takes a village to raise a child” the whole family (village) plays a part in the duty of care.

Culture has many different definitions, however, with relevance towards Pasifika culture, it can be defined as “traditional customs, values, belief systems, language, and other behaviours that are passed on from generation to generation within any social group” (Ennis-Cole et al., 2013). This definition can be interpreted in a way which mirrors a suggestion by Griffen, Peters, & Smith (2007), culture is what shapes familial and individual views and beliefs about disability, specifically autism spectrum disorder. When comparing Pacific culture to non-Pacific cultures or to the westernised cultural perspective on disability, a difference is apparent. For instance, the Pacific people’s views on disability will focus on the four aspects of well-being first: spiritual, physical, mental, and emotional wellbeing more than the medical and science behind the illness. Moreover, where did the disability come from and why it has affected the individual? It is seen as ‘normal’ to the Pasifika population to associate disability to many different causes and why the disability has happened. These associations are not linked to medical or scientific reasonings but associated to religious or cultural aspects (Ministry of Health, 2008). This is where the Pasifika cultural belief systems and traditions comes into action when specifying the impact culture has on general disability, specifically ASD.

Qualitative data has indicated that ASD in Pasifika communities may not be accepted as ASD, but rather looked upon and accepted as ‘different’. Therefore, the likeliness of seeking help from medical professionals and support services are low and are not considered a priority (Ministries of Health and Education, 2016). This results in families developing the perceptions that their child with ASD will ‘grow out of it’ and they are just ‘naughty’, perpetuating a cultural mindset that has developed through the cultural aspect towards ASD and potentially mental health in general.

### **Effects of Stigma towards Pasifika Mental Health**

Compared to non-Pacific people, Pacific islanders rarely seek professional medical treatment for mental health for reasons that are not widely understood (Kokaua, Schaaf, Wells, & Foliaki, 2009). This is often demonstrated by a comparison between Pacific Islanders and non-Pacific Islanders, where there is an increase in self-reported levels of psychological distress and a decrease in self-reported use of mental health facilities. Stigma towards individuals with mental disabilities has been associated with adverse psychosocial and psychological outcomes (Link and Stuart, 2017). Examples of psychosocial and psychological outcomes are decreased educational success, unemployment, poor mental health, and a decrease in self-esteem.



Stigma towards Pacific islanders with mental illness reflect the prejudicial beliefs, behaviours and emotions of the public which cause discrimination against them, and socially disadvantages and devalues them (Subica et al., 2019). Stigma is connected to disability within the Pasifika culture. Therefore, the presence of mental disability is considered as bringing 'shame' to the family. Bringing 'shame' to the family has also been highlighted in a study published by Samu & Suaalii-Sauni (2009), which indicated that stigma around Pasifika mental health is deprecating and shaming for the affected individuals. Fa'alogo-Lilo and Cartwright (2021) highlighted that all support services and Pasifika consumers expressed experiencing a sense of shame and anxiety along with their families when accessing services, thus creating a significant barrier.

Participants from a qualitative study conducted by Agnew et al. (2004) suggested that whether being a family member or service worker, destigmatisation was recognised as something that needs to start at home. Therefore, reinforcing that the mental illness stigma among the Pasifika people is a significant barrier in seeking professional assistance, and families teaching their family members to practice the 'Like minds like mine' destigmatised message is important. The destigmatise motto enables parents to become a role model to their children, which will normalise and decrease the stigma around Pasifika families and their view on mental health. 'Like minds like mine' demonstrates that individuals with mental illness are just as 'normal' as other individuals.

### **Parental stress and coping**

Parents of children with autism often face challenges and stressors which result in parents becoming more vulnerable to high levels of stress, anger, and depression (Benson & Karlof, 2009). Therefore, it is important for parents to develop coping strategies or mechanisms to learn the best methods of dealing with the ongoing stressors, and to care for oneself as it is just as important to care for their child. If the parents are not keeping themselves in a good healthy state, this will follow through with the children. Relevantly, the persistent stress, fatigue and worry may result in parents needing therapy (Rivard et al., 2014).

Findings from Goedeke et al. (2019) indicated that partner support was correlated with lowered stress levels. Parental supports include both formal (e.g., therapists, doctors and other professional healthcare services) and informal (e.g., family and friends) support sources when caring for a child with autism (King and Rosenbaum, 1999; Hastings, 1997).

Parent participants from a study conducted by Lai et al. (2015) reported experiencing more parenting stress symptoms (i.e., experiences with challenging child behaviours and low parental self-views), more depressive symptoms, and reverting to frequent use of active avoidance as a coping mechanism, compared to parents without autistic children. This was also shown in an earlier study by Hayes and

Watson (2012) where they also suggested parents experience higher symptoms of stress when caring for an autistic child. This further demonstrates an experience normality for parents to experience more symptoms of stress. Parents utilise a variety of coping mechanisms when facing parenting stress, and parents of ASD children engage in adaptive (looking for social support) and maladaptive (disengagement and avoidance) methods of coping, with a higher tendency towards adaptive coping strategies (Lai and Oei, 2014). Further, adaptive coping strategies were correlated with positive psychological health outcomes (Benson, 2010; Penley et al., 2002). Therefore, it can then be anticipated that parents of children with ASD utilising adaptive coping strategies will better adapt to the stress and challenges presented when caring for autistic children. In terms of maladaptive coping strategies, parent participants from previous studies endorsed more regular use of maladaptive strategies compared to parents with non-autistic children (Montes and Halterman, 2007; Piazza, 2014). However, findings on parenting stress and coping continues to be inconclusive and requires more exploration.

Although there has been an indication of support provided by healthcare professionals and family, Goedeke et al. (2019) suggested in their research that there is a difference between formal and informal support. Their results highlighted that parents of an autistic child felt most supported by their family and partners rather than healthcare professionals or friends. Relating these findings from previous studies to Pasifika people, it is highly likely that Pasifika people feel the same as Goedeke et al., (2019) participants due to having a holistic culture, where family are always involved in support and aiding care for family members. In terms of professional healthcare support, Goedeke et al. (2019) suggested that formal sources of support were not believed to be a primary source of support due to inadequate access. Indeed, Ataera-Minster and Trowland (2018) further argued that mental health within the Pasifika population have what seems to be almost automatic barriers in accessing any formal support services. However, Fa'alogo-Lilo and Cartwright (2021) also argued that Pasifika people experience shame and fear when seeking professional healthcare, which causes a significant barrier to access services, further supporting Goedeke et al (2019) suggestions as formal sources of support not being a primary support source but being a secondary source.

There were four reliable coping dimensions identified by a factor analysis conducted by Hastings et al., (2005) which was used to identify the structure of parental coping in parents of ASD children: problem-focused coping, active avoidance coping, positive coping, and religious/denial coping. Problem-focused and active avoidance coping correspond closely to the category of emotional and problem-focused which are used more generally in stress research. The positive and religious/denial coping were seen as more specific to distinctive situations which is associated with parents with ASD children (Benson, 2010).

The avoidance coping analysis manifested a gender difference, where mothers reported they engaged in active avoidance coping more frequently compared to fathers. However, the analysis of problem-focused coping not only conveyed an effect on gender, but also an effect on the child age group. This was due to mothers indicating they engaged in more problem-focused coping strategies than fathers and the effects of age was due to parents highlighting the use of problem-focused coping for more school-age children (Hastings et al., 2005). Vernhet et al. (2018) argued that problem-focused coping was correlated with parental quality of life, which further suggested that parents who engaged in this coping mechanism were seen to have a better relationship with their child and felt more 'fulfilled. In contrast emotion-focused coping (avoidance) was associated with a decrease in parents' quality of life (Dardas & Ahmad, 2015).

Hastings and colleges (2005) suggested that active avoidance coping was associated with an increase of anxiety, stress, depressive symptoms, and mental health issues for both mothers and fathers. Such findings have been similarly identified in previous studies, highlighting that active-avoidance coping is maladaptive and can be a worsening coping strategy when trying to meet the challenges and stressors of raising a child with ASD (Hastings et al., 2005; Paynter et al., 2013; Pepperell et al., 2018). Parents are more at risk in engaging in active avoidance coping strategies not only when they are stressed, but when they are also feeling unsupported.

Moreover, religious or denial coping strategies were associated with maternal depression, and both anxiety and depression in fathers. However, Benson (2010) argues that religious/denial coping strategies affect parents negatively and passively. For instance, Ekas et al. (2009) reported that religious beliefs and spirituality are correlated with improved parental mental health and increasing involvement in religious activities was associated with a decreased sense of stress. However, both mothers and fathers who reported using positive coping strategies were associated with lower levels of depression (Hastings et al., 2005). There has been published literature showing evidence that the use of positive coping strategies and positive reframing of stressful events may be the most effective coping strategy (Hastings et al., 2005). For instance, Folkman (1997) found positive coping strategies to be most effective when helping clients with AIDS adapt by reframing their mindset and thinking more positively. Furthermore, Affleck and Tennen (1996) conducted a study where they found that positive coping was strongly associated with heart surgery recovery. Evidence conveying the effectiveness of positive coping strategies may therefore be beneficial for parents of children with ASD, as the parents can positively reframe stressful situations which has shown in the literature to increase positivity and decrease stress and depressive symptoms.

### **Gender Differences in Caregiving Burden and Coping**

The published literature emphasises gender differences between the parenting stress experienced by fathers and mothers. Fayerberg (2011) suggested that both parents of autistic children report worry and depression, and further experience higher levels than parents without autistic children. Nevertheless, evidence has shown to be inconclusive in terms of gender differences in anxiety levels. Gender differences in caring for children with autism has shown fathers to be more actively involved in the early years (Goedeke et al., 2019). Relevantly, Pepperell et al. (2018) suggested mothers of autistic children carry most of the parenting responsibility in traditional gender-based parenting roles. Relevantly, Rivard et al. (2014) indicated that larger studies with more father participants compared to mother participants, or when samples of both fathers and mothers are equal, are associated with reports of father stress levels being higher than mothers. Whereas, in comparison to mothers conveying greater levels of stress, prior research has suggested the cause being due to the traditional greater burden of parenting (Hastings et al., 2005).

