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“E lē Ma’i, o le Malosi!” (He’s not Sick, He’s Strong!): Pacific Parents’ Journey of Raising Autistic Children in Aotearoa



A thesis presented in partial fulfilment of the requirements for the degree of
Doctor of Clinical Psychology
at Massey University, Albany, Aotearoa New Zealand

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Abstract

Ministry of Health data estimates there are 4,000 Pacific children in Aotearoa New Zealand officially diagnosed with an Autism Spectrum Disorder. This figure is likely underestimating the true prevalence of autism within Aotearoa Pacific communities, due to diagnostic disproportionality, and a lack of autism assessments completed since the COVID-19 pandemic. Children of Indigenous and ethnic minority populations globally tend to be diagnosed later, incorrectly diagnosed, or are not referred for autism diagnosis. Indigenous and ethnic minority parents regularly have their concerns dismissed by health professionals, face lengthy delays, and endure multiple attempts at diagnostic referral. Despite the growing autistic community globally, and Pacific peoples being the fastest-growing youth population in Aotearoa, Pacific peoples' perspectives and experiences have not been included in autism research. Consequently, no reliable data exist on Pacific autistic people, and just six percent (6%) of eligible Pacific families are accessing Disability Support Services within Aotearoa. This first Pacific-led study (based on three Pacific-Indigenous research frameworks) focuses on Pacific parents' expert knowledge from lived experience raising their autistic children, revealing key differences from a Pacific-Indigenous context in autism conceptualisation, support access, and language and culture maintenance. Fifteen Pacific parents of autistic children from the Pasifika Autism Support Group and Pacific community in Auckland Aotearoa, participated in eight research talanoa. Findings revealed parents sought an overall state of Diasporic Adaptation to Neurodiversity which involved acceptance, adaptation, and unlearning for Pacific parents. Four subthemes together explained the experience of Pacific parents of autistic children in Aotearoa: 1) Uncharted Islands: Understanding Autism; 2) Encountering Stormy Seas: Challenges; 3) Collective Unity through Relational Resilience; and, 4) Autism Support. Pacific-Indigenous knowledge and knowledge gained from Pacific parents was woven together to create the Tapasā a Tagata Sa'ilimalo (compass for people in search of success), which can be used for navigating the experiences of Pacific parents of autistic children within Aotearoa. Together with clinical implications provided, the Tapasā a Tagata Sa'ilimalo can guide clinicians, educators, and practitioners working with Pacific families of autistic children in Aotearoa to provide culturally appropriate, family-centred care and support prior to, during, and following autism diagnosis.

Keywords: Pacific, clinical psychology, autism, language and culture, Indigenous, research methodology

Attestation of Authorship

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

Signed: 

Date: 14/11/2022

Front cover Mika image credit: Ali Cowley, Auckland New Zealand (Samoan animator, illustrator). This artwork was commissioned by the Author to represent one of the children of a participating family. 'Mika' is described in the introductory paragraph to the thesis. Mika's name and Pacific origins have been changed to maintain his privacy.

Triple-braided cord and Tapasā a Sa'ilimalo image credits:

Matthew Luani, ML Designs, Porirua New Zealand (Cultural and Indigenous designer).

This project has been evaluated by peer review and judged to be low risk. Consequently it has not been reviewed by one of the University's Human Ethics Committees. The researcher named in this document is responsible for the ethical conduct of this research. If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher, please contact Professor Craig Johnson, Director (Research Ethics), email humanethics@massey.ac.nz

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migration and the word diaspora, the Aotearoa Pacific identity, 'being the change you want to see', Pac-tivism and where I first tasted Pacific and BIPOC women's literature, scholarship, and poetry. I was lucky enough to have benefited from Teresia's presence as a student, through community (PACIFICA Inc.), and professionally (Victoria University Pacific Staff Network) and I believe her to have been the greatest educator I have encountered. I have been inspired by further Pacific women trailblazers/poets/literary scholars/academics/Pactivists, including Professor Konai Helu Thaman, Emeritus Professor Tagaloatele Peggy Fairbairn-Dunlop CNZM, Professor Melani Anae, Associate Professor Jemaima Tiatia-Seath, Sister Vitolia Mo'a, Associate Professor Siautu Alefaio, Associate Professor Julia Ioane, Dr Karlo Mila MNZM, Dr Christina Fa'alogo-Lilo, Dr Emalani Case, Tusiata Avia MNZM, Grace Teuila Taylor—the list goes on—who bring such kaha, fire, truth, creativity, passion/alofa, and are yet real Pacific women with grassroots humility. A special acknowledgement and appreciation to my former pule Associate Professor Hon Luamanuvao Dame Winnie Laban DNZM QSO. Thank you for opportunities to sit and learn, to advocate, fight, create, connect, and lead. Thank you for setting fire to embers within me. Without the solid foundations of these matriarchs, I would not have had the requisite bravery to undertake this project.

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Glossary

Term in the Thesis	Meaning (Origin)
afakasi	Half-caste (Samoan)
‘āiga	Family (Samoan)
aitu	Spirits (Samoan)
alaga’upu	Proverb or traditional saying encoded with cultural values
Aotearoa	Land of the long white cloud, used to refer to the North Island, but also commonly an unofficial name for New Zealand (te Reo Māori)
fa’aaloalo	In a respectful way or referring to respect and humility (Samoan)
fa’asinomaga	Birth right, divinely bestowed inheritance (Samoan)
fanua (Samoan), fonua (Tongan)	Land
feagaiga	Covenant, relations (Samoan)
gafa	Genealogy (Samoan)
iwi	Bones, refers to Indigenous extended familial groupings within Aotearoa (tribes) (te Reo Māori)
kaha	Strength (te Reo Māori)
kalofa e	Alas (Samoan)
koha	Gift (te Reo Māori)
lagi	Heavens (Samoan)
mafanafana	Warm/th (Samoan)
ma’i	Unwell, sick, ill, with child (Samoan)
mea’alofa	Gift (Samoan)
Pākehā	Refers to New Zealanders of primarily European descent (te Reo Māori)

takiwātanga	Term for an autistic person, referring to fruition occurring in the person's own space and time as with the Tītoki tree (te Reo Māori)
tagata sa'ilimalo	Disabled person and their 'āiga/supporters (Samoan)
Tāmaki Makaurau	Indigenous name for Auckland, New Zealand (te Reo Māori)
tangata (o le) moana	People/s of the sea, refers to Pacific peoples (Samoan)
tangata whaikaha	Disabled person (te Reo Māori)
tangata whenua	People of the land, refers to Māori within Aotearoa (te Reo Māori)
tauiwi	New bones, used to refer to non-Indigenous peoples (te Reo Māori)
Taulāitu	Spirit medium (Samoan)
tausi tagata	Look after/care for people (Samoan)
teu le vā (Samoan), tauhi vā/vaha'a (Tongan)	To care for, to cherish, to maintain the relational spaces or relationships
toloa	Birds of the duck, goose, and waterfowl families (Samoan)
toto	Blood (Samoan)
tuli	Birds of the plover, dotterel, and lapwing families (Samoan)
vā	The relational space/space between (Samoan)
va'a	Boat, traditional sea-going vessel (Samoan)
vā fealoa'i	Relational arrangements (Samoan)
vā tapuia	Sacred spaces of relational arrangements (Samoan)
Whaikaha	Aotearoa's new Ministry of Disabled People (te Reo Māori)
whakapapa	Genealogy (te Reo Māori)
whānau	Family (te Reo Māori)

Notes to the Reader

The term 'Aotearoa' ([land of the] long white cloud; Crowe, 2018) is used in this thesis to refer to the country of New Zealand and its peoples. This term is generally accepted as being a pre-European contact name given to the land by navigator Kupe from Hawaiki, following his wife Hine-i-te-Aparangi's *mihi* (greeting) to the land on discovery (Adds, 2012; Crowe, 2018; Te Whetu & Best, 1893). Although Aotearoa is stated to refer only to the North Island, the term has become common parlance to refer to the nation and appears on many official documents including New Zealand passports (Breen et al., 2021). The term 'New Zealand' is used in this thesis when referring to the Government and other organisations or reports that use New Zealand (NZ) in their name.

In the past within Aotearoa, government ministries have used the Niuean transliterated umbrella term 'Pasifika' to refer to Pacific migrants and their descendants residing in or citizens of Aotearoa (Samu et al., 2019; Tualaulelei & McFall-McCaffery, 2019). Though a matter of preference, many have eschewed the term 'Pasifika' citing the continued colonisation of Pacific peoples through reducing their diversity and complexity down to one term (Anae, 2016; Alefaio, 2018; c.f. Matapo & McFall-McCaffery, 2022). The reclaimed term 'Pacific peoples' is therefore used in this work to refer to the Indigenous peoples of the Pacific triangle (often called Pacific Islanders), inclusive of Indigenous people from the more than 13 countries of the Melanesia, Micronesia, and Polynesia geographies, and their descendants living both in or outside of their island homelands (Alefaio, 2018; Percival, 2008, as cited in Cammock et al., 2021). Within Aotearoa, 'Pacific peoples' is used specifically to refer to those Pacific peoples who have migrated to and/or are resident within Aotearoa, and their descendants born in Aotearoa.

The term 'Pacific-Indigenous'¹/Indigenous is used within this work to refer to the particular ontological and epistemological frameworks that underpin the knowledge tradition and worldview of Pacific peoples or of first peoples Indigenous to other lands (Matapo & McFall-McCaffery, 2022; Tualaulelei & McFall-McCaffery, 2019). It is used in regard to restoring and re-privileging such knowledge bases as at least equal in value with non-Indigenous knowledge systems (Botha et al., 2021). The term Pacific-Indigenous is an umbrella term and has utility as a collective shortcut in academic writing, but should not be misunderstood or understated as the name of a singular culture, or knowledge system (Alefaio,

¹ This term was first published in Alefaio (2018) and is used with permission.

2018). To do so would be an injustice to the diverse peoples, cultures, and languages which are subsumed under this term.

The term 'autistic' is used in this thesis to refer to children who have received an official diagnosis of Autism Spectrum Disorder. This language has been selected to align with autistic adult community-preferred identity-first language (Crane et al., 2018; Folkema, 2022), and a desire to move away from stigmatising, ableist, and deficit-focused language. The term 'autism' rather than Autism Spectrum Disorder or ASD is used in this thesis to refer to the clinical meaning of autism or the wider community around autistic people, including family, professionals, and researchers (for example, the autism community; Folkema, 2022). The autistic adult community generally prefers autism terms which do not include the word 'disorder', due to autism being a part of identity and as one neuro-type within normal neurodiversity, rather than a deficit or disorder (Fletcher-Watson, 2022; Folkema, 2022; MoH/MoE, 2016). The term 'ASD' is used only in quoting others directly.

Finally, in the framing of this project the researcher has taken a broad approach in choosing to talanoa with families of various Pacific ethnicities/identities, rather than an ethnic-specific approach. The justifications for these decisions are as follows:

- The neurotype of autism is no respecter of persons including ethnicity, culture, or socio-economic status (APA, 2013).
- Global mobility, migration, and multicultural intermarriage has meant that increasingly Pacific people claim more than one ethnic identity (Census, 2018; Macpherson, 2015) and parents choose partners of mixed or other ethnicities (Mila-Schaaf, 2013). In short, to restrict the project to one ethnicity would be at the exclusion of people affected by the very subject matter of the project (for example, ethnicity prioritisation; MoH, 2017).
- Pacific cultures, while being very diverse, do share broad similarities such as key principles and values that underpin these cultures (Mila-Schaaf & Hudson, 2009). It is in this collective unity that we can harness our strengths and move forward together.

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Chapter 1: Introduction

Mika (front cover), a young Aotearoa Pacific boy of eight years old, loves to find out about the inside workings of things by opening them up and taking a good look. Others might call this destroying, but he has an enquiring mind. Mika also likes to take a stroll through his neighbourhood to the shop. He knows exactly how to get there across many busy roads, as he has walked there many times with family members. Some might call this escaping, but he did not want to bother anyone by asking them to take him, and everyone looked busy, anyway. Mika is intimately connected with his extended family, his Nana plaits his thick hair every morning before school, calming him with a lolly if he protests. Mika can verbalise, but he does not speak in the way that you would think of speaking to mean. Some would call him nonspeaking, but this does not mean Mika has nothing to say or that he does not have a wildly active thought life and imagination. At family or sporting events, Mika is often found communing with the birds. Some would say he was escaping sensory overload, but Mika knows how to calm himself when overwhelmed. He lifts his head to the sky to follow the “pathway of the birds”², the same pathway his ancestors took when they migrated to Aotearoa New Zealand. He beckons to the *tuli*³ and *toloa*⁴ birds by patting on his chest. Although Mika does not speak, perhaps he is more connected to his ancestors than we know.

It is a unique experience raising an autistic child. Parents therefore hold expert knowledge on the holistic impacts of autism on parents and families (DePape & Lindsay, 2015). As primary carers, mediators, and advocates for their child, parents’ knowledge from experience can inform health professionals as to what support and services are needed and appropriate for their autistic child/ren until their children are able to express their own agency (DePape & Lindsay, 2015). While there is a body of published research discussing parents’ experiences of raising autistic children, this research has not included Pacific families and their experiences (MoH/MoE, 2016). The intersection of culture with autism, for example, diversity in values, traditions, and socio-cultural and health experiences, are important for health professionals to be cognisant of when working with families of children with disabilities (Macfarlane et al., 2014). It is pertinent, then, to deduce cultural factors at all levels of the ecological system that could lead to earlier recognition of Pacific autistic children, improve the diagnostic process, and lead to early and effective intervention and support for families with autistic children from all cultural backgrounds (Bernier et al., 2010).

² Reference to a book history of Māori and Polynesian voyaging called *Pathway of the Birds* (Crowe, 2018).

³ Tuli: refers to dotterels and a number of migratory wading birds (Crowe, 2018; Pratt, 2007).

⁴ Toloa: black-browed Mollyhawks, ducks, and other large-winged sea birds (Crowe, 2018; Pratt, 2007).

Pacific-Indigenous peoples have differing conceptualisations of health, mental health, and disability to those of non-Indigenous conceptualisations (Tamasese et al., 2005). An example of this key difference in views is highlighted by the following statement: “when we [Pacific people] talk about mental health, it is not seen as a separate category of health. It is a part of the total health and wellbeing of people, land, and sea” (Tamasese, 2002, p. 68). Total health and wellbeing, when conceptualised through a Pacific-Indigenous lens, is more holistic than non-Pacific conceptualisations, incorporating the physical, spiritual, mental, familial, cultural, and other, including contextual factors, for example, as stated in the Fonofale Pacific health model (MoH, 1995). Currently, due to systemic factors, Aotearoa Pacific peoples continue to experience “longstanding and unacceptable health inequities” (MoH, 2020). To halt these inequities and change the health landscape for Pacific autistic young people, it is imperative to hear from Pacific parents of autistic children about their lived experience, support needs and use of existing services, and how they maintain their language and culture within their families. Due to Pacific peoples being the largest and fastest-growing youth population in Aotearoa New Zealand, research done with Pacific peoples will contribute to clinicians’ understanding and awareness of holistic Pacific health, in order to deliver services which are both responsive to the needs of Pacific peoples, and culturally competent (Ioane & Tudor, 2017). Mika deserves to be supported to live a ‘good life’⁵ in Aotearoa as a fully engaged, fully participating, Pacific young person with all the opportunities available to him, and to have his unique preferences and differences recognised and celebrated. To achieve this, Mika’s parents need to be supported to support him throughout his childhood, and later for Mika to live interdependently according to his preferences and capabilities.