A comparison between mothers and fathers regarding the emotional experiences of being a parent of an autistic child differ in some ways. For example, Gray (2003) indicated that mothers tend to describe their experiences as a sadness. Contrastingly, fathers of children with ASD highlighted experiencing more anger than sadness, frequently attempting to suppress their negative emotions rather than voicing them (Gray, 2003). Although this is consistent with Thoits (1995) research on gender and coping, burying these frustrations and negative emotions from family and friends or other social networks, or staying away from formal support services as highlighted by fathers in Burrell et al. (2017) study, can become an obstacle through the journey of acceptance, and can result in a more difficult and longer journey than needed.

## **Pasifika Fathers and Autism Spectrum Disorders**

### **Absence of Fathers in Autism Caregiving Literature**

The absence of parental agreement may not be disclosed as a foundation of stress if fathers do not participate in research as much as mothers (Johnson, & Simpson, 2013). Therefore, the absence of fathers in ASD studies is a loss of opportunity to distinguish sources of support and document stress. Although there is a small number of studies involving fathers within the autism literature, there is a need for more recognition for fathers, as they are generally absent in the ASD literature.

The recruitment process in ASD-related parent research generally has difficulties recruiting fathers and therefore the majority represent mothers (Johnson, & Simpson, 2013; Mulligan et al., 2012), thereby, conveying a limitation in the literature resulting in non-equal samples representing a generalised limitation of results and the extent where a comparison of genders can be completed (Rivard et al., 2014). Furthermore, fathers' perspectives are generally not represented in the literature, whereas

mothers' perspectives are frequently represented due to higher samples of mothers. This prevents the analysis of paternal data due to low father sample sizes, therefore, conveying a gap in the literature based on the ramifications of interpretations of mother-only data.

Recruitment struggles are usually the main reason why males are absent in research. This is generally justified because males are considered emotionally less sensitive than females, causing hesitation to participate in emotionally difficult studies (Affleck et al., 2012). The emotionally less expressive male is deemed a Pasifika cultural 'norm' as it is difficult for males to express their feelings due to the ideological position that Pasifika males should be strong and being emotionally inexpressive is taught from a young age (Nam et al., 2010). Masculinity is described as the 'ideal' which society deems as an appropriate male. This is important when exploring fathers due to results indicating that males are socially patterned on other's perceived expectations (Maurer & Pleck, 2006).

### **Rationale for Study**

Fathers with autistic children parenting experiences are frequently unnoticed in research. The literature conveys a strong bias focus towards mother experiences. However, when both parents are present in a study, the fathers are overwhelmingly underrepresented. The phrase 'parental experience' is regularly used to explain results which are mainly from mother population. Therefore, many models were established using mothers. Nevertheless, these models have later been applied to father experiences with no strong evidence that the models sufficiently represent the reality of fathers.

Limitations in applying worldwide literature to New Zealand suggest that the establishment of a New Zealand based body of research is essential, which is also suggested by the New Zealand autism guidelines (2008). Moreover, Jorgensen et al., (2010) further mentioned that the research based in New Zealand concerning the broader approach of caregiving has faced an unmet support need which has been conveyed by several carers discussing their experiences. The establishment of the Mahi Aroha (New Zealand) carers strategy action plan addresses the wide range of carers which also affect Pasifika fathers caring for children with ASD in the community. An important aspect in this action plan, which is held most valuable to Pasifika people, is the inclusion of family and implementing an aiga-centred approach. Due to Pasifika fathers being overwhelmingly underrepresented in research and support services, this action plan provides more support and includes Pasifika fathers in the scope of the plan. The carers strategy action plan (2019-2023) aims to create a fund to research the needs of carers which include more research on Māori and Pasifika carers, which will include Pasifika fathers. Therefore, it is appropriate to focus on obtaining an understanding of Pasifika fathers' experiences who care for a child with ASD.

This research will focus on the experiences of Pasifika fathers' caring for a child with ASD in New Zealand. A qualitative methodology was applied in this research to gain an in-depth understanding of the Pasifika fathers lived experiences. Interpretative phenomenological analysis was utilised to evaluate in-depth interviews as this method allows participants to articulate and share their parenting experiences that are deemed significant and relevant (Smith et al., 2009; Papadopoulos, 2021). The idiographic purpose of the approach is centred on analysing on a step-to-step basis rather than using a general approach to improve research generalisability. Therefore, if culturally diverse participants participate in the research, the idiographic nature of the interpretative phenomenological methodology allows the inclusion of significant cultural discussion, without the need for larger sample sizes. This research explored parenting experiences through both positive and negative experiences and establishes a stronger understanding of Pasifika father's role with autistic children in New Zealand.

### **Methodology**

The methodological approach used in this study is interpretative phenomenological analysis (IPA). The qualitative approach is more suited for this research compared to quantitative as it focuses on the lived experiences of Pasifika fathers. Qualitative research is the process of gathering, analysing, and interpreting non-numerical information (Silverman 2021). Relevantly, this research utilises a qualitative approach because the researcher focuses on Pasifika fathers in their everyday environment and attempts to make sense of their experiences of caring for their child with ASD.

Interpretative phenomenological analysis does not require a large sample size unlike qualitative descriptive methods (Smith et al., 2009). Moreover, Smith and Osborn (2007) suggested identical participant samples are uncommon when analysing experience and psychological phenomenon, resulting in an idiographic approach being more appropriate. The phenomenological approach focuses on the individual's perspective on life experiences and attempts to identify and make sense of their personal experiences related to their personal perceptions of situations or events, rather than trying to create objective reports of the situations itself (Smith & Osborn, 2007). Thereby, the researcher attempts to understand the participants' point of views.

### **Reflexivity**

Reflexivity is an integral part of ensuring the transparency and quality of qualitative research (Korstjens, & Moser, 2018). Therefore, as a psychology student conducting qualitative research, it is essential to recognise the importance of establishing a sense of self-awareness and to be reflective of my role as the researcher during the process of collecting, analysing, and interpreting the data (Korstjens & Moser, 2018). Furthermore, being self-aware in the pre-conceived assumptions brought

to the research. Thereby, the interviews, focus groups discussions, observations, and all analytical data requires to be supplemented with reflexive notes. Furthermore, correlating to research McNarry et al., (2019) which was supported by previous literature Hess-Biber & Piatelli (2012); & Buscatto (2021) where they suggested reflexivity being considered as a holistic process which is validated across all process stages in research, varying from problem formulation, through management of the research process and the relationship between both researcher and participant, to data analysis and writing. The reflexive observation incorporates appreciation of the external ability surrounding research, and the internal shifts towards the researcher.

The nature of the psychological phenomena and psychology emphasises the use of the qualitative methodology as it provides an understanding of experiences. The epistemological and methodological assumptions of IPA distinguish the participant's relationship being intersubjective which requires a level of researcher reflexivity (Grant & Giddings, 2002). The use of IPA corresponds with my position as a researcher which is educated by my interests in the experiences of individuals and evidence-based methods. Whilst conducting interviews, I was mindful of my personal and professional experiences not to affect the interviews. This was supported by using a semi-structure interview approach as it provided a sense of direction while still being flexible. Therefore, allowing relevant information disclosed by Pasifika fathers' to be understood, rather than receiving information that is not relevant to the research but relevant to my personal interests.

### **Ethical Considerations**

The ethical application (reference number 21/210) for this study was approved by the AUT University Ethics Committee on the 29<sup>th</sup> of July 2021 for three years until 29<sup>th</sup> July 2024 (See Appendix A).

Informed consent was attained from all participants (See Appendix B). The basis of this study indicates that confidentiality could not be certain due to the methodology consisting of face-to-face interviews, nevertheless, anonymity was guaranteed. This was supported through the use of pseudonyms for each participant, along with deleting other information that can be used to identify participants from the transcripts. Relevantly, Smith et al., (2009) suggested that the nature of anonymity contrasted with confidentiality and the possible research outputs, involving direct quotes, were discussed with participants. Recordings and transcripts were only viewed by the researcher and were made available to participants if requested. The researcher's supervisor was aware of identifying data in the collection of informed consent forms as he also had access to the interview recordings. Following the analysis, the transcripts were transferred to a memory stick to be kept with the informed consent forms in a secured cabinet in the supervisor's office at AUT university. The data gathered from this study will be kept for six years before being disposed.

The aspect of participant safety and prevention of harm underlies all research. Although uncommon in qualitative research, Smith et al., (2009) highlighted the importance of accepting that talking about sensitive information can cause participants to feel embarrassed, emotionally distressed, and irritated. Participants expressing their experiences and well-being of caring for a child with ASD poses a risk of vulnerability, specifically when expressing challenging and personal aspects. Utilising a qualitative methodology allows participants to control the amount of information they disclose, therefore, decreasing the risk of feeling unprotected through over disclosure. Participant safety was also achieved by reassuring participants they had control and could withdraw or pause the interview at any time and would not be disadvantaged in any way, and their information shared would be disposed.

The rich qualitative research results will be summarised and will contribute to the Pacific Autism Support Group (PASG) and the Tongan Autism Support Group (TASG) organisations and to wider case workers helping Pasifika fathers care for children with ASD. Participants had a choice whether to receive a summary of the research findings which was explained in the informed consent documents. The final research report will be made available to all participants, PASG and TASG.

If this study had focused on Māori fathers' experiences, the Treaty of Waitangi principles would need to be upheld, participation, partnership, and protection. Furthermore, the New Zealand Health Research Council guidelines for Māori research ethics, Te Ara Tika is a regulatory document that is used to ensure the Treaty of Waitangi principles are maintained throughout the study (Hudson, Smith, Milne, Reynolds, & Russell, 2010). When interviewing Māori participants, it would be respectful to provide them the option of opening with a karakia (prayer) or a pepeha (traditional introduction). However, it is important to keep in mind that not all Māori participants will have a strong cultural side for potential reason being brought up in a westernised worldview. These processes were not done as this study did not consist of Māori participants.

## **Participant Recruitment**

Participants were recruited through autism support organisations in New Zealand including the PASG, TASG and Autism New Zealand. These autism organisations provide support services and information to parents with children with ASD. An advertisement was created and shared with these organisations, which they shared on their social media accounts for their members to view.

Interested participants gave their contact details to the staff working for the autism organisations to pass on to the researcher to contact them directly. Fathers that were interested were contacted via mobile phone and email by the researcher and were informed about the study, the interview process, and were given the opportunity to express any concerns about the study. The participants were then emailed the interview protocols to ensure they were comfortable with the type of questions that would



be asked, thus, providing another opportunity for questions (See Appendix C). The interview dates and times were scheduled to suit the participants.

The selection criteria requested participants to be a Pasifika father of a child with ASD and must be a New Zealand resident residing in New Zealand. A total of five Pasifika fathers were successfully recruited to partake in this study and were all interviewed via zoom due to COVID-19 level restrictions.

## **Data Collection**

Semi-structured interviews were conducted as they were the most appropriate interview method to ensure in-depth and detailed information. Semi-structured interviews are commonly used in qualitative studies due to the flexibility in both questioning and the direction of the interview, whilst keeping the focus of the structure relevant to ensure adequate information answers the aims of the study (Cohen & Crabtree, 2006). Interviews were conducted accordingly to the overall principles developed by Smith and Osborn (2008).

Setting the interview like a normal conversation and building rapport with Pasifika participants was important as it is challenging for Pasifika fathers to openly express their personal experiences to a stranger. An interview schedule was used to ensure all research questions would be covered. However, the question order was slightly adjusted accordingly to the participants' responses. The research questions were open-ended questions to encourage participants to openly express their experiences. This participant-led interview method corresponds to the phenomenological epistemologies which ensures their experiences emerge in the study.

The interview schedule consisted of initial questions which then followed by relevant supplementary questions depending on the participant's responses (See Appendix D). The interview protocol was constructed to produce in-depth fathers' perspectives (e.g., feelings, thoughts, and experiences) through the development of the child's disability in past and present. Developing rapport is an important component when conducting in-depth interviews. Building rapport establishes a safe and comfortable interview atmosphere for the participants to openly express their experiences and attitudes (DiCicco-Bloom, & Crabtree, 2006). Hence why at the beginning of the interview the researcher spent time focusing on the participant, trying to build a connection, and professionally joking around. Then as the interview proceeded, rapport was further developed before asking more emotional sensitive questions, unless unexpectedly covered by the participant. The first few interview questions started off broad, "How do you feel about your role as a father?" and "What does your average day look like?" then it worked into asking more sensitive questions. An example from the interview questions, "How did you feel when you learnt your child had ASD?"

Interviews were meant to be conducted face-to-face at AUT South Campus. However, due to COVID-19 the interviews could not proceed, resulting in using online applications (e.g., zoom). To ensure the accuracy and quality of the data, with participant consent, the interviews were an hour long and audio recorded and transcribed by the researcher.

## **Method of Analysis**

Interpretative phenomenological analysis was used to analyse the interview transcripts to provide the participants with “a voice” to express their important life experiences. The aim of IPA is to comprehensively understand the underlying and masked information. The narrative of the interview was created by both participant and researcher. This was conveyed through the researcher’s interpretation of the interview. Moreover, the importance of the participants and the idiographic nature of IPA dictates that all cases are analysed in detail; thus, each transcript is carefully and comprehensively analysed prior to focusing on the whole dataset. The analysis can be explained in different ways with different steps. Smith et al. (2009) and Smith and Osborn (2007) mentioned that the analysis process emphasises how reflective and repetitive the IPA process is, along with the possibility of change. The IPA process is described with six different steps highlighted by Smith et al. (2009); Braun & Clark (2017), and was utilised as a guide during the analysis process:

### **Step 1: Multiple reading and familiarising**

The initial step consists of numerous close re-readings of the transcripts, along with listening to the audio recording if available. Positively resulting in a possibility of new themes or insights developing. This helps researchers engage and be more present in the data and remember the ambience during the interview.

### **Step 2: Initial noting**

This step and the initial note taking step is usually combined, where the researcher notes down their reflections and their observations about their experience during the interviews, or any statements or thoughts that may hypothetically be of importance. For example, the researchers focusing on what the participant is describing, the choice of words, and the initial explanatory statements.

### **Step 3: Creating Emergent Themes**

During this stage, it is recommended for the researcher to be working more with their notes rather than the transcripts. This stage is where reflections of the source material is commenced. The relationships, interrelationships, and patterns are put in order to decrease the data volume, whilst sustaining complexity. Each theme has a phrase created and included into the table describing the initial transcripts in conjunction with the explanatory reports.

#### **Step 4: Searching for Relationships Across Themes**

This stage involves searching for relationships between themes, rearranging them together accordingly to conceptual similarities, and giving each cluster a descriptive label. The most relevant themes to the research question will be included which will provide a thematic structure of the most significant and exciting factors of the account.

#### **Step 5: Proceed to Next Case**

The 'uniqueness' nature of IPA implies that stages one-four is organised for every case individually. Before moving onto the next case, this stage includes grouping prior case analyses.

#### **Step 6: Identify Patterns Across Cases**

This final stage consists of focusing on each case's thematic tables via evaluating notes. There are possibilities of relabelling themes to better suit the research. The final themes table will establish the themes being both relevant to each case and those that can relate to broader theories.

### **Quality and Credibility**

It is important that the research process is validated through reliability and competency. Research measures used to determine the reliability and validity in quantitative research are inappropriate when applied to qualitative research (Noble, & Smith, 2015). Instead, qualitative research utilises credibility, transferability, dependability, and confirmability (Morrow, 2005).

Credibility can be accomplished by persistent engagement with participants, prolonged observation in the field, and the use of peer researchers (Morrow, 2005). Credibility is where the researcher has reliably represented the data, considering the data's internal consistency along with the analysis and interpretation accuracy (Morrow, 2005). This is essential in qualitative methodologies and particularly in IPA, as the researchers are part of the study and therefore it is necessary for them to submerge themselves in the dataset as part of the analytical procedure (Smith et al., 2009). This encourages the need for research reflexivity, in which it is essential for researchers to reflect on current knowledge, preferences, personal assumptions, and backgrounds they incorporate as a researcher.

Transferability implies that the readers can generalise the research results to their own context outside of the study (Morrow, 2005). This varies from the generalisability aspect in quantitative research, and the ability for results to be generalised to larger population sizes, a rare attribute in qualitative research methodologies due to small sample sizes. Transferability can be explained through contextualising results as they correlate to broader literature and context (Morrow, 2005). Korstjens &

Moser (2018) highlighted that the researchers facilitate transferability judgements through thick descriptions.

Dependability refers to the constancy of findings over time. Dependability includes participant's evaluations of the results, interpretation, and study suggestions such that all are established by the data as received from participants of the study (Korstjens, & Moser, 2018). Dependability incorporates consistency, in which the research ensures the analysis process is in line with the expected standards for a certain design (Morrow, 2005; Korstjens, & Moser, 2018). Therefore, the process which the research findings obtained should be clear and repeatable as much as possible. Dependability is achieved by thoroughly tracking the developing study design and through keeping an audit trail, furthermore, a comprehensive chronology of research activities and processes, the effects on the data and analysis, evolving themes, and analytic 'memos' (Morrow, 2005). Moreover, a step-by-step description on how the study was established, conducted, and examined is required.

Confirmability refers to the extent which the research findings can be confirmed by other academic researchers, Thereby, it is involved with determining that the data and interpretations of the findings are not based on personal viewpoints and preferences, but are evidently grounded in the data (Korstjens, & Moser, 2018). IPA recognises that researchers can not completely be objective, however, through the reflexive processes the researcher has the ability to ensure that the analytic interpretations remain close with the research data (Smith et al., 2009).

## **Findings**

This section will focus on describing the discoveries among the five interpretative phenomenological analysis interview transcripts and displaying participant demographic information, followed by a summary of the themes categorised in superordinate, emergent and subordinate themes, with established quotes and descriptions to support.

## **Participants**

All Pasifika father participants in this research has one or two children with ASD. The fathers' ages ranged from 29-48 years. Most stated they were married, living with their wives and children, with full-time employment. One participant was a solo father, and two participants were full-time stay at home fathers. Participant demographic details conveyed in Table 1.

**Table 1***Participant demographic information*

<b>Father's details</b>		<b>Children details</b>	
<b>Pseudonym</b>	<b>Age</b>	<b>Child age</b>	<b>Age of diagnostic</b>
Mose	48	6 & 4	3 & 2
Junior	46	12	2
Hala	29	5	2
Tolu	34	7	4
Kiuga	42	9	3

**Summary of Findings**

This part of this section will explore the extracted themes from the data analysis. In the interviews, participants were encouraged to discuss their parenting experiences with their autistic child and their role as a Pasifika father. The interview questions focused on support, coping, and parenting responsibility (See Appendix D). The semi-structured interview approach encouraged participants to share more significant information about their experiences, which included, experiences with support systems, comparisons, and emotions. The established themes are highlighted in Table 2.

**Table 2***Established superordinate, emergent, and subordinate themes*

<b>Superordinate themes</b>	<b>Emergent themes</b>	<b>Subordinate themes</b>
Support.	1. Support experience.  2. Support for Pasifika fathers.	1A. Family support.  1B. Professional support  1C. Financial support.
Coping mechanisms.	3. Getting educated and aware.	3A. Reaction to diagnosis.

	<p>4. Pasifika cultural norms.</p> <p>5. Maintaining organised daily routines.</p>	
Emotional aspects of parenting experiences.	<p>6. Positive emotions.</p> <p>7. Negative emotions.</p>	

The subordinate theme ‘support’ incorporates two emergent themes, support experience and support for Pasifika fathers, followed by three subordinate themes linked to support experiences: family, professional, and financial support. The next superordinate theme is coping mechanism which incorporates three emergent themes: getting educated and aware, Pasifika cultural norms, and daily routine and planning, followed by one subordinate theme, reaction to diagnosis. The final superordinate theme, emotional aspects of parenting experiences incorporate two emergent themes: positive and negative emotions.

### **Superordinate Theme One: Support**

This theme consists of participant discussions of support. This was a strong focal point during the interviews and was incorporated in the semi-structured interview schedule. This part will consist of receiving support from family, professionals, and educational systems, along with support for Pasifika fathers and systemic limitations.