Structure of the Thesis

The introductory chapters of this thesis set the necessary background for this study. Chapter 1 seeks to answer two questions critical to the overall research design, being: *Who is the researcher?*, and, *Why a holistic approach?* It does this by situating the researcher through the type of self-reflexivity needed to understand the researcher’s potential influence on the interpretation and results of the study, and through a consideration of the appropriateness of current psychological models of enquiry when working together with cosmologically interconnected and collective groups such as Pacific peoples. Chapter 2 introduces Autism Spectrum Disorder and considers navigation of referral, diagnosis, and support from the international to the Aotearoa context. Chapter 3 explores the current literature regarding parents’ experiences of raising

⁵ Enabling Good Lives is an approach that centres and supports the choices and agency of people with disabilities so that they can live their own vision of a good life, see: <https://www.enablinggoodlives.co.nz/about-egl/>

autistic children, including their experiences of diagnosis, available supports, the intersection with culture, and heritage language maintenance. Chapter 4 then describes Pacific peoples in Aotearoa, highlights the Pacific-Indigenous knowledge tradition including conceptualisations of holistic wellness and unwellness/disability, barriers to accessing support, and finally, outlines what is currently known about Aotearoa Pacific autistic children. This chapter ends with the research questions for this project. Chapter 5 presents the project methodology which combines Pacific methodological frameworks and methods in new ways, discusses the key ethical principles and considerations underlying these decisions, and presents information on the participants, and data collection and analysis processes. Chapter 6 provides a synthesis of the interpreted data from the project, with reference to what these insights might contribute to practice through a combined results and discussion format. Finally, the concluding Chapter 7 considers what we might have learnt from this study overall through a summary of practice implications for clinicians, what could be useful for the Aotearoa Pacific parents of autistic children who participated in this study, and ultimately, how we will know when we have got it right. This thesis, originally intended for submission with publications, is presented as a monologue due to its comprehensive findings requiring adequate explication. Consequently, the originally planned publications are in preparation for peer-reviewed Indigenous and autism-related journals.

Researcher Positionality

A Malaga Journey of Two Worlds (abridged)

Metal wings, soar

And land in Tāmaki Makaurau.

Far from the salty oars,

Of *va'a* lashed with sennit,

In the land of my forebears – *feagaiga, gafa*.

Brown, and white, merge.

Culturally rich,

Lives meet,

And entwine.

Before I ever knew, my name.

European strengths met Samoan

Strengths to fashion me.

...

But, “you don’t look Samoan”!

What, you’ve never seen an *afakasi* before?

“Are you sure you’re a Samoan?”, or, *looks me up and down* “...Half?”

How is it OK for you to question who *I* am? O a’u o se Samoa⁶.

I am not half of this, or half of that,

I am wholly, entirely, and fearfully and wonderfully⁷ me.

Who are you to divide me up and lessen my claim,

To my heritage, my *’āiga*, my *fanua*, my *toto*?!

Under my breath of course – because *fa’aaloalo*.

O a’u o se Samoa. O a’u fo’i o se Pālagi. In the *vā* of the duality is me.

When I could, I flew in metal wings of my own,

to join spirits with the *tuli* and *toloa* birds,

of the land of the other part of me.

Descending from the plane,

my throat caught as the warm trade wind, *mafanafana*, wrapped around me.

Unsolicited tears fell.

My wandering spirit had found its home, in the duality of me.

(Nafatali, 2019, unpublished).

Why is it important to know *who* is doing the research? Firstly, Pacific researchers do not enter the research arena as individuals, particularly when working with their own peoples (Meo-Sewabu, 2014). As part of our collective identity (see chapter The Pacific-Indigenous Worldview), a Pacific researcher carries their ancestors past, and relatives past and present with them. This confers both a sense of responsibility for the ethical fulfilment of the work, but also for impactful outcomes for Pacific communities (Anae, 2016). It further confers a warning that any carelessness and mistakes also impact on your community and your family, before they impact on you as an individual (Fa’avae et al., 2016; Meo-

⁶ Reference to Lemalu Samau Tate Simi’s poem Identity/O ‘oe se a? (Simi, 1992), Appendix C.

⁷ Reference to Psalm 139:14 (Holy Bible, NIV) which speaks of the deliberate and considered design of people.

Sewabu, 2014). Secondly, equally important is critical reflexivity, or knowing where and how your cultural and personal positioning, collective and individualistic influences and beliefs, impact upon and influence—or bias—your research (Braun & Clarke, 2022; Holmes, 2020; Mila-Schaaf & Hudson, 2009; Patton, 2015). Like all socially constructed activities, research is rarely value-free (Holmes, 2020).

In contrast with a quantitative approach, which seeks to remove all potential sources of bias entirely (Holmes, 2020; Patton, 2015), a qualitative approach seeks to know the fuzzy edges of researcher positionality, disclose them outright, and acknowledge that study results are filtered through these multiple lenses (Mila-Schaaf & Hudson, 2009). Positionality can change over time and researchers often occupy more than one position simultaneously (Fa'avae et al., 2016). Moreover, even an outsider can become an insider across multiple research contacts (Holmes, 2020). Qualitative researchers argue that a critical reflexive approach is advantageous to research rather than detrimental (Braun & Clarke, 2022; Holmes, 2020; Mila-Schaaf & Hudson, 2009; Patton, 2015) and I concur; quantitative approaches are limited in their ability to convey the human aspects and *context* behind numerical data. The *Tā-Vā* (context-rich, relational, and time) continuums reject being severed into neat bins or other numerical data forms devoid of their context and history (Māhina, 2010, as cited in Matapo & McFall-McCaffery, 2022). For instance, the experience of raising an autistic child is unquantifiable. As a student of clinical psychology operating from a scientist-practitioner model, I believe that both quantitative and qualitative approaches contribute uniquely to our knowledge base (Hopner & Liu, 2021). However, within both human-centred and Indigenous research, I believe that qualitative methods are best-placed to explore the nuances of human experience within psychological contexts (Braun & Clarke, 2022; Hopner & Liu, 2021). As an Indigenous researcher within *this* project and concerning the research questions being asked at *this* time and in *this* context, Pacific-Indigenous qualitative research methods are appropriate.

As an antidote to presenting compromised research, Holmes calls us to provide “a description of the researcher’s lenses (such as their philosophical, personal, theoretical beliefs and perspective through which they view the research process), potential influences on the research (such as age, political beliefs, social class, race, ethnicity, gender, religious beliefs, previous career), the researcher’s chosen or pre-determined position about the participants in the project (e.g., as an insider or an outsider), the research-project context and an explanation as to how, where, when and in what way these might, may, or have, influenced the research process” (Holmes, 2020, p. 4). This is a tall order indeed. Therein also lies an uneasy tension; that while on your own journey of heritage exploration you seek to uphold an Indigenous knowledge

tradition you are only coming to know yourself while amplifying your community's voices to the academy who you also in some way represent. It is a similar tension to being taught within the academy, writing this thesis to be accepted by and enjoined with the academy, and yet trying to decolonise my mind from the academy and think for myself. It is akin to the phenomena I have outlined in the poem above of straddling two peoples and worldviews...what happens when you are both? When discomfort is felt, some action is often required. What can one do but adapt and grow? If unity is the goal—as the Samoan *alaga'upu* says, “*e so'o le fau i le fau*”: in unity there is strength—then when you are left straddling two contexts you had better build a bridge! Not only for yourself but for those who come after you. For “*o le ala i le pule, o le tautua*”: the path to leadership is through service, or, to lead is to serve. Therefore, know what it is to be both, learn to know both, so that you may speak one to another and empathise with both. Turn the tension into ascension.

Ascension is not without its challenges. One of the regularly confronting challenges to claiming both identities is that “identity carries the burden of recognition” (Butler, 1995, as cited in Mila-Schaaf, 2013, p. 51). In no way could this burden be felt more viscerally than for a fair-looking person of Pacific heritage with green eyes (a gene mutation, just to throw them off) who enters a room of Pacific people. It matters not how perfectly you present yourself in your Samoan *puletasi* with hair appropriately pinned up and with a *sei* on the correct ear, politely bowing *tulou*. If you are not recognised, you are not accepted, and belonging evades you until you legitimise yourself, or better yet, others do (Mila-Schaaf, 2013). Within Pacific circles, I have always had to justify my existence. I am an unmarked body and therefore unrecognisable by my own (Mila-Schaaf, 2013). Yet, while living in “the space between is uncomfortable”, it can also be transformative and liberating if we allow it to (Tamaira, 2009, p. 1). Tamaira alludes to the duality conferring a *choice* of if and when to slide in and out and between cultures, which many Pacific peoples do not share the luxury of. Holmes speaks of a similar “conscious manipulation” where researchers have the ability to adjust their presentation across situations to suit their agenda (2020, p. 7). Identity has always been political (Mila-Schaaf, 2010). Choose to be the bridge.

On my Father's side I am a second-generation Aotearoa New Zealand-born Samoan, and on my Mother's side I am third-generation New Zealand European, Kiwi⁸/Pākehā⁹, or Pālagi¹⁰. My maternal Great-grandmother migrated here from Scotland in 1925, and my paternal Grandmother migrated here from Samoa (Luatuanu'u, Lau'i'i) in 1951. Both

⁸ Kiwi: vernacular for those of any ethnicity from Aotearoa New Zealand. Also, a flightless bird indigenous to New Zealand (Neill, 2018).

⁹ Pākehā: New Zealander of European descent (Moorfield, 2003-2022).

¹⁰ Pālagi: from Papālagi, a foreigner (Pratt, 2007).

Grandfathers' families migrated here from England. Therefore, both sides of my family are visitors and newcomers to this *whenua* (land), we are *tauiwi*. Born in Ōtāhuhu, South Auckland, I was a *tamariki whāngai*, child of informal intra-familial adoption, entrusted to my maternal Grandparents to raise. Within Pākehā families this is not that common, but was necessitated by the experience of mental illness within my families. I was fortunate to have grown up in a small coastal town in te Tai Tokerau Northland, which was home to approximately 1,500 people. There are a collection of similarly sized districts across the region. Living in a small town within Northland, Aotearoa—which is well-known for its meagre infrastructure and low incomes—among other things meant adapting from a small primary school of 100 children to travelling approximately 30 minutes each way to attend a large co-educational public high school of approximately 1,300 students.

The dearth of career opportunities and higher education available in the region for young people saw me move to Wellington to attend Victoria University of Wellington because of its reputation for Law, Psychology, and Languages. Education was my ticket out of the region and to avoid certain stereotypical outcomes ascribed to Northland. I believed in the power of psychology to inform the law and saw the most effective way to practice law as having empathy and insight into peoples' struggles and therefore achieving the best outcomes for them through the legal system. At the time, my goal was to graduate and take my skills back to Samoa to learn my history and the language while serving in the public service, the reverse migrant's dream. Half-way through second-year Law, I recognised the inability of the legal system as it stood (and largely remains) to achieve justice and to effect real change in Aotearoa, particularly for minority ethnicities because of the inherently unjust and oppressive power structures and assumptions built into the law. Predicting a future of burnout and frustration ahead, I decided to concentrate on intervention at earlier points in people's lives which saw me continuing with Psychology. I met my husband at Victoria University through the Samoan Students' Association. Two years later we married and approximately 11 months later our son Israel¹¹ was born. My family became an immediate and present priority.

Israel was a beautiful and robust, healthy child who for all intents and purposes appeared to be developing perfectly normally according to his age. And yet on reflection with the knowledge we now have, there were signs. Although he seemed advanced in some areas—he would stand on a chair and read aloud the Keno numbers from 18 months old—he was behind in others such including gross motor movement, social interaction, and non-verbal communication. After

¹¹ Israel has given me permission to write about his story and to use his real name.

his initial words gained at the normal age he developed language very slowly and then regressed. At three years old a child should have 1,000 words and he had 140, many of which only I could 'translate' for others. Then repetitive self-stimulatory and focused behaviours became more prominent, and sensory overwhelm became a regular and distressing feature. Although he apparently had many of the 'classical' signs of autism, our concerns were dismissed by several health professionals—they reasoned that he was bilingual, a male child, had experienced many ear infections, and was not yet warranting concern. This continued until he was two and a half years old when his *a'oga amata* (Samoan language preschool) referred us to the Ministry of Education for developmental assessment. Israel was consequently diagnosed through the public Child Development Service at the age of three years and seven months. Imagine the shock—having consistently been told that our beautiful and affectionate son was developing normally—when Israel was diagnosed with a Global Developmental Delay of 18-26 months across all domains, and Autism Spectrum Disorder. We had never even heard these terms and had no understanding of them.

As a Pacific mother of an autistic child, I found cultural explanations of my child lacking. I knew of the conceptualisation of *ma'i*, and I had experienced first-hand its ugly judgment. What I wanted to know was more about how this related to Pacific knowledge traditions, and how widespread these beliefs were for contemporary Pacific peoples. I also wanted to find other, more positive narratives that could be harnessed (like the First Peoples' narrative of people with disabilities as higher evolved beings, or the Latinx Catholic narrative of children with disabilities as blessings [Welterlin & La Rue, 2007]), within our Pacific consciousness. As an able and neurotypical¹² parent to a neurodiverse Aotearoa Pacific young boy—as one father opined—"I wanted to understand my [son] as well as a neurotypical parent with [my] own limitations and [my] own biases can understand a neurodiverse child. I am full of flaw and misconception. I am full of error. And so is the language at my disposal to articulate an experience not mine" (de la Paz, 2019, p. 3). I recognise that I can never understand the autistic experience fully, because I am not autistic. I am a parent of an autistic child. Therefore, within my research I am not attempting to present or to know the autistic experience, but I am attempting to present the experiences of other Aotearoa Pacific parents of autistic children to hopefully indirectly influence the experience of Aotearoa Pacific autistic children. This story is not my son's, nor mine, but we are part of the collective whom we represent.

¹²Neurotypical meaning the most common neurotype. All neurotypes are normal, regardless of commonness (Fletcher-Watson, 2022).

Caring had always been a major feature of my life although I never knew it was a large part of Pacific culture. Parenting an autistic child also confers significant extra care, particularly in the pre-school years. These combined experiences have given me some idea of the holistic experiences, both blessings and challenges, that befall a family carer and so my first research question concerns where/whether these experiences converged or diverged from others' experiences and how caring within traditional Pacific families looked.

Language is also an important thread within this thesis. Language is both used to name and to describe and as such has been used as a tool to allow non-Indigenous knowledge traditions to remain privileged in most circles (Smith, 2021). Within Aotearoa, "English prevails without critique" (Samu et al., 2019, p. 131). Language, as a marker of group membership and authenticity, has also been found to be critical to a strong identity, wellbeing, and mental health (Mila-Schaaf, 2013), and is hypothesised as a marker of the health and productivity of cultural groups (Samu et al., 2019). Language loss, then, puts these factors at risk. Simultaneously, language is also political and can be used as a tool of inclusion and exclusion within communities (Smith, 2021). For example, Pacific communities often ascribe group members' level of belonging according to language proficiency (Samu et al., 2019). Pacific language loss in Aotearoa is a direct and deliberate result of the colonisation process and associated behaviours of the generations before us. For example, the language of trade and instruction in Aotearoa is English, and many Pacific migrants and diasporic parents and grandparents decided against the teaching of their heritage languages due to beliefs about succeeding in a Pālagi world, thus devaluing heritage languages (Samu et al., 2019). Those authors contended, a compounding issue is the lack of ecologically valid opportunities to learn Pacific languages within the community. Besides their centrality to identity and wellbeing, heritage languages are also critical to cross-generational communication (Howard et al., 2021). Consequently, there have been many community-led movements of reclamation¹³ for Pacific languages as, until recently (mpp.govt.nz), communities struggled to gain traction with successive governments (Samu et al., 2019).

With this history, it was intensely important to me that my children learnt their heritage language from a young age and so Israel was enrolled in a'oga amata from 10 months old. He significantly benefitted from this environment of immersion and Pacific caring. However, once he was diagnosed we were advised that he would be better served at a "mainstream" ECE as a'oga amata have diminished resources for educating neurodiverse children. This felt like grieving

¹³ such as Pacific language nests, Pacific Language Weeks, Aganu'u Fa'asamoa 101, O a'u o se Samoa, etc.

a death as I saw Israel's opportunities for learning his heritage language and enjoying an engaged Aotearoa Pacific identity disappear before my eyes. As Israel grew and we grappled with issues of language development, I knew that we could not be the only family of autistic children who were faced with these challenges and wondered how other families dealt language and culture maintenance. I wondered what we could learn and share about the unique and creative ways in which Pacific peoples adapt the teaching of language and culture with their autistic children. This became another key research question.

Education is often touted to Pacific peoples, and has been internalised, as a requirement or the destination of success and wellbeing (Dunlop-Bennett, 2019; Paterson et al., 2016; Taleni et al., 2018). However, Pacific peoples' engagement and achievement within the Aotearoa education system has been fraught with tension (Matapo & Teisina, 2021; Matapo & McFall-McCaffery, 2022). It has always perturbed me that Aotearoa seemed content with the educational achievement statistics of Pacific peoples consistently being behind NZ European/Pākehā and Asian, and Māori (Mila-Schaaf, 2013; www.tapasa.tki.org.nz), as if somehow the learning capacities of Pacific peoples were patently less. I experienced this many times while working in the Pacific office of a large Aotearoa university. Some researchers inculcate acculturative processes which privilege certain ideals at the loss of important others (e.g. Mila-Schaaf, 2013; Matapo & McFall-McCaffery, 2022), effectively forcing Pacific peoples to 'leave themselves at the door' to succeed within hostile educational environments (Makasiale, 2007; Tu'itahi, 2018). Yet Pacific peoples—or any Indigenous peoples—are not born with some missing element which affects their inherent capacity for intelligence or achievement; it is the wider (socio-historic -economic, -political, -legal, -cultural, -educational and -environmental) systemic conditions that we live in which ultimately determine our achievement and education level within Aotearoa (e.g. Matapo & Teisina, 2021; Simpson, 2021; Taleni et al., 2018).

In addition, success in academia "prescribes a particular subjectivity of the student or academic, which is often aligned with liberal and neoliberal 'traits' that are not always conducive to Pasifika ways of being and knowing" (Matapo & McFall-McCaffery 2022, p. 122). For example, viewing academic achievement as "economic self-interest" (Matapo & McFall-McCaffery, 2022, p. 128), which as a concept of individualism is anathema to Pacific peoples (Matapo & Teisina, 2021). While my pursuit of education was motivated by achieving entry into spaces and places where I would be able to serve others and effect change, I began to discover that I did not have the whole picture—the knowledge I was seeking was not *the* reality, but *a* reality. I began to ask questions such as "whose knowledge matters", "where are the other

knowledges?”, and to question how or if the various psychological theories and knowledge I was learning recognised Māori and Pacific communities, and to what end? I am still learning the answers to these questions, but what I know now is that knowledge comes in many forms and to be an ethically sound researcher it is our responsibility to be conversant in several knowledges. The choice to follow a holistic and strengths-based approach to the study of Pacific parents’ experiences of raising autistic children is therefore partly about casting off the negatively skewed descriptions that others write about us in favour of writing our own descriptions and sharing what works for us. Thus, I choose to situate myself as an ‘insider’ and declare an emic approach within this research. I further choose to use my ongoing education in multiple knowledges, to illuminate the experience of our people in the specific area of autism and thus inform both knowledges of that experience.

And so in weaving together threads of psychology, education, culture, caring, and language through my specific socio-cultural historical context, I have endeavoured to articulate my positionality thoroughly. I have outlined several intersecting identities, including as an Aotearoa New Zealand citizen of mixed European and Pacific heritage, a cis-gendered heterosexual White-passing working-class Christian female (in the 35+ age bracket), an able and neurotypical parent, a Western¹⁴-educated emerging Pacific researcher and intern clinical psychologist scientist-practitioner. Each one of these lenses brings with it experiences, beliefs, and biases. Holmes cautions that being reflexive is “not a guarantee of higher quality or more ethical research” (2020, p.3). Like Johari’s Window (Luft & Ingham, 1955), there are always parts forgotten, naively missed, or deliberately left out of the narrative. In anticipation of not covering all of my blind spots, *ua fa’amagalo mai pe āfai ua iai se upu ua sesē*, I humbly ask that you forgive me of any missteps and unintended mistakes that may belie my immaturity and naivety as a learner and researcher. *Tulou*.

A Holistic Approach

The seminal work of Russian psychologist Lev Vygotsky in the late 1970’s formed the basis of socio-cultural theory (Alefaio-Tugia, 2015), and in the 1980’s, his work on child development—particularly the Zone of Proximal Development—was informative to the field of learning and education (Assailly, 2022). Vygotsky’s work then had a significant influence on education and continues to do so today (Macfarlane, 2015). Unfortunately, many of Vygotsky’s theories received less attention within the clinical psychology space over the past 50 years or more, perhaps due to

¹⁴ “Western” in this thesis takes Henrich and colleagues’ definition: “those countries clustered in the northwest of Europe (the United Kingdom, France, Germany, Switzerland, the Netherlands, etc.), and British-descent societies such as the United States, Canada, New Zealand, and Australia” (2010, p. 83).

psychology's continuing battle with its inherently Western and bio-medical roots and heavy focus on symptoms and symptom alleviation (Alefaio-Tugia, 2015; Bennett et al., 2014; Cammock et al., 2021; Simpson et al., 2021). Modern clinical psychological science by contrast, appears to be heading towards a more dimensional view of mental distress (APA, 2013), and aims to produce targeted, ecological intervention where attenuation of client distress over their symptoms is optimised rather than diagnostic labels. This change in focus has led to a popularisation of ecological and systemic models within clinical psychology, including Bronfenbrenner's Ecological Systems Theory in formulation (1979, as cited in Ryan, 2019), and Systems Theory in family systems therapy (Priest, 2021). Around the same era, the Bio-Psycho-Social model became prominent as a particular ecology applicable to psychology (Engel, 1977). Within the bio-psycho-social model, biologically based predispositions and vulnerabilities make way for psychological phenomena to occur, which are precipitated and maintained through and within the particular social context (environment) of an individual (Listopad et al., 2021a). Including historical and cultural context and the importance of relationships within child psychological development would make it seem that Vygotsky's theories were proffered ahead of his time.

Despite the value brought to psychology through the bio-psycho-social model, the model itself and the discipline of psychology have often been criticised for their monocultural and constricted ontological and epistemological bases (e.g.: Carr, 2016b; Fa'alogo-Lilo & Cartwright, 2021; Gaines, 1991; Hopner & Liu, 2021; Mila-Schaaf & Hudson, 2009). Psychology's reductionist paradigm has led to an overall lack of acknowledgement of culture and context (Hopner & Liu, 2021). The bio-psycho-social model has also been self-limiting through the exclusion of spirituality and other crucial yet missing components such as people's sense of belonging, and the meaning of work (Listopad et al., 2021b; Te Pou, 2010). Psychological intervention has largely thus only been effective with people of Western Educated Industrialised Rich Democratic nations from whence the research originated (WEIRD; Henrich et al., 2010). Consideration of context and culture within psychological formulation is important, not least of all because "human activity and cognitive functioning do not occur in a vacuum" (Macfarlane, 2015), but importantly because these necessities flesh out the whole, situated person (Foulis et al., 2022). Further limitations to psychology's continued development have been denial of the contributions which Indigenous thought and practices have made to psychology over time (Hau'ofa, 1994; Johnson-Jennings et al., 2020).

Consequently overall, psychologists' competence in treating clients from backgrounds with knowledge bases and world views other than Western, are lacking (Botha et al., 2021; Levy, 2018). Psychology is now at the point of acknowledging some of these failures, however, remains unsure as to how to proceed in adequately addressing these

issues. The ever-expanding scope of the now proposed Bio-psycho-socio-spirito-cultural model (Esch, 2019, as cited in Listopad et al., 2021a) may be able to offer a bridge, however, Indigenous models and models further contextualised to specific populations might be the gold standard we seek (e.g.: Fonofale; MoH, 1995; the Meihana Model; Pitama et al., 2007). It is from this widened lens, taking into account the ecological context of a person, including their cultural and spiritual selves and their familial and social relationships—in this project, called holistic—that this project is conceptualised. A 'one-size-fits-all' policy is not appropriate or effective in increasing accessibility to services and support, therefore the development of *both* ethnic-specific and pan-Pacific approaches to health and disability support are critical (Kapeli et al., 2020).

A pan-Pacific approach is taken within this research because of the lack of research representing Pacific peoples within the autism field altogether. This study will provide the first research from a Pacific perspective which can then springboard further in-depth research and intervention design, for all Pacific groups. The following sections locate the clinical focus of this study as being with Aotearoa Pacific parents raising autistic children. However, due to the dearth of research on Pacific autistic people the literature review requires triangulation. Literature is therefore brought together from several disciplines, including Pacific and Indigenous studies, health, disability, nursing, education, social work, Pacific and Indigenous psychology, and clinical psychology.

Chapter 2: Autism Spectrum Disorder: From the International to the Local Context

Autism Spectrum Disorder (hereafter, autism) is the current¹⁵ diagnostic term for a group of neurodevelopmental conditions which can have profound effects (evinced differences, challenges, and strengths) on child and adult functioning; including on learning, development, and the formation and maintenance of close relationships (APA, 2022). Autism, first articulated by neurologist Kanner in 1943, has markedly evolved over time from its original description (Carr, 2016a). What is known to be autism now is experienced as a constellation of traits across a vastly heterogeneous spectrum; with the severity and specific presentation of symptoms varying greatly between people (Bevan-Brown & Moldovanu, 2016). In fact, the heterogeneity of autism causes problems for its validity as a diagnostic 'disorder' (Doyle et al., 2021; Mandy, 2018), however, an autism diagnosis still has clinical utility (APA, 2022; Mandy, 2018). Autism has early developmental onset and often lasting, pervasive effects across contexts in two key areas, both of which are required for diagnosis. These areas are: 1) social communication and interaction; and, 2) self-stimulatory/self-regulatory repetitive sensorimotor behaviours (stimming), and focused activities and/or interests (APA, 2022; Kapp et al., 2019). The etiology of autism is multifactorial, comprising both biological factors including a genetic contribution, and environmental factors such as the in-utero environment and other contextual factors (Le Couteur & Szatmari, 2015). Historically, the diagnostic sex ratio for autism disproportionately favoured males approximately 5:1 (Drysdale & van der Meer, 2020; Myers et al., 2019). Researchers found that females were often underdiagnosed and diagnosed later than males due to presentations that varied qualitatively from males, due to both symptoms and assessment findings being interpreted through socio-culturally-constructed gender roles (Lai et al., 2015). However, there is evidence that due to diagnostic overshadowing, autistic females' tendency to camouflage symptoms (masking), and professionals looking for a male autism phenotype, gender disproportionality in autism was a fiction (Happé, 2019). The purported true sex ratio favours males at a lesser rate of 3:1 (Loomes et al., 2017, as cited in Happé, 2019).

The previous Diagnostic and Statistical Manual, Fifth Edition (DSM-5; APA, 2013) collapsed former categories of Asperger's Syndrome, Autistic Disorder, and Pervasive Developmental Disorder – Not Otherwise Specified, into an overarching, singular Autism Spectrum Disorder label (Broadstock, 2014). Further, a new condition was included termed Social (Pragmatic) Communication Disorder, where the social and communication deficits of autism are present, without

¹⁵ Autism Spectrum Disorder has been known as 'Autism/Classical Autism/Infantile Autism/Childhood Autism' and 'Asperger's Syndrome/High Functioning Autism'.

the repetitive and/or focused behaviours, activities, or interests (APA, 2013). Asperger's syndrome was described by Hans Asperger in 1944 as a condition with social communication difficulties, and without marked intellectual or language impairment (Carr, 2016a). There is much controversy over the disadvantages and benefits of collapsing experiences, identities, and labels in this way, for example, strong opinions that the two conditions are qualitatively different and should therefore be acknowledged as separate entities (Le Couteur & Szatmari, 2015). In agreement, researchers have stated that autistic "individuals may choose to refer to themselves using their own terms of belonging" and that autistic people have "a culture that transcends psychiatric diagnosis" (Broadstock, 2014, p. 9). The ways in which culture and autism interact as one feature of lived experience is a key focus of this study and is therefore discussed in more detail in a later section.

In the Diagnostic and Statistical Manual, Fifth Edition, Text Revision (DSM-5-TR; APA, 2022), functioning labels are assigned based on the level of support required for the autistic person to function at subjective acceptable levels, and the level of inflexibility of the person's behavioural repertoire so that 'mild' designates requiring minimal support and 'severe' refers to requiring substantial support (Kasilingam et al., 2021). Specifiers are also included, to denote the presence of intellectual impairment, language impairment, or co-occurrence with medical, behavioural, environmental, neurodevelopmental, or psychological impairments (APA, 2022). One study in Aotearoa found that most autistic individuals are not intellectually impaired, however, a more recent study found high levels of co-occurrence with Intellectual Developmental Disability (IDD: APA, 2022; Te Pou, 2016; c.f. Bowden et al., 2020). Language delays affect clinical presentation but are not a required criterion, as language impairments are not pathognomonic to autism (APA, 2022; Barokova & Tager-Flusberg, 2018; Carr, 2016a). However, it is common for autistic individuals to experience either a period of language regression or delays in language progression during preschool years (Carr, 2016a, c; Le Couteur & Szatmari, 2015). The following section briefly highlights the current epidemiological evidence for autism prevalence rates.