### **Emergent Theme One: Experiences of support**

Participants stated both positive and negative experiences of receiving support and acknowledged the type of support that is available. The participants highlighted their experiences of receiving support was mostly positive from family, professionals, and financial support. However, a few participants conveyed perceived insufficiencies within the system and family support.

### **Subtheme 1A: Family Support**

Participants discussed their thoughts on the quote, “it takes a village to raise a child” and all stated they believe in it and have personally experienced it through their own and their children’s upbringing. They had highlighted that they were not the only ones raising their children, but always had the help from their parents, siblings, and extended family. The aspect of family can be portrayed differently in the Pasifika culture compared to westernised cultures. Family can be described as church, family, and friends who become family and a part of the ‘village’.

*Junior: “I believe it first-hand, it happened to me. Not so much family because they were split between different countries. But church was my village growing up. Now we’re active in the church helping raise other kids, as well as they are helping us. Both our parents are on the same page, they’re just full on supporting us.”*

Participants who conveyed more sibling and parent support highlighted it being beneficial for both parent and their children. They provided an extra assistance when needed.

*Hala: “Absolutely believe it. My household helps me look after him. My family would look after him while I go for a run or if I’m a bit slow getting up in the morning, they’d make his breakfast and get him ready. I feel like if I didn’t have my family support, I would breakdown a lot more.”*

Another participant mentioned:

*Kiuga: “Our in-laws help out a lot, they take care of our daughter when we need to go somewhere or when we need a break.”*

Participants who had more access to friend’s support conveyed that their friends became their family due to moving away to a different city, and therefore their friends assist in caring for their children. This gives the participant more time to organise the other children and have more time to do important tasks.

*Kiuga: “I believe it, the village always helps us. Our friends down the road help us, we drop our daughter off to their house in the mornings before school because their daughter is the same year and in the same class, and they drop them off at the same time.”*

However, from the examples above, all participants stated they had support from each family orientated aspect. Despite believing in the ‘village’ support, one participant explained a lack of ‘village’ support from their families. He portrayed this to be due to a lack of knowledge around ASD, resulting in decreasing support. However, he does try and educate his family about ASD.

*Mose: “I try show my family and friends who don’t have the village mentality with my kids, that I’m there for them and I don’t need an invitation to go and be a part of their lives. People have to be committed to the village mindset.”*

These references indicate there is a strong source of family support in Pasifika families consisting of mostly positive experiences and outcomes. Although one participant does not receive much family support, there is still a positive outcome as he tries to educate his family about ASD and what the right ‘village’ mentality is. The next subordinate theme focuses on professional support.

### **Subtheme 1B: Professional Support**

The participants conveyed they had received professional support from teacher aids, education support workers, psychologists, ministry of education, and others. The professional support received was considered positively by participants. Participants positively commented on their experiences with the Ministry of Education (MOE) support, from getting participants started with funding, to developing solutions for their children, and setting out a development plan with desired goals for each term.

*Mose: “The support from the ministry has worked well for us. The early childhood education (ECE) has helped get the ball rolling by getting the MOE involved and has helped start the process of getting the ORS funding. So, we were lucky.”*

*Tolu: “My son had bad behavioural issues in school and the school didn’t know how to help him in class, so we had received help from MOE. After talking with MOE and staff we were going back and forth trying to mediate a solution. Then within a year, my son was sitting down and had good behaviour.”*

*Junior: “Someone from the MOE helps us put a plan together. There’s quarterly visits to put together a plan for the next term, which plans out what we want to focus on with Losalia’s functionality. For example, focusing on toilet training, motor skills, and learning techniques.”*

Most participants discussed having teacher aid support for their kids, which has positively impacted not only the child but the parents too. Having teacher aid support benefitted both parents as they both work and the wife works shift hours.

*Mose: “Through organisation explorer, we were able to get a teacher aid/education support worker for a few hours after school and after hours, Fridays and Saturday morning. Having this extra support also helps my wife and I, due to my days being long and gives my wife time to get that extra rest and to get into things.”*

In terms of obtaining psychiatrist support, participants expressed the positive impact it has had on them and the development of their child. The support from the psychiatrist was conveyed as hugely significant following the diagnosis.

*Hala: “My son’s psychiatrist has helped us out a lot. She was the one that organised his applications for schools, support, and other government support we were entitled to. She made things a lot easier for me. I didn’t know much on what we were entitled to and what we could apply for.”*



When participants expressed negative experiences of professional support, they also expressed that the support is good, but it can be difficult in accessing it. Tolu discussed his experiences.

*Tolu: "When Devin [son] started school, he was analysed by professional stuff, and they said he needs a teacher aid. It's a hit and miss getting professional support. Depending on the severity of your child determines what support they can get. For example, my son is not far down the spectrum which means he will only be eligible for a teacher aid for three to four hours a day, despite needing more support for his development. Even though stuff see him making progress, they're like there's no need to continue this funding, which affects his development."*

These quotes conveyed the significance of receiving professional support which positively impacted their children's development. However, it also conveys what other Pasifika fathers can negatively experience. The next subtheme addresses financial support.

### **Subtheme 1C: Financial support**

Participants discussed financial support they had received from governmental organisations which ensured the children would get the necessary resources and support. All participants stated their experiences being positively beneficial. The financial support received included organisation trust funds and a subsidy from the government. Ryan's comment about receiving financial support demonstrated positive views.

*Ryan: "We are very lucky on financial support because when I left my job to become a fulltime solo parent, I went through work and income for support and it covers what he needs, food, clothes, and entertainment gadgets. So, we are fairly looked after in that regard."*

A participant conveyed that the financial support they were receiving was helping them invest in their daughter in other ways to help her communication skills and help her build confidence.

*Junior: "We get financial support from the government via Taikura trust and provided to us from enlivened Presbyterian church trust. They work hand in hand to give us funding to sort of help my child get extra things like speech therapy, swimming lessons, or other developmental skills she needs to improve, which is great support."*

Receiving financial support also included government subsidies.

*Kiuga: "We had to navigate the system and connect with others in support groups to receive financial assistance. For example, we receive \$90.00 a week to cover after school care, without that extra support, we would not be able to afford after school care every week. So, we are supported well financially by the government and organisations."*

Some participants did convey the limited amount of funding support that was available and the difficulties of receiving support. Although there was limited funding support, all participants still received some sort of financial assistance.

*Mose: “There’s not a lot of funding support, we’ve just started to tap into the funding support through the organisation explorer to get funding for Respite care, which will provide extra learning support for my child.”*

*Tolu: “It can be hard to receive funding support. For example, when my child started school, the staff analysed the severity of my child and said my child needed a teacher aid. Then if they see your child is making progress, they’ll reevaluate and say there’s no need to continue with funding, even though my child still needs the support.”*

Although Mose discussed a limited amount of support, he also discussed in detail what respite care provides his children. This quote also interrelates to the next theme ‘support for Pasifika fathers.’

*Mose: “We have employed a teacher aide from his school who helps with 5-6 hours of care for Polu [son], taking him out to the park, on the bus, and to playgrounds. This is massive because she [teacher aide] becomes another trusted helper for mum. We employed a former day care worker to give mum and I respite once a month if we choose to go out for 3-4 hours.”*

These quotations emphasise the importance of receiving financial support as it further supports the children’s development and a potential need for more financial support and an easier method to access extra funding. It further highlights the benefits of parents receiving respite care for their children as it not only provides extra education assistance, but also provides support for parents. The next theme focuses on the support for Pasifika fathers.

### **Emergent Theme Two: Support for Pasifika fathers.**

Participants discussed they all felt supported as a parent from support services such as PASG and TASG. From all information provided from the Pasifika fathers, their main support came from connecting to autism support groups, especially Pasifika orientated groups. The reason being was discussed by Kiuga:

*Kiuga: “I feel very supported as my wife, and I are connected to the PASG. To be honest, I’d rather go to the Pacific autism groups rather than Autism NZ groups because I feel more comfortable speaking to islanders as we have similar backgrounds and can relate more.”*

Another positive note relating to Kiuga’s comfortability statement, Mose also expressed his experiences with the support for Pasifika fathers provided from PASG which is regarded as a safe space.

*Mose: "PASG has a men's group for us to talanoa (talk) and connect. This is a big support system for us Pasifika fathers because our talanoa is different to what we have with our wives."*

Some participants have had more positive support experiences where they have received good support for their children and have received extra for themselves. The following quote from Junior demonstrates the positivity in experience.

*Junior: "The support my child gets is good as it covers her schooling and helps her development. We also get a little extra for support at home after hours and during the weekends. This support also goes towards us having a break and getting someone to look after my child during the weekends."*

Although participants expressed a range of support for their children, they also mentioned there could be more support for them as parents to ensure the children are given the best care. Therefore, with more support, the participants can always be in a more positive mindset. As previously stated by Mose that he gets support for him to have a break on Friday after school and Saturday morning, he further expresses the need for extra support when asked "In an ideal world, how much support do you think would help your child?"

*Mose: "Although we get support that allows my wife and I to take a break for a couple hours, in an ideal world, we'd appreciate getting extra Respite care two or three times during the week from 3-5pm and maybe 1-2 hours support during the weekends. This would be ideal because we don't have much support from our families."*

Moreover, some participants discussed the need for a social support worker during the school holidays due to participants working from home, and it can be difficult to complete their work whilst looking after their autistic child.

*Kiuga: "It's hard to find someone to look after my child during school holidays, so I look after my child. But because I've got work to do in the holidays, it is difficult to look after my child and work at the same time. I'd appreciate an extra helping hand. It's hard to find some support that can help in this way."*

Contrast between the amount of support available was conveyed across participants. Some had mentioned there being plenty of support for Pasifika fathers, whereas some argued against. An example was shared by Tolu.

*Tolu: "There's heaps of support and it's everywhere, it's just the matter of knowing where to look. There are Facebook groups that help such as PASG, TAG, and Autism NZ."*

These quotes revealed the different experiences Pasifika fathers and parents go through when seeking and receiving support for themselves. One common aspect among participants was that parents need to know where to look for support. The next theme focuses on systemic limitations.