Autism Prevalence Rates

Globally, prevalence rates of autism diagnosis are trending upward, reflective of a suspected growing phenomenon (Baio et al., 2018; Drysdale & van der Meer, 2020; c.f. Happé, 2019). It remains unclear whether the observed diagnostic increase is due to a real increase in numbers, or whether the increase is due to factors such as the establishment and later changes in the DSM-5 diagnostic criteria for autism (APA, 2013), more refined developmental assessment tools, increased services and support available, and streamlined referral processes leading to more likely diagnoses (Carr,

2016a; Drysdale & van der Meer, 2020; Fombonne, 2020; Le Couteur & Szatmari, 2015; MoH/MoE, 2016; Myers et al., 2019; Ooi et al., 2016; Ramsey et al., 2016). In addition, growing professional and public awareness is likely contributing to higher rates of autism diagnosis (Carr, 2016a; Drysdale & van der Meer, 2020). Autism researchers opine that all of these factors are likely to be occurring, plus a natural increase in autism population over time (Carr, 2016a). Current prevalence rates for autism diagnosis in the United States of America (hereafter, US) are as high as 1:44 in children aged eight years old, up from 1:68 previously (Maenner et al., 2021). One recent US study based on the 2014 health data of 1,133 'Native Hawaiian and Pacific Islander' children aged three to 17 years reported a weighted prevalence rate of autism of 1.2% (14:1,133), however, noted that this figure was likely underestimating (Payakachat et al., 2019).

In Aotearoa, no epidemiological or population-level published data exists on autism prevalence rates as the national health system does not systematically collect this data (Drysdale & van der Meer, 2020). An earlier Aotearoa disability workforce report estimated that there were 47,000 autistic citizens (Te Pou, 2016). Autism NZ's website estimates¹⁶ that there are currently 93,000 autistic people in Aotearoa (www.autismnz.org.nz)—suggesting a two-fold increase in six years. In addition, the New Zealand Health Survey 2019/2020 data estimated that general autism prevalence in children under the age of 14 years was 2.5%, or approximately 21,000 children (MoH, 2021), significantly increased from 1.6% and 13,000 children in 2018 (MoH, 2018a). Until recently, only small-scale prevalence studies had been completed in Aotearoa. The first study in Aotearoa to estimate autism prevalence in young people using linked administrative health data found a prevalence rate in those under eight years of 1:102, with a total number diagnosed of 7,356 under 14 years of age (Bowden et al., 2020). However, the authors cautioned that the study was aimed at establishing the utility of administrative data to track autism diagnosis trends, and not an official prevalence study due to known data gaps. In addition to incomplete data, autism prevalence figures are presumed to be underestimates due to several issues discussed later, which have led to underdiagnosis and misdiagnosis internationally (Bernier et al., 2010; Bowden et al., 2020; Mandell et al., 2002, 2007; McPartland et al., 2012; MoH/MoE, 2016). Prevalence rates also vary as a function of methodological differences in the way study data is collected, differences in what data is collected across health settings, and variance in diagnostic practice (Drysdale & van der Meer, 2020). For example, in the Bowden and colleagues study, Childhood Disintegrative Disorders were included within the autism category (2020). Overall, Myers and

¹⁶ Autism NZ uses the current CDC autism estimates (www.autismnz.org.nz).

colleagues (2019) stated that “under-identification [is] a widespread phenomenon” and that “prevalence estimates must be understood as underestimates of “true” prevalence rates” (p. 28).

Within the Aotearoa Pacific community, approximately 19% or 51,000 people live with a disability of some kind, and an estimated 9,000 of those are children (Le Va, 2014; MacPherson, 2014). Prevalence rates of autism within the Aotearoa Pacific community have not been systematically studied (Bevan-Brown & Moldovanu, 2016; MoH/MoE, 2016), however, the latest available estimate suggests that the prevalence rate for Pacific children under 14 years was 3.2% or an estimated 4,000 children (MoH, 2021). The adjusted odds ratio for Pacific children was 1.38 compared with the comparison group of non-Pacific children (MoH, 2021). Prior to this, the estimated prevalence rate for Aotearoa Pacific children was approximately 1.1% or over 1,000 children (MoH, 2018a).

Specifically in relation to Aotearoa Pacific prevalence rates, hints at underestimation can be seen. One study concentrated in a suburb of the greater Wellington region between 2012-2016, revealed an overall diagnostic prevalence rate of 1.48:1,000 (Drysdale & van der Meer, 2020). Of the 228 autistic young people in that study, over half (55.2%) identified as New Zealand European, just under a quarter (23.6%) were New Zealand Māori, and just 4.4% were Pasifika (10 children). That study noted that the Pacific diagnosis rate was lower than the Pacific population rate in the region at the time (compared with a 23% diagnosis rate for Māori which was higher than the Māori population of 15%). As well, the current patronage of the Pasifika Autism Support Group Facebook page which is predominantly Auckland-based has almost 2,500 family members (compared with the 2018 national estimate of 1,000 diagnosed Pacific children; <https://www.facebook.com/PASGNZ>).

While they acknowledge significant delays and lower rates of diagnosis within ethnic communities, Le Couteur and Szatmari (2015) stated that the increased sensitivity and specificity of the revised DSM-5 criteria provided more accurate diagnosis than previously. Regardless of how accurate reported prevalence rates are, for families who receive a diagnosis, a range of support and interventions become available which requires much navigation. Both parents and professionals have reported difficulties in accessing supports post-diagnosis, for example, one parent stated, “after diagnosis, there is often a ‘black hole’ for families” (Crane et al., 2018; MoH/MoE, 2016, p. iv). The next section outlines the current position regarding universal early screening for autism in Western countries including Aotearoa, and the early intervention and support available to families in Aotearoa once an autism diagnosis is received.

Autism Screening and Early Intervention

Internationally, it is recognised that early intervention with autistic children produces better outcomes for the child and their family (Brett et al., 2016; Carr, 2016a; Downes et al., 2021; MoH/MoE, 2016; Sansosti et al., 2012; Zwaigenbaum et al., 2015). Early intervention with autistic children is typically focused on the development of motor and communication skills, social behaviour and reciprocity, and a reduction of any harmful and self-injurious behaviours (Kasilingam et al., 2021). Without evidence-based early intervention, symptoms tend to remain unchanged (Shochet et al., 2020). However, to receive funded early intervention supports, diagnosis is required (Evans et al., 2022). Globally, official diagnosis tends to occur between 4.5-7 years of age, which for families means long delays to accessibility for intervention support, disability funding, or autism-specific services (Boshoff et al., 2019; Brett et al., 2016; Gibbs et al., 2019; Sansosti et al., 2012). Diagnosis also takes longer for children with higher verbal and cognitive capacities (Crane et al., 2018). Typically, parental concern around their child's development heightens between 12-18 months when the child does not show or respond to affection, has reduced eye contact, is slow to develop verbally, has difficulties eating or sleeping, is emotionally dysregulated, and may show disruptive or challenging behaviours (Assailly, 2022; Le Couteur & Szatmari, 2015; Ooi et al., 2016). Between 17%-30% of parents are concerned before their child is 12 months old (Assailly, 2022; Crane et al., 2016), and mounting evidence states that many children under 24 months of age can be reliably diagnosed (Johnson & Myers, 2007; Zwaigenbaum et al., 2015). Universal screening could capture children likely to be diagnosed during early childhood checks through clinical observation, parent concerns, and use of standardised autism screening tools (Waddington et al., 2022b). While the American Academy of Pediatrics has recommended universal autism screening practices for children since 2007, there had been mixed uptake on screening in the US, due to concerns of inadequate screening tools and a lack of screening outcome evidence (Johnson & Myers, 2007; Zwaigenbaum et al., 2015). The United Kingdom National Screening Committee recommend against early screening for autism. The Committee were taking submissions, and cited reasons for their current position being, a lack of specificity and sensitivity of current screening tools, a lack of evidence of positive outcomes following early screening, and parents' unacceptability of screening approaches (UK National Screening Committee, 2022).

Aotearoa researchers also agree that early intervention with autistic children is critical (Bevan-Brown & Moldovanu, 2016; Kasilingam et al., 2021; Wallace-Watkin et al., 2021). Early intervention is defined as intervention implemented before the age of five years and before the child begins primary school (MoE, 2022). In Aotearoa, small

studies have estimated the average age at autism diagnosis is 6.4-6.6 years old (Eggleston et al., 2019; Drysdale & van der Meer, 2020). This reported average is likely to be conservative currently, due to COVID-19 disruption lengthening delays to assessment globally over the past three years (Jang et al., 2022). Early screening could assist with earlier diagnosis, yet while Well-Child/Tamariki Ora (WCTO) nurses in Aotearoa are well-placed to provide autism screening services, routine screening for autism is not yet underway (Waddington et al., 2022b). The authors proffered the Social Attention and Communication Surveillance-Revised scale (SACS-R)—developed by La Trobe University’s Autism Research Centre—as a potentially appropriate and user-friendly tool for use in Aotearoa, but called for more research on its psychometric soundness and best-practice referral processes. Recent implementation of the SACS-R with Aotearoa WCTO nurses showed high acceptability, increased autism sign knowledge, and confidence in the SACS-R, however, all of these decreased at 3-8-month follow-up (Waddington et al., 2022b). Phenoscreening is an interesting new approach to neurodevelopmental screening which may provide better clinical utility (Doyle et al., 2021). Phenoscreening proposes the use of Research Domain Criteria to screen for multiple at-risk developmental profiles in young children rather than a singular ‘autistic’ profile which, due to autism’s heterogeneity, could lead to high rates of false-negatives and misdiagnoses (Doyle et al., 2021). Using transdiagnostic criteria and a dimensional approach could be an improved strategy to describe treatment targets for individuals, particularly those with heterogeneous autism presentations, and co-occurring features (Doyle et al., 2021; Pacheco et al., 2022).

For now, the New Zealand Ministries of Health and Education advocate for primary health professionals to discuss individual child development and any concerns with parents at a minimum between 8-12 months, again between 2-3 years, and again between 4-5 years (MoH/MoE, 2016). The Ministries stated that these baseline checks were intended to address any potential developmental delays in a timely manner and for parental concerns to be heard and responded to quickly. Unfortunately, despite the intention to address parents’ developmental concerns early, many parents—particularly first-time parents—would not know what to look for in recognising milestone delays or idiosyncratic behaviours due to a lack of comparison and child developmental knowledge (Crane et al., 2018; Lilley et al., 2020; Ooi et al., 2016). Thus, early intervention for many autistic children in Aotearoa remains elusive.

Two studies had surveyed a small sample (n=64) of Aotearoa parents/caregivers of autistic children on what types and the amount of early intervention their children were receiving¹⁷ (Kasilingam et al., 2021; Wallace-Watkin et al., 2021). The authors found most children were receiving two interventions (publicly funded speech and language therapy, 51.6%, and education support workers, 39.1%), but parents would have liked them to receive an average of five further interventions¹⁸ (Kasilingam et al., 2021). Importantly, publicly funded speech and language interventions were not directly provided to the child, but rather advised parents and teachers working with the child (Wallace-Watkin et al., 2021). Just under half of respondents' children were receiving less than 10 hours of intervention monthly, far short of the recommended 60-100 hours monthly, which only six respondents' children were receiving (MoH/MoE, 2016). The most commonly provided early interventions were "speech and language therapy, intervention through a teacher or education support worker, specific parent education or training programs, occupational therapy, ABA therapy, general parent education or training programs, and intervention through a psychologist" (Wallace-Watkin et al., 2021, p. 3,200). It is clear that parents found the types and amount of publicly funded early intervention supports inadequate to meet the needs of their autistic child/ren, and some parents were privately funding services to help meet this need (Wallace-Watkin et al., 2021).

Support and Services for Autism in Aotearoa

The Disability Support Services arm of the Ministry of Health (MoH, 2016), and the Learning Support unit of the Ministry of Education (MoE, 2020), provide support and allocation of services and funding to families in Aotearoa. The Ministry of Health provides autism-specific supports, including Disability Information and Advisory Services, parent education (ASD Plus, TIPS for Autism, Growing up with Autism), Communication and Behaviour Support, and Developmental Coordination (MoH, 2018b). Ministry of Health Disability Support Services provides several types of funding for people with disabilities, including: "home-based support, respite and carer support, equipment and other environmental supports, and community residential support" (MoH, 2008b, p. 11; MoH, 2022b). According to diagnostic best-practice (Carr, 2016a), the Ministry of Health through the Child Development Service, provide government-funded diagnostic services within a multidisciplinary team typically consisting of a developmental paediatrician, a clinical psychologist, and a

¹⁷ The same sample was used in both papers and included four children of mixed Pacific/non-Pacific ethnicity (Wallace-Watkin et al., 2021).

¹⁸ In ranked order: "Behaviour support (53.1%), Music therapy (48.4%), Intervention through a teacher/education support worker (45.3%), Speech and language therapy (43.8%), Occupational therapy (42.2%), Intervention through a psychologist (39.1%), Routine/play-based interventions (39.1%), Specific parent education/training programmes (32.8%), ABA therapy (Applied behaviour analysis) (29.7%), and Relationship based programmes (26.6%)". Information taken from Table 3 (Kasilingam et al., 2021, p. 529).

speech and language therapist/pathologist (MoH/MoE, 2016; MoH, 2018c). Occupational therapists are also available through this team, and behavioural support referrals can be made (MoH, 2018c). Additionally, Ministry of Education Learning Support (formerly Special Education) coordinates early intervention services including education support workers (teacher aides for preschools), early intervention teachers, speech and language therapists, and manage the transition from early childhood education to primary school (MoE, 2021). Further government-funded supports included parenting programmes, autism-specific workshops, employment brokerage and other broad disability support services for autistic people (Te Pou, 2016). Publicly funded interventions focused on the provision of professional advice to parents rather than direct therapy intervention with the child, while privately funded services were necessary to obtain intervention delivered directly to the autistic child (Wallace-Watkin et al., 2021).

Without a diagnosis, none of the above-mentioned supports are available to families. One complication leading to long lead times or non-engagement with diagnostic and support services is that early intervention requires engagement with health services such as regular GP and/or nurse visits; through WCTO and Plunket early years services; early childhood education; or other social or health organisations (MoH/MoE, 2016). Referrals are made from primary health professionals to public or private diagnostic services, for example, paediatricians, the Child Development Service, or private practitioners, to gain an official diagnosis (Eggleston et al., 2019). Where engagement from health and social organisations has not been effective with families and clinician knowledge of autism is low, referrals for diagnosis are unlikely to eventuate (Waddington et al., 2022b). Variations in cultural beliefs, geographical location, and lower socio-economic status, are further hindrances which led to delays in diagnosis and lower rates of diagnosis for affected families (Bilaver et al., 2021; Myers et al., 2019). To provide evidence-based guidance for decision-makers on the diagnosis and management of autism support, the Ministries of Health and Education (2016) produced the New Zealand Autism Spectrum Disorder Guideline (Guideline). The Guideline's goal is to facilitate improved outcomes for autistic people's lives across health, education, and social domains (Te Pou, 2016; MoH/MoE, 2016). The 2016 update collated several adjunct supplementary papers, providing empirical and practitioner guidance in specific areas including various therapies, co-occurring physical conditions, and the impact of ethnicity on diagnosis, education, treatment, and support (MoH, 2018d). The Guideline's second edition (MoH/MoE, 2016, p. 220) set out recommendations regarding better serving Pacific autistic people which remained unchanged in the third edition (Whaikaha, 2022; see Appendix F). Regrettably, it appears that little

traction has been made towards these recommendations, likely due to little resourcing and no follow-up or incentivisation for health professionals to adapt their practice.

A number of non-governmental organisations support families with autistic children in Aotearoa. Altogether Autism, and Autism NZ (now incorporating the Children's Autism Foundation), support families with autistic children nationwide. Parent to Parent is a not-for-profit nationwide network providing information and support groups for parents of children with all disabilities and is connected to Altogether Autism. The IHC provides services to families of children with intellectual disabilities, some of which are government funded. At the time of writing, Autism NZ received government funding to provide several autism programmes and workshops for parents of autistic children and professionals, an outreach service, a pilot low-cost diagnostic service (Wellington only), and an employment brokerage and transition service (www.autismnz.co.nz). In addition, Altogether Autism was funded for the provision of their research and advisory services to the wider autistic and autism communities (www.altogetherautism.org.nz). A small number of not-for-profit groups have also successfully supported families in Aotearoa. Auckland Whānau Special Needs Support Group is a grass-roots organisation—established by parents seeking to support other parents. The Pasifika Autism Support Group and the Chinese Autism Families Support Group were also both started by parents in Auckland who desired connection with other like-minded families who sought a cultural frame of reference (Te Pou, 2016) and who could not wait for public services to provide families with support. These parent-run organisations are increasingly being asked to engage with members on behalf of government agencies and other organisations due to their successful outreach (Trezona, 2018).

There is a dearth of Aotearoa-based research with the autism community (Bevan-Brown & Moldovanu, 2016; Whaikaha, 2022). Particularly lacking is data relating to the demographic information of families of autistic children and their access to support services (Te Pou, 2016; MoH, 2013; MoH/MoE, 2016). A 2013 disability workforce status report found that just 16% of all disability support service-users in Aotearoa were families of autistic children (MoH, 2013). Within this small group, the most commonly accessed disability support service was carer support funding, and few families were accessing this (MoH, 2013). The *Demographic Report for Clients Allocated the Ministry of Health's Disability Support Services: 2018 update* reported on those receiving Disability Support Services funding in Aotearoa up to September 2018 (MoH, 2019). The report stated that 23% of funding recipients were autistic, and a total of 4,997 children under 14 years received funding for autism as their principal disability (MoH, 2019). The updated report represented a 7% increase in all families accessing disability support services specifically for autism over five years.

Autism Intervention in Aotearoa

There are no government-funded direct therapy interventions for autistic children in Aotearoa (Wallace-Watkin et al., 2021). Families must learn about and decide on the type/s of therapy that they want for their child, navigate where and how these therapies are accessible and effective, and cover them financially. Without opportunities for behavioural, social-cognitive, educational, and other interventions, quality of life for autistic individuals and their families can be unnecessarily limited (Welterlin & La Rue, 2007; Shochet et al., 2020). Regrettably, information on the most commonly accessed therapies for autistic children in Aotearoa is unknown as this information is not systematically collected or recorded (Altogether Autism, personal communication October 28, 2019; Autism NZ, personal communication, October 30, 2019). A Google search confirms that there are therapies available in Aotearoa for autistic individuals. These include therapies using Applied Behavioural Analysis techniques (see Appendix E for comment on ABA); therapies based on Early Intensive Behavioural Intervention, and therapies based on Social-Cognitive theories. Kasilingam and colleagues (2021) collated a list of autism interventions available in Aotearoa. The list included, “Speech and language therapy, Intervention through a teacher/education support worker, Specific parent education/training programmes, Occupational therapy, ABA therapy (Applied behaviour analysis), General parent education/training programmes, Intervention through a psychologist, Behaviour support, Multidisciplinary interventions, Physiotherapy, Music therapy, Routine/ play-based interventions, Riding for the disabled” (Kasilingam et al., 2021, p. 529). The study reported a stark 18.8% of respondents were receiving no intervention. The study included no Pacific parents’/caregivers’ perspectives.

Disability Funding in Aotearoa

Current child disability funding streams within Aotearoa are disparate and confusing for parents to navigate. Government-contracted organisations regionally called Needs Assessment and Service Coordination (NASC) providers deliver resource allocation, providing funding including respite, carer support and individualised funding for people with disabilities and their families and assist with connecting families with other services (MoH, 2008b; MoH, 2016). Meanwhile in some areas, different funding schemes or pilot allocations are underway, such as Mana Whaikaha, Enabling Good Lives, and Enhanced Individual Funding, which are trialling increased self-determination and flexibility in the administration of self-directed funding to families of disabled individuals (MoH, 2019). Since 2020 in Aotearoa, family carers are paid for the care of their disabled children with high- or very high-needs through the Ministry of Health Funded Family Care policy (New Zealand Public Health and Disability Amendment Act 2020). Prior to this legislative change, parents who could not

work due to the care needs of their disabled family members received no payment for this work. Learning Support administers the Ongoing Resource Scheme for in-school support for a minority of disabled children with the highest and most complex needs (3% of school-aged children; MoE, 2021). Finally, the Ministry for Social Development supports families through a small Child Disability Allowance and later a Disability Allowance for adults, both of which are not asset- or means-tested (Work and Income, n.d.). One of the objectives of the establishment of the new Whaikaha – Ministry of Disabled People was to create personal budgets for disabled people (or their trusted family members) to self-administer, which would hold funding from governmental agencies, streamlining funding access (Enabling Good Lives, 2022).

Uptake of Autism Support by Pacific Peoples in Aotearoa

Aotearoa data from the *Faiva Ora 2016-2021: National Pasifika Disability Plan* showed Pacific peoples represented just 5.9% of all Disability Support Services recipients, a number disproportionate to the Aotearoa Pacific population then of 7.4% (MoH, 2017). Reasons for low uptake were cited as a lack of culturally appropriate disability services available, Pacific peoples' tendency for within-family caring, and stigma around disabilities within Pacific communities (MoH, 2017). Faiva Ora stated that the most common supports Pacific people claimed were Carer Support funding (8.2%), Home and Community Support services (7%), and Community Residential services (3%). The report also recorded that 50% of Pacific service-users lived in Auckland, 42% were aged under 19 years, and only 6% of Pacific service-users were autistic (MoH, 2017). Overall, Pacific disabled people were less likely than non-Pacific to have received assessment from a NASC, accessed less services, were less likely to know about disability support services, and were less likely to receive the Child Disability Allowance (MoH, 2008b; MoH, 2017). In addition, barriers to accessing support for Pacific families involved policies that precluded family at the same address being paid for caring, and difficulties securing Pacific carers, particularly in the evenings (MoH, 2017). Similarly with low rates of Pacific presentation at primary health settings, Pacific peoples were unlikely to seek out services until they were at or past breaking point (Tukuitonga, 2013; MoH, 2017).

There are currently approximately 51,000 Aotearoa Pacific disabled people, including 9,000 Aotearoa Pacific children (Le Va, 2022a). In 2022, only 2,000 Pacific disabled people were receiving Disability Support Services funding for any disability (Le Va, 2022a). Perhaps because of Pacific peoples' strengths of resiliency, adaptation (Mila-Schaaf & Hudson, 2009; Simpson, 2021), and values of *tautua* and serving others first (Fuluifaga, 2017), they may hold beliefs that by not engaging with a service someone more needy will be able to access that service. Sadly, according to the data this

is unlikely to be the case (MoH, 2017). The latest data still shows low rates¹⁹ of Pacific disability service access (6%; MoH, 2019). Further, where Pacific families are not accessing primary health services the likelihood of gaining a diagnosis for their child and of accessing supports, is low (Fa'alogo-Lilo & Cartwright, 2021). Even with a diagnosis, parents struggle to access the supports they are eligible for (Boshoff et al., 2019; Crane et al., 2018), and many aspects of needed support are lacking (Wallace-Watkin et al., 2021). The next section details the current literature on the experiences of parents raising autistic children.

¹⁹ The report was likely to be underreporting Pacific support users due to the 'ethnicity prioritisation' methodology (MoH, 2019).

Chapter 3: The Existing Literature on Parents' Experiences, Language, and Culture in Autism

Parents' Experiences of Raising Autistic Children

Parents of autistic children have expert knowledge on the experiences of raising their children which health professionals need to understand to provide appropriate and adequate care for these families (DePape & Lindsay, 2015). Families provide the majority of care, protect quality of life, and fulfil or arrange the necessary support needs their autistic child presents with, which for many would extend into adulthood (up to 80%: Carr, 2016a; Te Pou, 2016). In doing so, families often play many unremunerated but critical roles, including full-time and/or primary carer/s; first teacher; home-school educator; advocate and mediator of relationships between healthcare/medical staff, educators, disability rights and legal representatives (as examples); negotiator/advisor (financial, education, employment, legal); landlords; day-programme providers; and where needed, legal mediators (Bekhet et al., 2012; Crane et al., 2018). Naturally, these responsibilities fall mostly on the shoulders of the parents—particularly the mothers' (DePape & Lindsay, 2015; Grebe et al., 2022; Ooi et al., 2016)—and their effects are holistic. The extra effort put into each of these roles can be demanding, time-consuming, and at times overwhelming (DePape & Lindsay, 2015; Johnson et al., 2011). The extant literature tends to focus on the challenges of raising autistic children. This is useful as health professionals need to be cognisant of the issues for parents of autistic children in order to exercise empathy, to understand how issues may impact on parents' capacity to care for their children, and to provide appropriate care for families (DePape & Lindsay, 2015). However, although receiving less coverage in the literature, positive effects, key resilience factors, and blessings are attributed to the parents of autistic children also (Bekhet et al., 2012; DePape & Lindsay, 2015; Higgins et al., 2022; Ooi et al., 2016). This section will therefore attempt to provide a more balanced view of the experience of raising an autistic child, and it is expected that further positive perspectives will be added by the Pacific parents of autistic children participating in this study.

Key parental tasks include seeking and accepting a formal diagnosis, obtaining the help and support needed for their child, and integrating supports and treatment interventions into family lives (Bernier et al., 2010). Decision-making impacts on the family's way of life, the parents' and siblings' lives, and that of the autistic child themselves, particularly in the face of the many uncertainties that come with autism (Ooi et al., 2016). One example concerns parents in contemplating assessment and diagnosis for their child. It is not uncommon for autistic children to experience normal development until 12 or even 18 months before idiosyncrasies are recognised (DePape & Lindsay, 2015), and a third of parents first notice

atypical development between two and five years (Crane et al., 2016). For some parents, friends, family, or teachers are the first to suggest signs of autism (Boshoff et al., 2019). At this stage, some parents will enter a denial phase and/or plunge into emotional turmoil, searching for other plausible explanations for their child's differences (Boshoff et al., 2019; Luong et al., 2009). Furthermore, when parents do raise concerns with health professionals they are often left unacknowledged, resulting in parents feeling "distress, anger, humiliation, and frustration" and deferred diagnosis for up to four clinic visits (Boshoff et al., 2019, p. 151; Crane et al., 2016). Parents must consider "whether [their child] *requires, would value, and would benefit* from a diagnosis" (emphasis added; MoH/MoE, 2016, p. 40). Some families already choose not to seek diagnostic assessment (Simpson, 2021). Parents are often in denial, fearful of a lifelong condition, reticent to adjust life goals and expectations, or concerned that the child and family will be treated negatively following receipt of an autism label (Crane et al., 2018; Downes et al., 2021; Jacobs et al., 2020). Therefore, parents must balance the need for formal supports and answers to questions, with the dignity of the child and the potential effects (positive and negative) on the child's and family's life and wellbeing (Jacobs et al., 2020).

Following receipt of an autism diagnosis, one of the most difficult challenges for parents is formulating their response to it. As Bernier and colleagues describe: "the most important adjustment for a parent raising a child with ASD is to successfully modify the original expectations of raising a typically developing child and to accept the child and the child's unique developmental trajectory and behavioural differences...For the family caring for a child with autism, the hardship is tangible and creates more substantive changes to the family system because of the permanence of the condition" (2010, p. 859). Parents coming to terms with the diagnosis and the associated implications is called resolution (Downes et al., 2021). Resolution leads to more sensitive and adaptive parenting of the autistic child, and a greater understanding of the child's behaviour, but it is important for health professionals to note that resolution does not often occur simultaneously within couples (Downes et al., 2021). Often, the path to acceptance alluded to above involves shock, trauma, and palpable grief in parents for the 'normal' child they were expectant for (Bernier et al., 2010; Boshoff et al., 2019). One parent stated, "when the doctor told me, I had the same feeling as when my grandmother died" (Hutton & Caron, 2005, p. 184, as cited in DePape & Lindsay, 2015). Grieving can resurge as parents are confronted with the stark differences between their child's developmental trajectory and that of a typically developing child (Bernier et al., 2010). Autism as a life-long condition rather than a finite challenge requires continual learning and adaptation as presentation and features change with each developmental stage (Boshoff et al., 2019; Carr, 2016a; DePape & Lindsay, 2015; Ooi et

al., 2016). The disparity between parental expectations and the new reality of raising a child with significant verbal, social, and potentially intellectual delays or challenges could lead to despair and self-blame (Ooi et al., 2016), but also to a tempering of expectations and to parents easing off on themselves (Jacobs et al., 2020). For others, denial of the diagnosis, anger about unfairness, guilt, and trepidation for the child's future are not uncommon responses (Ooi et al., 2016). Some described the initial shock of diagnosis giving way to taking action (Boshoff et al., 2019). As a result, many parents take to completing all manner of genetic and other testing, searching through personal and family histories to find causation and regain control (Ooi et al., 2016). The authors stated that often these searches, despite best efforts, could be unfruitful or even harmful to the parents and family.

Conversely, relief and vindication are also common responses as parental concerns have finally been heard and validated, and parents can now 'get on with it' (Boshoff et al., 2019; Crane et al., 2018; Downes et al., 2021). In addition, acceptance, defined as both adjustment and adaptation to a child's disabilities, together with peace in the situation, is a significant indicator of resilience and positive coping (Boshoff et al., 2019; Luong et al., 2009). Acceptance further encourages parental gratitude and promotes secure attachment with the autistic child (Bekhet et al., 2012). Interestingly, the time it takes parents to reach acceptance and adaptation is largely influenced by their experience of the diagnostic process (Downes et al., 2021). Parental resolution and acceptance could be described as stages along the journey of "negotiating knowledge" when receiving an autism diagnosis for their child/ren (Carlsson et al., 2016, p. 332). The authors explained how this negotiation included an iterative knowledge-weaving process, whereby parents considered their own prior knowledge and experiences along with new knowledge gained from health professionals, while primarily seeking to uphold their child's needs (Boshoff et al., 2019). The authors explained the negotiating knowledge process as moving through phases of seeking knowledge, through privileging or challenging expert opinion, to finally deciding on and consolidating new knowledge. Although this process empowered parents, it also highlighted their sense of loneliness as other parents were not having to go through the same experiences; feeling confident in their new knowledge did not assist parents in dealing with the emotional consequences of the new knowledge and its implications (Boshoff et al., 2019). Knowledge negotiation was considered to be a recurrent process as children developed and moved through stages of support needs (Boshoff et al., 2019).