### **Summary of Superordinate Theme One**

In summary, participants indicated receiving positive experiences of support from family, professionals, financial services, and support for Pasifika fathers. However, one participant had a weak family support system which could be due to their family not having adequate knowledge about ASD. The family support also came from an individual's church and friends. Although participants discussed positive experiences, some had discussed negative experiences. However, they highlighted that the positives outweighed the negatives as the support was improving their children's development. Participants expressed positivity when receiving financial support. However, participants highlighted a limited amount of financial support which may have been due to a lack of awareness and knowledge around autism support sources.

Regarding support for Pasifika fathers, participants have experienced an adequate amount of support from local support groups. These groups educated and connected participants to other families that are going through the same situation.

### **Superordinate Theme Two: Coping mechanisms**

Coping mechanisms are strategies that are utilised by participants to manage internal and external challenges when parenting their child with ASD. This superordinate theme is divided into three emergent themes; getting educated and aware, Pasifika cultural norms, and daily routine and planning.

### **Emergent Theme Three: Getting educated and aware**

All participants explained that they had little knowledge of ASD, which led to everyone getting educated and aware of ASD. Strategies included both formal and informal approaches such as attending courses, connecting with other parents, and personal readings. This was the case for Junior:

*Junior: "There were classes explaining autism which lasted a month, one hour a week. We went and there were a few other parents whose child was recently diagnosed. We got to ask questions, we received a booklet and other items explaining what autism is and what it does not mean."*

Some participants discussed that their wives would attend ASD courses and then inform the fathers. Whereas other participants attended these information courses with their wives. From these courses they highlighted they were able to learn about Autism and parenting strategies.

*Kiuga: "My wife has friends that tells us to go join this autism group and that autism group. So, my wife goes and joins these support groups and attends their courses and comes back with so much information and informs me.*

*Tolu: "We didn't know much about Autism, so we tried to upskill and develop our knowledge, we pretty much went back to school. We attended every free autism and behavioural courses which helped us learn how to manage our son's behaviour."*

Participants mentioned they connected to support services to become more educated. Pasifika Autism Support Group and TAG were the most common services they used. Through these support services, participants were able to connect to other parents with autistic children. Mose discussed his positive experiences seeking information from PASG.

*Mose: "The Pasifika autism support group is incredible; they just inform you and you can tap into their workshops and connect to other partners that are going through the same situations. It's a good place to network, to get smart quick and learn about what you can do out there."*

### **Subtheme 3A: Reaction to diagnosis**

Having limited knowledge of ASD influenced the establishment of this subordinate theme. This captures the participant's heartfelt emotional experiences when discovering their child had ASD. All participants discussed similar experiences when asked about their feelings when they learnt their child had ASD. They had also conveyed a sense of not knowing how to feel as Autism was something they had never encountered. A comment discussed by Junior describes his feelings and portrays a common insight of awareness among the participants.

*Junior: "We just broke down into tears, imagine being punched in the ears and your ears are ringing and you're nodding your head saying you get it, but you don't, but you know it's something bad. You're trying to figure it out, "Why my daughter? Who did this? Was it the vaccines? We didn't know what caused it. We didn't have much knowledge about ASD, it was a total new concept to our family."*

An example of the common emotions expressed by the participants came from Tolu.

*Tolu: "It's a hard concept to grasp. I felt numb, sad, lost, and heartbroken."*

Hala discussed a similar experience and highlighted not knowing the effects of autism.

*Hala: "I was really unfamiliar with what it was. I didn't know what to expect because it's not really exposed to our people, and I didn't realise it could affect his verbal skills."*

However, a participant with two children on the spectrum conveyed the same emotions when he discovered his second child had autism.

*Mose: "It was heart breaking. I found it hard because you have hopes and dreams for your kids, and those hopes, and dreams become near impossible. You just sort of see it go in an instant, it's just been a little bit harder."*

These quotes demonstrated participant emotional experiences when discovering their children was diagnosed with ASD. Participants expressed experiencing similar emotions and experiences. The next emergent theme focuses on Pasifika cultural norms.

#### **Emergent Theme 4: Pasifika cultural norms**

Pasifika peoples' perspectives on ASD or disability in general is looked down upon and is conveyed as abnormal. It is usually seen as a spiritual imbalance leading to Pasifika families using traditional healing practices to bring balance to the individual's spiritual well-being. Normalising ASD and other disabilities in Pacific cultures were discussed as a coping mechanism among participants, in terms of altering the way Polynesians perceive ASD in a positive light rather than the same fixed holistic perception that the child is abnormal, even though it is considered normal in the 21<sup>st</sup> century. This resulted in more positive attitudes towards autistic children and other disable individuals.

Furthermore, positively affecting the children and their parents as they will not be seen as an 'outcast' or 'weird'. Participants discussed a high need for the Pasifika culture to normalise ASD and bring more exposure of ASD and other disabilities to the Pasifika community. Participants expressed Pasifika mentality and attitudes towards ASD, along with discussing how a person with disability is viewed. Mose's comment encapsulates Pasifika people's perspectives on disability and cultural norms.

*Mose: "In our culture, disabled (additional needs) kids are not often spoken about. I don't know if it's taboo or whatever, but for example, my late mother [Respectfully] had a low tolerance for people with additional needs. Therefore, I grew up with that mentality. I don't know how she would have reacted if she saw my kids, hopefully it would have been a turning point."*

Mose's comment shows how an individual's mentality and perspective is passed on from generation to generation. Disability is often ignored and moved to the side. This has been normalised for generations, hence why it's still present in today's generations. Although Mose had a negative mentality towards disability, he now has a different perspective on disability due to having two children on the spectrum. Mose also discussed having a conversation with his minister which led to spreading awareness and taking a step to normalise ASD within the Pasifika community. Participants also expressed that Pasifika people are not getting the proper exposure needed around disability.

*Mose: "My uncle who is a minister took my wife and I aside and was in tears, "We didn't know what to do when your boy was running around and didn't know how to look after him [minister]." So, he asked us to educate our family."*

*Hala: "Disability [ASD] is not really exposed to our people, which needs more exposure because it's affecting a lot of our people."*

Participants also discussed Pasifika being a communal focused culture and the impact ASD has on the community in a sense of not wanting to be part of community activities. Tolu covered the community aspect in his comment.

*Tolu: "Culturally, everything is communal and it's hard out community and then to find out someone who doesn't like being around others and would rather be by themselves and not talk to anyone. They're [disabled individuals] seen as the outcast and weird, but that's not the case nowadays. A lot of things are changing now. Our Pasifika culture needs to adapt because a lot of these sicknesses and disabilities are affecting us."*

A common attitude Pasifika cultures have towards disability is negative, until a family member or someone familiar has a disability. Participants discussed their families changing their attitude when they were more educated about ASD, which led to greater acceptance. This was the case for Kiuga.

*Kiuga: "You know our culture, they think it's a waste being autistic [disabled] like my mum, she still says that stuff and I'm always telling her, "It's okay mum we are happy to have Selafina, it's not like she's a bad person." Now, my parents love Selafina, they're always spoiling her."*

These quotes describe how disability is perceived among the Pasifika culture. It is often overlooked and not spoken about until someone close has a disability. The next theme daily routine and planning.

### **Emergent Theme 5: Daily routine and planning**

Daily routine and planning were highlighted as an important mechanism for coping with their child and sustaining family function. All participants disclosed that daily routine and planning was important as it made their children feel less anxious and more relaxed. Moreover, participants mentioned that a strict routine was followed, but if changes needed to be made then they would need to inform their children.

An example provided by Tolu discusses planning for the following day.

*Tolu: "A lot of preparation is done the night before. We make sure his lunch; school uniform and stationery are ready. This is important because he's not a morning person, so we wake him up at the last minute, enough time for him to wash up and get dressed. This all needs to be done the night before because if we rush in the morning and are rushing him to get ready, he becomes more resistant and feels like we're yelling at him and shuts down."*

Kiuga and Mose discussed a need to follow a strict routine to decrease the chances of their children becoming emotional and anxious.

*Kiuga: “She’ll [Selafina] cry if we break routine, so every morning before school she likes to go to her friend’s house and after school she enjoys going to after school care. Sometimes, I would take Selafina straight to school which doesn’t happen anymore because she would be bawling her eyes out.”*

*Mose: “Routine is key for both kids, for example, how their toast is made, the plate it goes on, and the route I take to day-care must be the same. Likewise, to any destination they are familiar with. Any spontaneous changes must be discussed with our kids.*

Most participants discussed their wives being the main parent that gets their children ready in the mornings whilst the fathers are working. Therefore, conveying the participant’s routines mainly begin with the mothers with their children. An example was provided by Junior:

*Junior: “I work full time and so I get up early and go work and my wife works part time, so she gets herself and the kids ready. My wife drops them off to school and picks them up. Our family routine is no different to a household without an autistic child.”*

These quotes demonstrate the importance of planning and following a daily routine as it helps with the children’s anxiety levels. Moreover, the fathers’ wives were mostly in charge of the daily routine for the children due to fathers working full time. The next superordinate theme focuses on the emotional aspects of parenting experiences.

### ***Summary of Superordinate Theme 2***

Participants had insufficient knowledge of ASD which resulted in everyone attending autism courses and seeking information from other parents. Participants expressed similar reactions towards their child’s diagnosis. It was seen as a new disability that affected their child, therefore causing more intense emotional reactions. Focusing on Pasifika cultural norms, participants highlighted the normality of not speaking about disability in general and would rather ignore it and look down on the individual. Therefore, participants emphasised the need to normalise disability within the Pasifika cultures. Daily routine and planning were conveyed by participants as essential because it decreases their child’s anxiety levels. Moreover, the children were aware of the activities occurring throughout the day and nothing new would develop stress. The results of planning for the next day benefitted the child as the household were aware of what was going on.

### **Superordinate Theme 3: Emotional aspects of parenting experiences**

All participants discussed emotional aspects of their parenting experiences. They shared both positive and negative aspects of their experiences. These emotional insights provided by the participants were



shared throughout the interviews and were openly discussed without coercion from the researcher. This section will cover positive and negative themes with the subordinate theme ‘future worries, and the last theme focusing on emotional burden.