Often, parents feeling pressured to do the best for their children led to resilience through action-oriented strategies (Boshoff et al., 2019). For example, the authors found parents' concerns about their child being ignored spurred them into

advocacy behaviour. Although advocacy encompasses a broad set of behaviours and is poorly understood by health professionals, Boshoff and colleagues described advocacy as parents redirecting negative emotionality to achieve positive progress and outcomes (2019). Particularly in countries with self-directed funding such as Australia and Aotearoa, there was a need for parents to exercise informed and resolute agency in regard to identifying the child's needs, supporting change, promoting the child's welfare and autonomy, accessing services and supports for their child, being their child's voice, and educating others (Boshoff et al., 2019). Advocacy led some parents to attain "expert-level" knowledge of autism (Tupou et al., 2021, p. 1852). Following diagnosis, obtaining help and support is a singular challenge because often agencies and organisations do not inform families of everything that is available to them (Crane et al., 2016, 2018; Searing et al., 2015). Many parents state that navigating the plethora of systems, providers, agencies, organisations, and funding options available is daunting (Boshoff et al., 2019; Crane et al., 2018; MoH/MoE, 2016). Moreover, families without the resources to pay for private programmes may relocate to areas which have more autism-related support (DePape & Lindsay, 2015). By contrast, some families do not need or align with formally organised services but will seek out and engage funding sources to sustain and bolster their own established within-family or community supports (Dai & Carter, 2022; Te Pou, 2010, 2016; Tupou et al., 2021).

Effects on relationships could be multifaceted as parents and families rearranged themselves to accommodate the autistic child's needs (Dai & Carter, 2022). Parents must 'tag team', dividing time between caregiving, work, and siblings and are rarely able to spend time alone together (Downes et al., 2021). Often parents became highly focused, leading to rigid divisions between caring and work roles with most caring falling on the mothers and most paid work on the fathers, resulting in less relationship satisfaction (Downes et al., 2021). Partners, where available and engaged, were considered to be very supportive and helpful (Searing et al., 2015). Added stress came from extended family members' (particularly grandparents') unhelpful responses or non-acceptance of the diagnosis, well-meaning but unrealistic or impractical suggestions, and an inability to provide practical support (Bernier et al., 2010; Downes et al., 2021; Lilley et al., 2020; Mauigoa-Tekene et al., 2013; Searing et al., 2015; Tupou et al., 2021). Particularly if family were unable to help, a perceived lack of adequate support from spousal partners led to resentment (Downes et al., 2021; Luong et al., 2009). Additionally, the toll on siblings is difficult. Siblings often missed activities because they were not tolerated by the autistic child (Bernier et al., 2010). Relocation to access further supports may have been beneficial for the autistic child but further isolated the parents and siblings if there was less or no social support in the new area. A review of autism literature reported

divorce rates were higher in families with autistic children (Weastall, 2017). However, in newer studies, divorce rates were either not higher in families with autistic children (Corcoran et al., 2015), or, reported divorce rates were attributed to other factors (Weastall, 2017). Other studies have found that while strain was acknowledged within spousal relationships, many partners were still together, and some were stronger for having overcome difficulties together (Corcoran et al., 2015; Downes et al., 2021). One study examining the relationships of parents of autistic children found that relationship quality prior to the diagnosis predicted strength and survival of the relationships post-diagnosis (Downes et al., 2021). The authors hypothesised that a united front and a cooperative approach between parents were significant factors in relationship survival.

Financially too, parents can experience a heavy and constant strain on limited family resources (Bernier et al., 2010; DePape & Lindsay, 2015; Ooi et al., 2016). Examples of these expenses may include paying for therapies, adapted sport and leisure activities, special equipment and technology (including wheelchairs or assistive communication technology), required special items (such as continence-, GPS-tracking, or sensory-related products), annual mobility passes, and assistance dogs for safety. In the US, health care costs per autistic person were estimated at more than USD\$5,979 per annum (Le Couteur & Szatmari, 2015), and likely to be more in today's climate. In Aotearoa, Government funding contributes towards family costs through a small Child Disability Allowance of \$52.79/week²⁰, but as mentioned earlier, there are no publicly funded therapies for autistic individuals. Families with more resources, therefore, have a much higher likelihood of obtaining the support and early intervention their child needs (Myers et al., 2019; Wallace-Watkin et al., 2021). Many other families are financially pinched by parents stopping work or reducing work hours to better coordinate their child's care, including providing transport, attending medical and other appointments, adhering to scheduled therapy sessions, and meeting increased care needs outside of often reduced school hours (Bernier et al., 2010; DePape & Lindsay, 2015; Downes et al., 2021; Ooi et al., 2016; Sansosti et al., 2012).

Many daily practical stresses are borne by parents of autistic children at home and in accessing local community resources which families without autistic children do not experience (Boshoff et al., 2019; DePape & Lindsay, 2015; Ooi et al., 2016). Increased stress levels impact on parenting practices, increase conflict, impact family functioning, and affect the parental relationship (Downes et al., 2021). Daily stresses include the child's irregular sleep and eating habits, delays with achieving independent elimination, the parents' inability to understand the child's communication and/or the child's

²⁰ As at 1 April, 2022 (<https://www.workandincome.govt.nz/products/a-z-benefits/child-disability-allowance.html>).

under-developed communication skills, child safety concerns, and difficulty in finding appropriate carers and respite options (Bernier et al., 2010). Autistic children can display unpredictable, inappropriate, and disruptive behaviours, which can disrupt daily routines and limit social activities (Khanlou et al., 2019). This leads to parents avoiding social situations and isolation and frustration results (Boshoff, 2019; Lilley et al., 2020). At the more extreme end of the scale, some parents deal with material damage to homes and property, and physical violence from their autistic children or to others in the family; these issues cause real financial, mental health, and physical burdens (DePape & Lindsay, 2015; Ooi et al., 2016). Fortunately for parents who can access it, respite given by trusted family members is associated with increased relationship quality and lowered stress levels (Downes et al., 2021; Mauigoa-Tekene et al., 2013; Searing et al., 2015; Tupou et al., 2021).

The current literature states that parental mental health can be at risk in families raising autistic children, even more so than in families of children with other disabilities, and those with neurotypical children (Boshoff et al., 2019; DePape & Lindsay, 2015; Jacobs et al., 2020; Ooi et al., 2016). Several factors in parents of autistic children reliably increased mental distress, including: the severity of challenging features, low-quality spousal relationship, higher parental anger, and more than one autistic child in the family (Bekhet et al., 2012). The higher levels of psychological distress in parents of autistic children, particularly arising from the diagnostic process, often manifested as depression and anxiety (Boshoff et al., 2019). Additionally, the pressure to adhere to the rigid requirements of treatment regimes, such as intensive ABA-based intervention, could cause stress and depression in mothers (Schwichtenberg & Poehlmann, 2007). However, it was also found that optimism had positive effects on maternal psychological wellbeing, also reducing stress and depression, and leading to improved maternal coping (Bekhet et al., 2012). Furthermore, positive family functioning reduced the negative impact of parenting stress on parental mental health (Johnson et al., 2011).

Parents of autistic children are primarily seeking to be understood, and as such often only find solace in communities of other parents of children with disabilities who appreciate the shared experiences (DePape & Lindsay, 2015; Downes et al., 2021; Lilley et al., 2020; Te Pou, 2016). Online and real-life communities of parents can provide an ironic sense of normalcy for parents who constantly feel that themselves, their family, and their child are anything but normal (Crane et al., 2018). Support groups can further provide a source of support, some much needed relief and a rare break from having to explain one's situation to others, otherwise inaccessible advice, and information on support and services which families have accessed that other parents were unaware of (Crane et al., 2018; Downes et al., 2021; Ooi

et al., 2016). However, a number of parents found support groups unhelpful for various reasons, including: no groups in their area or perceived autism severity requirements for joining, a facilitator who lacked knowledge or engagement skills, a lack of information or practical support provided, significant differences in parental experiences, and no parental desire to hear or share experiences with strangers (Clifford & Minnes, 2013; Ooi et al., 2016). An additional concern was that professionals might leave parents to it and not intervene with extra supports, which would be “hopeless” as many parents while supporting other parents were “on the verge” themselves (Crane et al., 2018, p. 3,768). While all of these experiences are valid, most support group attendees cited more benefits than disadvantages (Crane et al., 2018; DePape & Lindsay, 2015; Downes et al., 2021; Lilley et al., 2020; Ooi et al., 2016; Te Pou, 2016).

Several protective factors were found to enable parents to be resilient despite the challenges of raising an autistic child. These included: positive perceptions of autism, older age of the autistic child (in part as challenging behaviours lessened over time), parental self-efficacy, parental internal locus of control, and presence of faith beliefs, spirituality, and faith-based activities (Bekhet et al., 2012; Bernier & McCrimmon, 2021; Higgins et al., 2022; Luong et al., 2009; Pearson et al., 2022). Faith not only increased resilience, but also encouraged both personal and communal coping behaviours, and solidified a belief that parents were equipped by God with the tools they needed to raise their autistic child (Bernier & McCrimmon, 2021; Pearson et al., 2022). Additionally, researchers found that family, spousal, and social support was protective, reducing parental distress, incidence and severity of depression, reducing negative emotionality and increasing optimism, increasing parental coping ability and satisfaction in spousal relationships, and improving family functioning (Bekhet et al., 2012; Boshoff et al., 2019; Downes et al., 2021; Higgins et al., 2022; Khanlou et al., 2019; Ooi et al., 2016; Searing et al., 2015). Accordingly, Australian Aboriginal parents focused on the special abilities autistic children were gifted with, such as their interesting minds, artistic abilities, and hypothesised that they were more evolved beings than non-neurodiverse individuals (Lilley et al., 2020). Additionally, Aboriginal mothers of autistic children in that study spoke of the child's transformative power in helping their mothers to be better mothers.

Although several benefits of raising an autistic child have been reviewed, the overall literature appears to be skewed towards the negative impacts on families with autistic children. More research is needed to fully appreciate the positive lessons and sometimes unexpected blessings of raising an autistic child. Culture, as a dynamic and socio-historically constructed framework, also influences our experiences and the meanings which we assign to them, such as our experience of autism. The next section discusses culture and its influence on autism experiences and outcomes.

Culture and Autism

Jenkins (2015) defines culture as “an orientation to being-in-the-world that is dynamically created and re-created in the process of social interaction and historical context” (p. 9). Culture is all-encompassing and complex; its effects influence thought, feelings, responses and agentic behaviour, and impact upon gender, position in social strata, expression of sexuality, faith, exceptionality, and is associated with both nationality and ethnicity (Bevan-Brown & Moldovanu, 2016). As a dynamic force, culture is always moving and changing (Cammock et al., 2021). Strauss-Hughes and colleagues (2019) discuss the importance of acknowledging culture in working therapeutically with individuals. This is because culture is an important part of an individual’s ecological system, influencing the development of their mind and behaviour, individual experience, and language (Macfarlane et al., 2015; Strauss-Hughes et al., 2019). Even what is experienced as mental distress is shaped by one’s culture (Jenkins, 2015; Lewis-Fernández & Kirmayer, 2019). For example, only if something is aberrant to a majority of the reference culture does it become pathological (APA, 2013), symptoms can look different across cultures (Paralikar et al., 2020), and cultural concepts of distress²¹ are not classified as DSM-5 disorders as such (APA, 2022; Lewis-Fernández & Kirmayer, 2019). The cultural formulation guidelines of the American Psychiatric Association state that “levels of functioning, disability, and resilience should be assessed in light of the individual’s cultural background” (2022, p. 938). Ethnicity and culture are not the same but interact to form representations which are responded to by others in positive and negative ways (Reid & Robson, 2007).

Intersectionality results when society’s response to neurodiversity, disability, and minority cultural position which each separately confer difficulties, co-occur within a person, causing compounding difficulties (Dai & Carter, 2022; Kapp, 2011; Lilley et al., 2020; Simpson, 2021). Where these social difficulties are related only to ethnicity and mental health stigma it is called “double stigma” (Gary, 2005, as cited in Fa’alogo-Lilo & Cartwright, 2021, p. 754). When intersectionality has led to a lack of services and acceptance within education, health, and faith-based environments it has been called “double disenfranchisement” (Pearson et al., 2022). Despite these facts, there is a dearth of research with autistic Indigenous peoples (Shochet et al., 2020; Simpson, 2021). Bevan-Brown and Moldovanu stated, “culture definitely needs to be considered when working with children and young people with ASD” (2016, p. 163) and this also applies to the provision and development of supports and programmes for Pacific families. It is therefore important to examine the ways

²¹ Cultural concepts of distress including “cultural idioms of distress, cultural explanations or perceived causes, and cultural syndromes” have replaced culture-bound syndromes (APA, 2022, p. 937).

in which culture and autism interact for Pacific families of autistic children and the difficulties that result in order to ameliorate these in these families' lives.

The DSM-5-TR is based on a medical model of disability which implies that variations from the neurotypical, able-bodied norm should be fixed or are otherwise pathologised as deficits (Dyches et al., 2004; Gaines, 1991; Simpson, 2021). These premises can make acceptance of diagnostic labels difficult for cultures whose approaches to health and illness instead value diversity and inclusion (Lewis-Fernández & Kirmayer, 2019; Lilley et al., 2020; Shochet et al., 2020; Simpson, 2021). Historically, trauma experienced by Indigenous peoples as a result of colonisation processes have led to a lack of trust in colonially operated systems such as health (Lilley et al., 2020; Simpson, 2021). As a consequence, children from minority Indigenous cultures are less likely to interact with health systems and gain an autism diagnosis in time to benefit from evidence-based early intervention (Lilley et al., 2020; Searing et al., 2015; Simpson, 2021; Tupou et al., 2021). Additionally, the ways in which we perceive our culture to regard disability or conditions affects when people choose to seek help or disclose conditions (Macpherson & Macpherson, 1990).

Autism in children from minority and Indigenous cultures is often misdiagnosed as a behavioural issue, including hyperactive or oppositional behaviour disorders, or as IDD, severe psychosis, or Foetal Alcohol Spectrum Disorder, leading to further marginalisation as pathologised, delinquent children and no helpful intervention (Lilley et al., 2020; Simpson, 2021). It is likely that clinicians are misinterpreting significant distress arising from communication challenges, and challenging behaviours, as behavioural dysregulation. It has been suggested that if children are not correctly identified as autistic due to diverse beliefs and practices, they will not be successfully integrated within their societies (Bernier et al., 2010). However, it is not cultural beliefs or practices per se that make diagnosis elusive, but the ways in which others perceive and respond to cultural difference, and the normalisation of health inequities (Lilley et al., 2020; Reid & Robson, 2007).

Within the theories of social constructionism and ethnomedicine, medical knowledge itself is socially constructed (Gaines, 1991). Different cultures have varying perspectives on the meanings of disability and autism according to the histories of the development of such within their communities (Gaines, 1991; Lewis-Fernández et al., 2017). For example, researchers looking at cultural explanations of disability have reported that Navajo people view children with disabilities as children first, celebrating their idiosyncrasies as unique differences and not deficits (Kapp, 2011; Welterlin & La Rue, 2007). In addition, the authors noted that some Native American and Turtle Island tribes' perspective on disability within their

communities was one of special gifting, that disabled family members were spiritual guides and teachers. Welterlin and La Rue (2007) further found that Latina Catholic mothers saw disabled children as a blessing, while differences occurred in other cultures including some Turtle Island, Asian, and Latinx cultures who viewed disability as family punishment for past sins. Other studies have discussed some Western, African, and Asian cultures' beliefs that parents', particularly mothers', incompetence was the cause of their child's autism (Lindblom, 2014; Welterlin & La Rue, 2007).

By contrast, Aboriginal and Torres Strait Islander communities perceived the categorisation of people according to their impairments to be distasteful (Bailey & Arciuli, 2020). These groups accepted children's neurodiversity including autism, seeing children as special, and potentially medicine people or healers (Lilley et al., 2020). Within *te Āo Māori* (the Māori world) also, conceptualisations of health are holistic, including elements such as spirituality and emotional development (Tupou et al., 2021). The Māori term for autism is *takiwātanga* (Te Pou, 2020). *Takiwātanga* is a noun taken from the phrase [*tōku/tāna*] *anō takiwā* which translates as 'in [my/his or her] own time and space' to acknowledge the different life-rhythm and inherent agency and strengths of autistic people, taken from a *whakataukī* (proverb) about the Tītoki tree which blooms irregularly (Opai, 2017). Within *te Āo Māori*, differences such as autism varied in their conceptualisations from a gift to be appreciated to a punishment for negative behaviour, and in between, deserving of nurturance, and encompassing both strengths and challenges (Tupou et al., 2021) but were generally viewed from an inclusive ethos (Bevan-Brown, 2013). As in many cultures (Bernier et al., 2010), there is no Pacific cultural conceptualisation of autism itself and no specific linguistic term. A Pacific cultural explanation of all mental and physical difference is discussed in Pacific-Indigenous Conceptualisation of Disability.

Additional narratives from general disability literature which may fit for Pacific families include those of accommodation and acceptance. Acceptance is a state of being that views a child's diagnosis and presentation of autism as an unchangeable truth. Due to autism's lifelong trajectory, acceptance, despite its positive effects on coping and attachment (Bekhet et al., 2012; Bernier & McCrimmon, 2021; Luong et al., 2009), can also lower expectations for improvement and progression, therefore colouring responses and planning for the child. Early research by Faleafa suggests that within Aotearoa Pacific families, autistic children are often accepted as just being "different" or "odd", family members may believe that the child will "grow out of it", or that the child is "naughty" (as cited in MoH/MoE, 2016, p. 222). Acceptance related to the child's autism being God's will and blessing has also been found in Muslim families (Bernier & McCrimmon, 2021). Accommodation, refers to a strategy where families protect and care for family members within their

own family resources, often adapting family functions, occupations, and structure significantly to do so (Dai & Carter, 2022; Gray, 2001). Accommodation in this sense could either be seen as insular or as efficiently harnessing the power and resources of the collective. Family caring—family carers who undertake significant caring responsibilities—is normalised within Pacific families and families of autistic children alike (Broadstock, 2014; Foliaki et al., 2009; Le Va, 2014; MoH, 2017). Pacific family caring is reflected in the ethos of Pacific health organisations such as The Fono’s slogan: “caring is our culture” (The Fono, 2020). More research is needed however, to explore the narratives of accommodation and acceptance specifically, and other unique narratives, with Aotearoa Pacific families of autistic children.

Researchers have found that the identification of autism within ethnic communities is affected by the description, interpretation, and acceptance of symptoms varying “tremendously” across cultures (Bernier et al., 2010, p. 855). Differences in what is considered normative developmental behaviour across cultures will affect when parents seek a diagnostic assessment for their child. To illustrate, reduced eye contact is one example under the DSM-5-TR non-verbal communicative behaviour criterion for diagnosis of autism; indeed it is often cited as an early concern from parents (APA, 2022; Assailly, 2022). However, Māori, Asian, and Pacific cultures often defer eye contact from higher-status individuals and authority-figures as a sign of respect, and so reduced eye contact within these cultures would not be a concern that warranted further investigation (Shochet et al., 2020; Truong et al., 2022). Further, a child who is playing independently in a corner during a large family gathering may be viewed as a ‘good’ child who is no trouble while adults talk, rather than a marker of reduced social interest in autism (Truong et al., 2022). Furthermore, a child who can recite scripts from their favourite TV show or movie may be perceived as having excellent memory and heightened intelligence, rather than displaying echolalia, a classic example of idiosyncratic verbal behaviour in autism (Carr, 2016a). While no one feature of autism is diagnostic, it is understandable that different interpretations of behaviour across cultures such as those mentioned could lead to significant delays in diagnosis for families (Lilley et al., 2020; Zwaigenbaum et al., 2015).

Compounding cultural difference in recognition of symptoms was a sense of mistrust of health professionals (Boshoff et al., 2019), reticence to challenge health professionals (Tualaulelei & McFall-McCaffery, 2019), and clinician bias (Myers et al., 2019). Clinician bias against ethnic minority parents in the US, particularly if they were also of a low income and/or rural, led to these parents being less likely to have their developmental concerns screened or proactively dealt with by health professionals (Guerrero et al., 2011; Luong et al., 2009; Zuckerman et al., 2015). Doctors’ disbelief, lack of acknowledgement of concerns, and dismissal were also reported by minority ethnicity parents in the UK, Canada,

Australia, and by Māori parents in Aotearoa seeking autism diagnosis for their child (Bailey & Arciuli, 2020; Bevan-Brown, 2004; Boshoff et al., 2019; Broadstock, 2018; Crane et al., 2018; Legg & Tickle, 2019; Simpson, 2021; Tupou et al., 2021). Clinician bias and differential treatment across families seeking diagnosis led to impacts on rates of diagnoses within ethnic minorities, and on choice of treatment (Begeer et al., 2009; Dyches et al., 2004; Mandell & Novak, 2005; Simpson, 2021). Lower and delayed rates of diagnosis, and misdiagnosis, meant that ethnic minority families with autistic children were not accessing important supports and resources when they were eligible (Broadstock, 2018; CDC, 2019; Shochet et al., 2020; Simpson, 2021). For example, in the US, Hispanic children experienced lower rates of diagnosis compared with both non-Hispanic American and African American children (CDC, 2019; Shaw et al., 2020). One study found that non-Hispanic, non-African American parents received diagnoses for their children around 1.5 years before African American children and 2.5 years before Hispanic children (Bernier et al., 2010). Other studies have shown that the mean age of diagnosis of ethnic minorities in North America is over seven years old (Khanlou et al., 2017), and even longer for less impaired minority group children (Simpson, 2021). Two reviews reported higher rates of autism diagnosis in American non-white, ethnic communities, particularly in immigrant and foreign-born families (Becerra et al., 2014; Dyches et al., 2004). However, both those studies cautioned a lack of rigor in underlying studies around the defining of 'ethnic', 'minority', and 'immigrant' status that the reviews were based on.

Disproportionality in autism diagnosis for ethnic families has further been demonstrated in Australia (Bailey & Arciuli, 2020; Foley et al., 2018; Lilley et al., 2020), Canada (Khanlou et al., 2017; Lindblom, 2014), the Netherlands (Begeer et al., 2009), the UK (Brett et al., 2016; Crane et al., 2018; Legg & Tickle, 2019), and with Māori in Aotearoa (Bevan-Brown, 2004, 2013; Waddington et al., 2022a). Evidence shows that the diagnostic disparities are multifactorial: differential geographical access to services, language barriers between families and clinicians, diverse conceptualisations of disability (non-deficit focus) that affect urgency for diagnosis, misdiagnosis, delays to receiving diagnosis, clinician bias, prejudice and institutionalised discrimination of Indigenous families, intra-cultural stigma, low socioeconomic status or non-citizenship, deficient outreach and poor cultural competency of healthcare services, a lack of healthcare available for non-English speaking communities, and a tendency for families to rely on family and friends' advice (Bernier et al., 2010; Bilaver et al., 2021; CDC, 2019; Lindblom, 2014; Myers et al., 2019; Ouellette-Kuntz et al., 2009; Shochet et al., 2020; Simpson, 2021). However, parents who felt comfortable to push for diagnosis generally gained diagnosis for their child (Boshoff et al., 2019). Furthermore, improved outreach to Hispanic communities in the US has shown it is possible to close the

diagnosis gap between ethnic groups (Baio et al., 2018; Shaw et al., 2020). This may have had a flow-on effect as a recent US study with Medicaid-enrolled autistic children reported “no disparity for Latinx children” in service use, while receipt of services by African American, Asian, and Native American/Pacific Islanders remained lower than White and Latino groups (Bilaver et al., 2021, p. 3341). Interestingly, while one of these reviews concluded that autism rates were generally *higher* in immigrant and foreign-born families, this excluded migrant Latinx families who had *lower* rates of autism and better health outcomes than US-born Latinx families despite similar income and education status, a phenomenon the authors called the “Latina paradox” (Becerra et al., 2014, p. 68).

During diagnostic assessment, cultural differences also become evident between the assessors and the families, particularly through the assessment tools used to diagnose autism (Bevan-Brown & Moldovanu, 2016; Lilley et al., 2020; Simpson, 2021). For example, within the Checklist for Autism in Toddlers (CHAT) and in the modified version (M-CHAT), eye contact and pointing are observed and assessed (Bevan-Brown & Moldovanu, 2016). This is problematic given the different value placed on eye contact within different cultures (Shochet et al., 2020; Truong et al., 2022). These assessment markers may not be relevant for Pacific children either. Further, within the Vineland Adaptive Behaviour Scales (VABS), 11 items were deemed inappropriate for non-Western families due to lack of exposure to specific adaptive tasks, and a reliance on English grammatical rules (Bevan-Brown & Moldovanu, 2016). Furthermore, in the Childhood Autism Rating Scale, the authors found that some culturally appropriate and encouraged behaviours were interpreted as inappropriate by assessors without knowledge of the child’s cultural background. While these comparisons were in relation to the assessment of Chinese children, similar inadequacies in autism assessment tools and lack of cultural knowledge of the assessors have been found during the autism evaluation of South African, South Korean, and Māori children also (Bevan-Brown, 2004; Bevan-Brown & Moldovanu, 2016). Translation of parent-report autism assessment tools into other languages has typically been plagued by a lack of rigour in systematic and appropriate cultural translation, rendering the resulting translations of little value to non-English speaking families (DuBay & Watson, 2019).

Differing etiological understandings across cultures were found to influence parents’ views on treatment, the treatment goals chosen, and the treatment/s sought for their child (Bernier et al., 2010; Khanlou et al., 2019; Mandell & Novak, 2005; Ravindran & Myers, 2012; Tupou et al., 2021; Welterlin & La Rue, 2007). Treatment goals can be markedly different across cultures, with Western-American mothers often prioritising goals towards language skills and independence, while other cultures such as First Peoples, Southeast Asian, Pacific, and Māori, may value collective-

oriented behaviour and ability to participate in cultural practices more (Bernier et al., 2010; Lilley et al., 2020; Lindblom, 2014; Macfarlane et al., 2014; Mo'a , 2015). Further, cultural beliefs and values will encourage families towards various treatment approaches and treatment options (Mandell & Novak, 2005; Paterson et al., 2016; Ravindran & Myers, 2012; Tupou et al., 2021; Welterlin & La Rue, 2007). For example, these may be more regularly prescribed behavioural and language-oriented, or medical interventions, or treatments which incorporate therapy through many different modes such as animal-assisted therapy, music-, art-, or dance-based therapies, and dietary, chiropractic, traditional/cultural, herbal, or faith-based interventions (Bernier et al., 2010; Lindblom, 2017; Mandell & Novak, 2005). Still, other families may integrate treatment from both Western and cultural paradigms together (Truong et al., 2022; Tupou et al., 2021).

For example, Taiwanese parents attributed both supernatural and biomedical causes to autism (Shyu et al., 2010). Such beliefs led to a multitude of treatments being sought, including both biomedical and more traditional treatments, such as acupuncture and seeking the wisdom of fortune-tellers (Shyu et al., 2010). Aboriginal families described differing etiological causes such as the consequences of a Western lifestyle, or of having always been there as a result of divine bestowal, and described the use of 'going on country' as an intervention to help their autistic children self-regulate (Lilley et al., 2020). In Aotearoa, Moldovanu worked with an Asian family who believed that their child's autism was a result of the mother's liver dysfunction or the ingestion of bad food during her pregnancy (Bevan-Brown & Moldovanu, 2016). This led to Indigenous Taiwanese interventions focused on the gastrointestinal causes at the exclusion of professionals' recommended autism interventions for the child (Bevan-Brown & Moldovanu, 2016). Indigenous researchers have suggested that health professionals, in taking into account diverse world views, should be more receptive to a range of treatment modalities including Indigenous healing practices, Western approaches, and an integration of both of these when working with Indigenous families (Durie, 2019; Truong et al., 2022; Tupou et al., 2021).

Finally, the autistic community also has its own culture (Broadstock, 2014). As with a strong Pacific identity, an acknowledged autistic social identity is associated with increased self-esteem and psychological wellbeing (Mila-Schaaf, 2013; Simpson, 2021). Positive Indigenous and autistic identities are directly associated with increased self-concept, resilience, and adaptive coping in those experiencing difficulties (Simpson, 2021). Therefore, appreciating diversity in values, traditions, and socio-cultural experiences is important for health professionals when working with families of disabled children (Dyches et al., 2004; Lewis-Fernández & Kirmayer, 2019; Macfarlane et al., 2014). Deducing cultural factors relevant to the diagnostic process is important in earlier recognition of autistic children, and early and effective

intervention (Bernier et al., 2010; Khanlou et al., 2019). One intervention required for many autistic children, and specifically related to culture, is support with language development. The following section briefly highlights the literature on language development in autism, and heritage language use/bilingualism within families of autistic children.