### **Theme 6: Positive emotion**

Positive emotions were expressed by all participants as it was shown to personally affect the fathers and their families. Participants conveyed a stronger family bond along with obtaining a positive mindset of acceptance. This was conveyed by Junior:

*Junior: “Caring for Losalia has impacted me in a positive way. If you have a daughter with special needs, it forces you to grow stronger because of your love for her. It’s made us tighter as a family unit and it’s made us stronger. My attitude towards Losalia having ASD is that it’s happened, I wish it didn’t, but it has. I can’t change it, so what are we going to do as a family unit to move on positively to help Losalia grow? Our attitude is also, she doesn’t know she’s got it, to her that’s normal, she doesn’t know any better. I can either be negative about it which won’t help anyone, or I can be positive about it and move on and make the best of the situation.”*

Participants emphasised having a sense of honour and appreciation when having an autistic child, along with feeling more purposeful and happiness. They also expressed positive emotions when seeing developmental improvements. This was discussed by Hala and Kiuga

*Hala: “I’m very proud and lucky to be a father to an autistic kid. There are heaps of positives being a parent to an autistic kid, you appreciate the things they do which I think some parents take for granted. For example, my son riding a bike, which I didn’t think he could and him going to the toilet by himself.”*

*Kiuga: “I feel honoured, and I feel like being a parent brings your life more purpose. I am truly happy to be Selafina’s father, she makes me very happy. I love every moment being a parent to Selafina.”*

Participants further expressed positive self-improvements when being blessed with their children. These improvements varied from an increase in patience to stopping bad habits. This was encapsulated by Tolu.

*Tolu: “He [Devin] has made a better person. I probably would have come out a jerk, but he calmed me down and made me more patient as a person and as a parent.”*

These comments show participants experiencing positive emotions despite their children being autistic. Therefore, conveying autism to be positive rather than a negative disability. However, it depends on the individual’s perspective and mindset. The next theme addresses negative emotions.

## **Theme 7: Negative emotions**

Negative emotions were described as experiencing feelings of future worries, independence, and life stressors. It was clear that the participants became emotional when discussing this topic as their voices became shaky and frequently paused to breathe between sentences. Participants discussed future worries with a fear of whether their children can care for themselves and live a happy life when they [participants] pass away. Future worries were constantly expressed regarding the distant future. Mose conveyed his worry through potential actions:

*Mose: "something that comes to mind is a career, what will they do for a living? I need to know what's going to happen. So, I spoke to my wife about getting a small business where I can set my kids up, but my wife keeps challenging me and asked why I'm trying to determine their future? just let them do what they want to do. It's hard for me to let go, I need to know if they're going to be in good hands and taken care of."*

In contrast to Mose, Kiuga demonstrated protection by leaving everything they own to his daughter and raised his sons to always protect their sister throughout life.

*Kiuga: "We instil in our boys to always look after their sister because we're not going to live forever. In our will we left the house and everything we own to Selafina because she won't be able to get these things herself. We have done this because we're concerned with her safety and fear of how she's going to be when we pass away."*

However, Junior expressed worry through future independence. All participants disclosed similar worries regarding communication and protection.

*Junior: "The key future challenge will be her independence, being able to look after herself. If she can't, who will? My concern is knowing if she is going to be alright in the real world. Just to put it into content, she's 12years old, but she's reading at a five-six-year-old level and her communication understanding isn't great, she's a very agreeable girl. So, if you ask her questions, her answer is usually yes, even if it's a bad question. So that's not going to look after her in the real world as well."*

Life stressors were commonly added onto the stress of parenting, causing participants to become frustrated and sometimes emotional. They were not frustrated at the child but frustrated with personal circumstances. However, participants discussed their child's inability to complete daily tasks as future adults.

*Hala: "I think about how he's going to be in the future, and it keeps me up at night. There are heaps of future challenges Siaoosi will face. I don't think he'll be driving, working, and will struggle to set himself up financially. He might not have the mind frame to apply for grants he's entitled to because his reading comprehension isn't good. I don't often feel like my well-being is being*

*compromised by long periods of care, but when it does, I really feel the affect mentally and emotionally. It's not because of parenting but because of the build of life's stressors."*

Statements of negative emotions were frequently discussed throughout the interviews by all participants.

### ***Summary of Superordinate Theme 3***

The diverse emotions expressed by the participants explains both positive and negative emotional aspects of parenting experiences. There was a clear mixture between positive and negative emotions experienced. The positive emotions discussed by the participants were established through obtaining a positive attitude and unconditionally appreciating their parenting role. However, negative emotions were established through the children's inability to properly care for themselves, always needing daily support, and the distant future.

## **Discussion**

The current study has used a qualitative approach to explore the experiences of Pasifika fathers' who have been blessed with a child diagnosed with ASD in New Zealand. Given the limited research on Pasifika fathers', this study has provided an insight on their experiences and as a result, generates potential ideas for future research. Applying interpretative phenomenological analysis in this research has allowed the researcher to investigate participant's parenting experiences along with support experiences. Seven themes were identified and categorised into three superordinate groups: support, coping mechanisms, and emotional aspects of parenting experiences. This chapter provides an examination of the themes that are categorised by the superordinate themes as they relate to previous revised literature, followed by a description of the research implications, then suggestions for future practice improvement. Lastly, a description of the research limitations is provided.

### **Experiences of support**

When participants discussed family support, they included church members and close friends as part of their family, resulting in a strong family support system. Although most participants expressed positive experiences of family support, one participant had negative experiences from extended family and friends, but still expressed a strong support system from his wife. This was consistent with previous literature focusing on the effectiveness of social support (Boyd, 2002, Ekas et al., 2010, and Stuart, & McGrew, 2009) which showed parents that expressed greater social support had positive

parenting experiences compared to parents with a lack of social support (Paynter et al., 2013). Furthermore, recent research found fathers expressing the desire for their extended families support, although their support was rarely provided in times of need (Paynter et al., 2018). A few participants expressed negative experiences when seeking professional support as it was difficult to obtain, which conveyed an example of inadequate understanding of autism. This was consistent in previous studies conducted by Paynter et al. (2018) who had fathers describing difficulties when accessing professional support and was seen more directed towards mothers. However, New Zealand research found service organisations and improving professional and caregiver communication skills as being crucial in achieving the demands of support (Jordensen et al., 2010; McPherson et al., 2014). This supports the recommendation for improved communications among services and parent caregivers (see Table 3: Suggestion 6).

Increased understanding and awareness of autism is generally portrayed as the cause of increased prevalence (Matson & Kozlowski, 2011). However, Tolu's experience with his son's professional support and education staff implies there is an issue in some domains regarding the comprehension and awareness of autism, therefore, expressing his son's need for continual teacher aid support. The New Zealand Autism Guidelines highlight numerous recommendations for both professionals and Pasifika fathers regarding what needs to be established (Ministries of Health & Education, 2016) (see Table 3: Suggestion 4 & 5). Nevertheless, the Education Review Office (ERO) has utilised different approaches to improve learning and professional development for staff, along with the inclusion of the individual's family, and outside support which aims to enhance inclusiveness in primary schools (Education Review Office, 2013).

The New Zealand Autism Guidelines highlight recommendations to improve information regarding financial assistance (see Table 3: Suggestion 3). Consistent with participant financial support experiences, when discussing a limited number of financial assistances, Sharpe & Baker (2007) also identified limited private and public support available in their research, with their participants reporting inadequate support through public education providers. Participants expressed the gratitude towards receiving financial assistance as it was a high demand due to extra costs for their autistic child. A study conducted by Reilly and Platz (2004) identified financial support to be associated with increased parental satisfaction. Financial support included subsidies, therapy, and extracurricular activities. This is consistent with current research as participants did not express low satisfaction whilst being financially supported.

Although participants stated they had received just enough financial assistance they also expressed needing more in an ideal world which will provide comfort. Some participants felt that financial entitlement was a carefully protected secret. This is generally conveyed by parents with autistic children (Rivard et al., 2014; & Wang et al., 2011). Considering fathers' tendencies to concentrate on

financial factors, practical assistance to help simplify the eligibility and financial systems could be significant in decreasing Pasifika father's stress. Thus, corresponding to a suggestion previously established by the New Zealand ASD guidelines (Ministry of Health and Education, 2008) which provided the recommendation that both support groups and health agencies work together to increase relevant information and availability (See Table 3: Suggestion 1).

Participants indicated that they felt very supported by Pacific based organisations, where they were provided with information about ASD and what they can do for their children. These Polynesian groups provided participants with a support that was described as a "dad club" which offered a non-judgemental safe space for fathers to express their concerns, to connect with other fathers going through the same situation, and to have an open discussion that is different to what fathers discuss with their partners (Banach et al., 2010; Dewey, and Hodgkinson, 2021; & Dyson, 1997), therefore, reinforcing the effectiveness of having social support along with engaging in support groups. This further correlates to a study by Paynter et al. (2018) where they reported that their paternal participants explained talking to other fathers of children with ASD as a high value of support which was also found to be consistent with a study conducted by Carpenter and Towers, (2008). The effectiveness of support groups is consistent with Mandell & Salzer (2007), in which they found that parents with autistic children were more likely to be associated with a support group if they were referred by a formal or informal source. This provides a suggestion that health professionals have details about accessible support groups and referral at diagnosis be pursued (see Table 3: Suggestion 1).

### **Coping Mechanisms**

Participants discussed a variety of coping mechanisms that they used to manage stress. The coping mechanisms participants utilised were to reduce parenting stress. Though previous literature (e.g., Barak-Levy & Atzaba-Poria, 2013) distinguishes males as more likely to utilise cognitive tactics, participants described skills that include the three approaches conveyed by Pinata et al. (1996); cognitive, emotional, and action-based methods. The cognitive method seeks to get educated and aware, whilst emotion coping seeks to normalise Pasifika cultural norms, and lastly, action relates to daily routine and planning.

Participants discussed their lack of knowledge around ASD which led to them actively seeking education and awareness. Information is required among parents with newly diagnosed children. This is portrayed in an international study conducted by Ellis et al. (2002) which reported 47% of parents recognising information as their main demand. This is also consistent with the New Zealand autism

guidelines, where they have suggested information being the crucial aspect for supporting families (Ministry of Health & Education, 2008). This suggestion is supported in the present research (see Table 3: Suggestion 6). Participants discussed receiving information not only from professionals but also from Pasifika focused support groups and other parents, which has been acknowledged by Pain (1999) as a valuable information source.

Participants discussed how ASD and disability in general is portrayed in the Pacific culture. It is almost considered as taboo to talk about disability and Pasifika people tend to 'look down' on the disabled individual. A study conducted by Shin (2002) compared social support for families of children with intellectual disabilities in Korea and USA. The cultural differences were highlighted as Shin identified numerous factors such as Koreans traditionally demonstrating more negative attitudes towards individuals with disabilities. For example, in some cases families lived further away due to their family having a disabled child, which is regarded as shameful (Luther et al., 2005). The purpose of normalising statements in cognitive strategies were also utilised by mothers characterised as being resolved to the diagnosis (Pianta et al., 1996). Normalising ASD in the Pacific culture is more interconnected towards not being accepted as yourself and being more emotionally separated and related to paternal fears about not having competency to have a relationship with their children (Barak-Levy & Atzaba-Poria, 2013). Participants made comparisons between their expectations of parenting before, and their reactions after receiving, the diagnosis. In coping theory these are known as cognitive reappraisals and are needed prior to the progress of the coping strategies (Taylor & Stanton, 2007). The established comparisons further support the process of resolution to a child's diagnosis. Then, parents include both pre and post diagnostic representations of their child in the process of being completely accepted for the real child (Pianta et al., 1996).

Participants expressed the benefits of incorporating daily routine and planning as a mechanism to cope with the parenting demands. Most participants mentioned their wives staying home to look after their children while they work to support the family. This is commonly conveyed in two-parent family systems as both share parenting roles, but the participant's partner generally takes on a greater part of the responsibilities, taking care of daily routines and planning (Meadan et al., 2015). Furthermore, Lewis and Lamb (2003) suggested that although fathers play a crucial role in a child's development, the fathers are most likely to focus on providing for the family rather than participating in childcare (Hartley et al., 2014; Rafferty et al., 2020). The participants from the current study have demonstrated a connection to previous studies by reporting the same behaviours other fathers did. Poslawsky et al. (2014) related daily routines and planning to an increase in self-efficacy and a decrease in parental stress and child anxiety levels.

## **Emotional aspects of parenting experiences**

Participants expressed positive emotions in relation to the benefit of their family and self-improvement. All participants discussed that their child's condition positively impacted them and their family. As a result, a closer family bond was developed which provided their lives with more purpose and true happiness. Negative emotions were described by participants as short and long-term worry, independency, and life stressors. They had expressed negative emotions they felt for their child rather for themselves, thus, conveying that the father's priority were their children. When expressing heartfelt experiences, participants became emotional and as the interviewer, you could not only see, but could also hear the heartfelt emotions in the participants' voices. Although participant emotions can be portrayed as less intense, that does not imply that they are less distressing (Barak-Levy and Atzaba-Poria, 2013).

Descriptions of intangible, negative, and stressful emotional experiences correlate with subjective responsibility (Louiska, 1994). Negative emotions are generally identified in research referring to psychological distress of parents with autistic children. A few participants discussed they seek jobs to better suit their childcare situation. This course of action was the case for Hala which resulted in him leaving his job to become a fulltime solo father due to his son becoming increasingly challenging. This was common among previous research reports (Koydmir-Ozden & Tosun, 2010; Luong et al., 2009; McCabe, 2010).

Although fathers' description of positive emotion focuses more on their families, discussions of negative emotions were mostly directed towards their child being on the spectrum. This is because of the effect autism has on their child's development, therefore, causing an increase in future challenges and a decrease in independency.

## **Research implications**

Numerous recommendations have been produced from the research results and have been explored above (refer to Table 3: Suggestions 1-7). Results are given strength by supporting and correlating with current international and New Zealand centred research, specifically regarding participants need for adequate information and respite services. Furthermore, several recommendations provided have been suggested previously in the New Zealand Autism Spectrum Guidelines and in the New Zealand Careers Strategy Action Plan (NZCSAP). This is motivating because it informs these documents which are targeting the broader population of New Zealand guardians, and respectively autism professionals, and further appropriate and relevant to Pasifika fathers with children diagnosed with ASD.

Table 3

*Suggestions for healthcare professionals, the field and policy makers, and researchers*

<b>Suggestions for clinicians</b>
1. Clinicians suggest fathers to attend accessible support services at diagnosis.
<b>Suggestions for the field and policy makers</b>
2. Provide better approach to respite services.
3. Providing more adequate information regarding financial support.
4. A programme of research that would support standard information about ASD and the Pasifika population should be established.
5. A plan should be established aimed at improving cultural competency of the normal workforce to acquire knowledge and understanding of Pasifika cultural values, beliefs, and worldviews and appropriately use this in the workforce.
6. Increase communication efficiency and management between Pasifika fathers/parents and services.
<b>Suggestions for researchers</b>
7. Increase caution and improve clarity when using the terms: paternal, maternal, and parental.
8. Utilise caution conceptualising father's experiences using models established with mother populations.
9. Repeat this research after NZCSAP focus time to review change among the experiences of Pasifika fathers.
10. Explore Pasifika fathers' experiences by utilising greater sample sizes for a more generalisable focus rather than an idiographic focus.

### **Limitations**

Throughout this research, there have been many limitations identified. For example, the research results cannot to generalised to the total Pasifika population. This continues to be true for numerous qualitative methodologies and remains true specifically for IPA which includes an idiographic emphasis. The five participants showed a narrow demographic range, aging between 29-48 years, and all classified themselves as Pacific Islanders residing in New Zealand. The homogeneity in the research sample is an outcome of the objective of the study being Pasifika fathers of children with ASD. The IPA methodology has the capability to be inclusive in terms of all participants of all cultures. Therefore, the nature of the semi-structured interviews allows the researcher or the highest associated culture biases to decrease in the interviews. However, the realisation of this potentially occurring in the study was not noticed due to the nature of the demographic responses to recruitment.



Another limitation in this research was the self-selection process as previously supported in past literature by Smith et al., (2009) suggesting that self-selected participants may increase the risk of potential bias towards those with “stories to tell”. Therefore, this research could have directed Pasifika fathers who are more involved with their autistic children to have a prominent interest in the research topic. As a result, participants responding to recruitment invitations. Moreover, the methodology required face-to-face interviews but due to COVID-19 restrictions, all five interviews were carried out using Zoom as the safest and most effective option. Considering participants’ availability, they were flexible and cooperative in providing a suitable time and date for the interview.

Consistent with the researcher reflexivity that is required for the IPA approach, it is crucial to reflect on how the characteristics of the interviewer may have influenced the data and analysis. As a male researcher endeavouring in gaining insight into the parenting experiences of Pasifika fathers, being the same gender may have had an influence on the interviews. For instance, in the Pasifika culture, it is seen as not normal for males to discuss sensitive information. Therefore, conveying the difficulty of recruiting Pasifika fathers, moreover, resulting in a small sample size.

Participants expressed comments that showed their understanding and awareness of the research process such as a comment made by Hala “it’s hard to explain, but it’s easy to explain.” This comment is an example of what participants demonstrated in the interviews. Furthermore, implying that although rapport between interviewer and interviewee was being made in the interviews, the participants continued a clear level of awareness and attentiveness of the interview purpose as being part of the research procedure. Considering this as a limitation of IPA methodology was suggested by Smith et al. (2009) because the documented experience is continuously reliant on participant disclosure.

## **Conclusion**

This research explored the parenting experiences of Pasifika fathers with children diagnosed with ASD, residing in New Zealand. This research has provided various insights into Pasifika father’s experiences along with contributing to the field of study by validating and supporting previous literature which correlated to the parenting experiences of mothers with autistic children. Participants expressed positive perspectives about their experiences of family and professional support. However, regarding these support systems, they also explained negative experiences which were due to their families having a lack of autism awareness and education, and information and knowledge about the help they were entitled to, until being properly informed. Although support groups have been significantly considered as highly effective for Pasifika fathers, the inadequate amount of support groups for Pasifika fathers indicate that establishing a more Pasifika father focused support group will have a greater impact. Results also validated previous literature indicating stressful difficulties in

receiving respite care services for Pasifika fathers' and their autistic children. For example, Brenner et al., (2015) reported that families accessing respite care found it challenging due to the system complexity in accessing services, along with families having a lack of knowledge about existing services that are available to them (Cooke et al., 2020). This has showed the relevance and effectiveness of current standards and strategies for the Pasifika population of fathers with children diagnosed with ASD. As a result, this research accomplished a detailed idiographic analysis of fathers with a Polynesian background that has a lack of published experience in research, therefore, being a platform for their voices to be acknowledged and included in the literature of parenting experiences in New Zealand.

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## APPENDICES

### APPENDIX A: Ethical Approval



**Auckland University of Technology Ethics Committee (AUTECH)**

Auckland University of Technology  
D-88, Private Bag 92006, Auckland 1142, NZ  
T: +64 9 921 9999 ext. 8316  
E: [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz)  
[www.aut.ac.nz/researchethics](http://www.aut.ac.nz/researchethics)

29 July 2021

Daniel Shepherd  
Faculty of Health and Environmental Sciences

Dear Daniel

Re Ethics Application: **21/210 Experiences of Pasifika Fathers who care for children with autism spectrum disorder (ASD)**

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

Your ethics application has been approved for three years until 29 July 2024.

**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 AUTECH 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 AUTECH prior to being implemented. Amendments can be requested using the EA2 form.
5. Any serious or unexpected adverse events must be reported to AUTECH 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 AUTECH 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.

AUTECH 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 AUTECH Secretariat  
**Auckland University of Technology Ethics Committee**

Cc: [ioa.apulu@gmail.com](mailto:ioa.apulu@gmail.com)

## APPENDIX B: Participant Consent Form



### Consent Form

**Project title:** *Father's lived experience caring for their autistic children.*

**Project Supervisor:** *Dr Daniel Shepherd.*

**Researcher:** *Nicholas Apulu-Pamatatau.*

- I have read and understood the information provided about this research project in the Information Sheet dated DD/MM/YEAR
- I have had an opportunity to ask questions and to have them answered.
- I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- I agree to take part in this research.
- I wish to receive a summary of the research findings (please tick one): Yes  No

Participants signature: .....

Participants name: .....

Participants Contact Details (if appropriate):

.....  
.....  
.....  
.....

Date:

**Approved by the Auckland University of Technology Ethics Committee on *type the date on which the final approval was granted* AUTEK Reference number *type the AUTEK reference number***

**Note:** The Participant should retain a copy of this form.



## Participant Information Sheet

### Date Information Sheet Produced:

01/06/2021

### Project Title

Experiences of Pasifika Father's caring children with Autistic Spectrum Disorder (ASD).

### An Invitation

Talofa Lava, Malo e Ielei, Bula Vinaka, and warm greetings, my name is Nicholas Apulu-Pamatatau, I am a Bachelor of Health Science student and the Primary Researcher for this study. I am interested in ensuring that you as a father (Matu'a/Matua/Matavuvale) are supported with the resources and services in providing support for your children/fanau/gone/ on the autism spectrum. For this purpose, I am interested as the valuable information you provide as there is limited research on Pasifika fathers' caring for a child with ASD.

### What is the purpose of this research?

The purpose of this study is to document our father's (Matu'a/Matua/Matavuvale) perception of the challenges of caring for a child with ASD. Interviews will be conducted to examine your experiences and journey. Questions will be focused on you as the father, the challenges (positive & negative), support and wellbeing. The data I receive from the participants after the interviews is therefore important as a research based for Pasifika fathers' or in general especially in New Zealand.

All data will remain confidential, and examples used in the final report will be by way of pseudonym and not include the names of the participants or give information that would enable the participant to be identifiable.

### How was I identified and why am I being invited to participate in this research?

You will have responded to an advertisement from the researcher, inviting you to participate in this research.

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

To take part in this study please make direct contact with Nicholas Apulu-Pamatatau as the Primary Researcher, via email or phone (see below), who will address any questions you may have about the research. Once you have agreed, I will arrange an interview at AUT University offices (South Auckland). Your participation in this study is voluntary (it is your choice) and your participation will neither advantage nor disadvantage you. You may choose to withdraw from the study at any time. If you choose to withdraw from the study, you will be offered the choice between having study data that you have given, removed, or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

A Consent Form has been forwarded with this Participant Information Sheet and must be signed and returned just prior to being interviewed.

### What will happen in this research?

You will be invited to a one-hour semi-structured interview. There will only be yourself, which is the participant, and Nicholas Apulu-Pamatatau present at the interview, unless you would prefer a support person, or whanau member, of your choosing to be present.

The interview structure itself will involve some simple questions relating to our topic and will allow for additional questions if elaboration is needed. The information you provide is private and confidential and will not be used for any other purposes other than the analysis relating to this research topic. To further protect your privacy, I will use pseudonyms in any and all correspondence and publications relating to this research. The research findings may be used for academic publications and presentations.

### **What are the discomforts and risks?**

I will take all reasonable precautions to ensure that you do not experience discomfort or risk whilst participating in this study. I will conduct the interviews at the venue of your choice and ensure the rooms are quiet and private. I will endeavour to word the interview questions in a clear and respectful manner; however, you only need answer questions if you feel comfortable. You may withdraw from the study at any time.

### **How will these discomforts and risks be alleviated?**

If for any reason you feel this experience has caused issues to arise, and you believe this is as a direct result of participating in the research please contact the AUT Health, Counselling and Wellbeing service.

AUT Health Counselling and Wellbeing can offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research and are not for other general counselling needs. To access these services, you will need to:

- Drop into our centres at WB219 or AS104 or phone 921 9992 City Campus or 921 9998 North Shore campus to make an appointment. Appointments for South Campus can be made by calling 921 9992
- Let the receptionist know that you are a research participant and provide the title of our research and names and contact details as given in this Information Sheet.

You can find out more information about AUT counsellors and counselling on <http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing/counselling>.

Alongside AUT counselling, the participant can receive appropriate specialist counselling available free of charge from the Tongan Autism Group and the Pasifika Autism Support Group.

You can find out more information about AUT counsellors and counselling on <https://www.aut.ac.nz/student-life/student-support/counselling-and-mental-health>

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

This study will provide information regarding experiences of our Pasifika father's caring for a child on the autism spectrum. This will enable fathers who are struggling or who are going through the same experience to know that they are not alone and there are Pasifika support services that are available. The findings will be of interest to families, other Pasifika support groups and health service providers will allow them to develop more programmes and support to better meet the needs of our Pasifika children on the autism spectrum in New Zealand. Furthermore, it is hoped that capturing the impact of your experience will enable other Pasifika fathers to come forward despite the stigma that is surrounded our Pasifika fathers' and families and seek the support for their children along with further government funding to aid in helping provide a safe environment that will allow our Pasifika children to enjoy doing activities they love.

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

You will be asked to provide a pseudonym by which you will be known in the study, or I can provide a pseudonym for you. Only the research team will have access to data during the data collection and analysis stage. Only the project supervisor, Dr Daniel Shepherd, will have access to the data after the final reports are produced. Audio-recordings of interviews will be destroyed following transcription.

Consent forms and transcripts, using only pseudonyms, will be kept for six years in a locked filing cabinet in the Psychology Department on AUT premises.

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

I anticipate that interviews will take no longer than one hour plus your travel time. If you wish to review your transcript prior to the completion of the research this will take an additional, small amount of time.

**What opportunity do I have to consider this invitation?**

Once you have completed the Consent Form, I request that the forms be returned to the researchers at the interview. If you have any questions regarding these forms, you are encouraged to contact the research team. Receipt of these completed and signed forms acts as your acceptance to participate in this study.

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

As a participant you will be provided with a summary of the dissertation's research findings via email at the conclusion of the study. Both Autism organisations, Tongan Autism Group and Pasifika Autism Support Group will be emailed a dissertation summary of the research findings.

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

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Assoc Prof Daniel Shepherd, [daniel.shepherd@aut.ac.nz](mailto:daniel.shepherd@aut.ac.nz), ph. 09 921 9999 extension 7238

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), (+649) 921 9999 ext 6038.

**Whom do I contact for further information about this research?**

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

**Researcher Contact Details:**

Nicholas Apulu-Pamatatau / Email: [iloa.apulu@gmail.com](mailto:iloa.apulu@gmail.com) / Mobile: 0223530858

**Project Supervisor Contact Details:**

Assoc Prof Daniel Shepherd, [daniel.shepherd@aut.ac.nz](mailto:daniel.shepherd@aut.ac.nz), ph. 09 921 9999 extension 7238

**AUT South Campus Address:**

640 Great South Road, Manukau City Centre, Auckland 2025.

Approved by the Auckland University of Technology Ethics Committee on type the date final ethics approval was granted, AUTEK reference number type the reference number.

## Interview Schedule

### Recording

Participant interviews will be recorded for transcription using audio recorders (video will not be used).

### Indicative Questions for Semi-Structured Participant Interviews

**Purpose of the study:** To establish the Pasifika parent's experiences of caring for a child that has been diagnosed with Autism (ASD) in New Zealand. The questions will seek to understand the context of caregiving, support, services and well-being.

**Form of welcoming:** will be used in welcoming the participants as part of the cultural relevant in the interview process as English being the second language.

Tongan: Malo e lelei, oku oatu emi ha fakamālō loto hounga ia mo'omi ʻi ho'omou loto lelei ke vahevahe 'a e ngaahi taukei moe a'usia kuo mou feia ʻi he tauhi moe tokangaekina homou ngaahi pele 'ofu'anga. (Translation: Hello, thank-you for taking the time to share your journey/experiences with us).

Samoa: Talofa, faafetai tele lava mo le faaavanoaina o le taimi e faasoa mai ou poto masani ma i matou (Translation: Hello, thank-you for taking the time to share your journey/experiences with us).

### Information about individual being interviewed (Parent):

Demographics:

Biological parents? (if not, how long have they been caring?)

Age

Ethnicity

Time as parent

Parent to other children

Engaged in other paid employment

### Information about the child with ASD:

Demographics:

Age

Are they attending school?

Length of time since diagnosis

**Section II: Initial questions – establishing context**

- Can you tell me a little about your role as parent?
- How do you feel about your role as parent?
- Daily structure – What does your average day look like?
- How did you feel when you learnt that your child had ASD?
- How has your life changed since you found out your child has ASD? If yes how?
- Do you think this maybe different to how life may have been if your child did not have ASD?
- What are the challenges do you think you will face regarding your child's future?
- What has been most helpful/rewarding for you as a parent navigating the joys and struggles of caring for a son/daughter with autism?
- How have other people treated you and your family/whanau since you found your child has ASD?
  - (If people have reacted differently):
  - A) What do they do (or not do) that is different?
  - B) Can you tell me why you think they have changed how they might treat you?
  - C) Can you give some examples of a time and place when you notice this difference occur more often?
- People sometimes say that "it takes a village to raise a child" (translate) what are your thoughts on this quote?

**Section III: Support**

- **How well supported do you feel as a parent?**
  - *Single / married / divorced / widowed*
  - *Family nearby*
  - *Help at home*
- How well financially supported do you feel?
- In an ideal world how much support do you think would help (Child's name) more and in what type of community setting?
- What are the biggest barriers and biggest facilitators (helpers) in providing support?
- How accessible is it for support?

#### Section IV: Services

- Do you have access to any support services to help you? If so, which services are they and how do they help you?
- Does the interviewee consider the support by professionals to assist in all the above important?
- Do the services provided feel enough to support you?

#### Section V: Overall feelings of wellbeing

- How would you describe your overall wellbeing?
  - stresses / anxieties / hopes / content
  - How does caring for an Autistic child impact your overall wellbeing?
- What actions do you consider/take to keep your wellbeing in check?
- Do you feel like your wellbeing is often compromised due to the large periods of care?

#### Section VI: Other areas / Final remarks

- What advice would you give to other fathers who have a child that is on the autism spectrum?
- Is there anything else you'd like to discuss in relation to your role caring for an Autistic child?