Atypical Language Development and Heritage Language Use in Autistic Children

Approximately 25% of autistic children are nonspeaking²² (Koegel et al., 2020), and still more have reduced language (Barokova & Tager-Flusberg, 2018; Tager-Flusberg & Kasari, 2013). One third of autistic children develop language skills only to lose them after turning two; indeed language concerns are a clinical 'red flag' which often leads to earlier diagnosis (Carr, 2016a; Waddington et al., 2022a). Most autistic children will show language delays, however, the language abilities of many of these children catch up over time (Carr, 2016a). There is significant variability across language abilities in autistic people, and often mixed language profiles within this group (Barokova & Tager-Flusberg, 2018). The authors state this includes variability within speakers, for example, those with less than five functional words, those who speak with a limited number of phrases, through to those who are fully speaking, but also includes variability in individuals' mastery across language domains, and in expressive and receptive language. Delays in expressive language acquisition are common in autism and are important as they share an inverse relationship with challenging behaviours, due to these children's inability to express their core needs (Barokova & Tager-Flusberg, 2018). Additionally, long-term nonspeaking in autism has been associated with reduced social motivation and increased social withdrawal (Tager-Flusberg & Kasari, 2013). Language delays typically become apparent by 12 months of age and may be one of the symptoms that prompt parents to seek developmental assessment (Carr, 2016a; Koegel et al., 2020). Early signs of speech delay include a lack of speech-like cadences and pre-words typical around 12 months, a clear lack of understanding, and a lack of pointing to communicate (Carr, 2016c). Autistic language features can be distinguished from Specific Language Delays by phenomena including: echolalia, reversal of 'I' and 'you' pronominals, repetitive utterances, use of neologisms, a lack of gesticulation and other body language, hypersensitivity to certain sounds, a lack of back-and-forth conversation, perseveration, and an absence of narrative creation and imaginative play (Barokova & Tager-Flusberg, 2018; Carr, 2016a, 2016c).

²² The term nonspeaking is preferred by the autistic community over the term non-verbal, as it is more accurate and positive (autisticadvocacy.org).

When Pacific parents of autistic children are confronted with their child's delayed or non-development of language, how they choose to deal with culture and language within their families becomes important. It is well-established that a strong Pacific identity is key to wellbeing, and identity is often anchored in a family's connection to their traditional or heritage language and culture (Hastedt et al., 2022; Glasgow, 2019; Manuela & Sibley, 2013; Tiatia-Seath et al., 2021). A solid Pacific identity positively influences mental health by bolstering one's sense of belonging, felt acceptance, and inclusion within family and also within your cultural group (Mila-Schaaf, 2013). Pacific families face extra challenges including at times conflicts between their Pacific cultures and the dominant New Zealand culture (Mila-Schaaf, 2013; Paterson et al., 2018; Samu et al., 2019). Parents must decide what the relative priorities will be for them of teaching their heritage language/s versus English (Howard et al., 2021), and of passing on their traditional culture versus mainstream New Zealand culture (Mila-Schaaf, 2013). If it is too hard for parents to decide, the decision will be made for them by well-meaning professionals who ultimately devalue heritage languages (Hastedt et al., 2022; Howard et al., 2021). However, Macpherson warned against writing Pacific peoples off as hapless victims of circumstance, stating that Pacific peoples are used to negotiating multiple identities in multiple places (Macpherson, 2015).

For those who consider the challenge, relative priorities will vary across families as differing levels of cultural identity and personal experience of culture influence parents' level of acceptance of and adherence to their culture's norms and traditional views (Bernier et al., 2010; MoH/MoE, 2016; Paterson et al., 2018; Pulotu-Endemann & Faleafa, 2017; Te Pou, 2010). In a recent health-focused study of just under 800 Pacific people in Aotearoa, a striking 68% described their level of acculturation as "marginalised"; endorsing that they felt little affiliation to either their Pacific heritage culture or the mainstream New Zealand culture (Firestone et al., 2020). Coupled with Pacific language loss within Aotearoa (Mila-Schaaf, 2013), restoring both cultural identity and heritage language seem important goals for all Pacific peoples in increasing self-esteem and wellbeing, but particularly for autistic Pacific peoples in forming a positive social identity (Simpson, 2021).

Research shows that if a child, autistic or not, cannot communicate with their family or understand their family's behaviour, strong attachment relationships are unlikely to develop (Hampton et al., 2017; Toffoli, 2016), and family relational health is key to young people's flourishing (Whitaker et al., 2022). Furthermore, when language does not develop as expected and attachment is affected, there is the potential for a range of unhealthy outcomes for the child, including: isolation, neglect, behavioural issues, malnutrition, violent behaviour from or toward the child, and a lack of developmental progress or regression (Lim et al., 2018; Ooi et al., 2016; Schofield & Beek, 2014). Children delayed in developing

expressive language and linguistic understanding, particularly if severely delayed, also fare worse at school and in peer relations than children with only transient language delays such as those due to illness, or no language delays at all (Carr, 2016c). Despite language delays, autistic children with a non-verbal IQ in or above the normal range and who develop functional language skills before five or six years of age have a much-improved prognosis (Carr, 2016a; Barokova & Tager-Flusberg, 2018; Broadstock, 2011), even if they only develop one expressive word (Tager-Flusberg & Kasari, 2013). Given the inevitable focus for families on helping their autistic child/ren to catch up on delayed language or to acquire it, it is understandable that parents may want to pare down non-essential tasks. Thus, teaching the family's heritage language and culture to the child may be a task that is viewed by parents initially as too difficult or non-essential, and relegated to later, once the child has learnt English (Drysdale et al., 2015). In addition, parents are often advised by professionals to speak only in the majority language (usually English) with their autistic child to avoid hindering overall language development (Hastedt et al., 2022; Howard et al., 2021; Lim et al., 2018, 2019; Zhou et al., 2019). Depending on the parents' relative language priorities and personal levels of cultural identity, the decision to prioritise English will be more difficult for some families than others.

There is scant evidence to suggest that prioritising majority language-learning is more beneficial (Hastedt et al., 2022). For example, both bilingual and monolingual children with neurodevelopmental disabilities have similar language capabilities overall (Drysdale et al., 2015; Lim et al., 2019). Furthermore, bilingual autistic children have been found to display more pre-verbal and gesturing behaviour, increased vocabularies, improved perspective-taking, and increased verbal fluency than monolingual autistic children, suggesting that bilingualism conveys increased learning, theory of mind, socially valid meaning, and reciprocity for children from bilingual families (Valicenti-McDermott et al., 2013; Zhou et al., 2019). Successful code-switching between language may convey useful cognitive flexibility benefits to autistic children who often have difficulty with executive functioning tasks (Zhou et al., 2019). Moreover, bilingual intervention with autistic children has shown improvements in challenging behaviours (Banerjee et al., 2021).

Overall, across nine international studies there were no significant differences in functional language learning, and across five international studies no significant differences in social communication, between bilingual or monolingual autistic children (Hastedt et al., 2022) suggesting that there is no longer any reason to promote monolingualism (Zhou et al., 2019). Restricting heritage language use further impacts family relationships, which in autism may already be affected, particularly when parents are not fluent in English and therefore stop speaking to their children (APA, 2022; Hastedt et al.,

2022; Zhou et al., 2019). Consequently, the disability education policies of the US, the Netherlands, the UK, and Canada now recognise that bilingual children with disabilities should be encouraged to attain and maintain their heritage languages, and should be given the same opportunities other children have to do so (Pesco et al., 2016). Indeed, bilingualism could align with US policy where children are to be provided with the least restrictive environment (Howard et al., 2021). However, the authors reported that bilingual teaching of neurodiverse children has been difficult to achieve in practice. Integration of heritage language into mainstream interventions has been posed as a solution (de Valenzuela et al., 2016).

Research regarding bilingual autistic children is scarce (Howard et al., 2021). However, a systematic review of interventions for neurodiverse, including autistic children, found that integrating heritage languages into interventions produced small gains over providing interventions only in the majority language (Lim et al., 2019). Moreover, having parents as the intervention facilitators may be more appropriate due to parents being the natural utilisers of heritage language both at home and within the child's community, thus having increased social validity while solving the current dire shortage of bilingual instructors (Barokova & Tager-Flusberg, 2018; Lim et al., 2019). Given that in the US 22% of people do not speak English at home (Hastedt et al., 2022), and 15.3% of all funded English Language Learners were children with disabilities, there is a clear need for establishing bilingual Learning Support (Banerjee et al., 2021). Globally, heritage language speaking is more common than not (66%; Zhou et al., 2019) and bilingualism and multilingualism are also on the rise (Howard et al., 2021; Lim et al., 2019). In Aotearoa, te Reo Māori is an official language although it is yet to receive the recognition it deserves, and revitalisation and maintenance strategies have been implemented (www.tetaurawhiri.govt.nz). Pacific language loss is also apparent, and bilingual education initiatives have been considered “critical” for some time to support flourishing Pacific languages (Samu et al., 2019, p. 132). There are now associated language maintenance and revitalisation strategies for Pacific languages within Aotearoa (www.mpp.govt.nz).

In summary, the current chapter has outlined the literature on parents' experiences of raising autistic children. Additionally, it has shown that while there is a good amount of literature on bilingualism, and some literature regarding bilingual autistic children, this tends to focus on whether neurodiverse children have the capacity to learn more than one language. There appears to be no literature on *how* heritage language is maintained within autistic families and what adaptations have been made if any which would inform the strategies that families could use. Similarly, the extant literature on autism and culture tends to focus on a narrow range of accessible cultures, and discusses some cultural and Indigenous conceptualisations of autism, how culture may intersect with autism regarding identification, diagnosis, and treatment, and

how autism is accepted. Even so, there appears to be no literature on *how* culture is maintained or passed down within families of autistic children. It may be instructive to follow the potentially unique and innovative ways that Pacific families have successfully navigated passing on their language and culture to their autistic child/ren. To begin to understand the lived experience of Pacific families raising autistic children it is important to understand that culture impacts families holistically. The following chapter therefore seeks greater understanding of the Pacific-Indigenous world view which influences conceptualisations of health and disability, and the experience of autism.

Chapter 4: The Specific Socio-Cultural Context

Pacific-Indigenous Peoples in Aotearoa New Zealand

In setting the scene for this project, it is important to understand the socio-cultural context of Pacific-Indigenous peoples within Aotearoa. This is important because Pacific-Indigenous peoples in Aotearoa are diasporic settler communities. Pacific cultures too, “are fluid, ambiguous and ever evolving” (Tualaulelei & McFall-McCaffery, 2019, p. 198), meaning that Pacific cultural explanations and conceptualisations may differ across generations, particularly when situated in diasporic environments (Enari & Taula, 2022; Mila-Schaaf, 2013). Diasporic communities face many new challenges and opportunities in their new lands. Cultural differences, language differences, the challenge of finding and maintaining community in the new place, the level of acculturation/adaptation/assimilation people are willing to tolerate, how skills and formal qualifications in the home country are valued in the new country (and therefore affect employability), adjusting to often colder climates, and adjustment to different value systems and dominant colonial discourses and values, represent just some of these challenges (Bernier et al., 2010; Cammock et al., 2021). It is against this backdrop that Pacific peoples in Aotearoa have made their home and continue to raise their families, which is a testament to the adaptation and resilience of Pacific peoples (Anae, 2005; Macpherson, 2015; Thaman, 2014). This liminal status leads to several differences in the way Pacific peoples may view aspects relevant to this research that are important to understand (Sanga, 2004). For example, differences within and between Aotearoa Pacific peoples’ societal and familial structures; differing concepts of health and wellbeing; the importance of the introduced Christian faith; what constitutes a disability and what impacts one might have on a Pacific family collective; differing experiences with health professionals; and, varying options for effective treatment and intervention and who provides these if accepted that these are warranted.

Pacific peoples have rich histories entrenched over millennia in their island homelands, which includes a history of two-way navigation to all parts of the Pacific Ocean, including Aotearoa (Addis, 2012; Crowe, 2018; Hau’ofa, 1994; Te Whetu & Best, 1893). Common discourse indicates that Eastern Polynesians, ancestors of Māori, arrived in Aotearoa in the mid to late 1200’s and settled, (although Māori oral histories indicate occupation by ancestors of contemporary Māori extended back far beyond the 1200’s), adapting their faith, culture, and language to the context to become *tangata whenua*, Māori (Addis, 2012; Crowe, 2018; McFadgen & Addis, 2019). Thus, the familial connection between *tangata whenua* people of the land and *tangata o le Moana*, Moana (Pacific) people was established (Salesa, 2012; Matapo & Teisina, 2021; Tu’itahi, 2020). Following large-scale, planned Pacific navigation to discover all of Oceania, there was a cessation of

voyaging for a period following the 1400's (Addis, 2012; Crowe, 2018). As Pacific peoples were busy settling the rest of Oceania during this time, they were relatively recent settlers in Aotearoa as compared with Māori, with the first accounts of Pacific peoples living in Aotearoa as whalers and sailors circa 1800, as religious scholars in the 1840s, and as labourers and scholars from the 1860s (Addis, 2012; Crowe, 2018; Mallon, 2012). Pacific-Indigenous peoples have a long history and relationship with Aotearoa.

Resulting from Aotearoa's position as a large Pacific Island and following New Zealand administration in the 1900s briefly over Samoa, Rarotonga (the Cook Islands), and Niue, there are established historical, political, economic, and defence links with Polynesia (Fraenkel, 2012; Salesa, 2012). Pacific peoples began settling in Aotearoa in greater numbers in the early 1900's, with Pacific peoples from the realm states of Rarotonga, Tokelau, and Niue²³ coming first (Fraenkel, 2012). However, early contact was not without its flaws. New Zealand's relations with its Pacific protectorates in the 1900s have been described as paternalistic (Salesa, 2012), discriminatory and oppressive (Fa'alogo-Lilo & Cartwright, 2021). Spawning the historical distrust of Pacific peoples in Western health systems was a lack of care by New Zealand government and health officials in the form of foreign disease introduced into Samoa (Ministry for Culture and Heritage, 2020). Most prominent was the 1918 spread of Spanish influenza to the unprotected island peoples (MCH, 2020). The impact of this fatal disease delivered a huge blow to the population of Samoa, and mirrored the devastation of *whānau* Māori (5%) in Aotearoa and *iTaukei* Fijians (5.5%) also (Rice, 2019). Through fatalities arising directly from influenza and from an associated famine, death came to almost one quarter (22%) of the Samoan population, wiping out an entire generation of families in Samoa and most of its workforce (MCH, 2020; Rice, 2019). Eighty-four years later in 2002, the Right Honourable Helen Clark Prime Minister of New Zealand delivered an official apology to Samoa for the 1918 introduction of the Spanish influenza (NZHerald, 2002).

Pacific peoples from the rest of the Polynesian triangle and Melanesia started emigrating to Aotearoa from the 1940s onward (Mallon, 2012). Pacific workers, who enjoyed a good reputation owing to their strength and navigational prowess (Mallon, 2012), were even more highly sought after from the 1950s onwards during labour market shortages in Aotearoa following post-war industrialisation (Coutts & Fitness, 2018; Fraenkel, 2012). Consequently, the Pacific population in Aotearoa rose significantly between the 1960s and mid-1970s (Coutts & Fitness, 2018; Mallon, 2012). New Zealand Statistics recorded the Pacific population in 1945 to be 2,200, markedly increasing to 65,700 by 1976 (Coutts &

²³ Tokelau is a non-self-governing territory, while Niue and Rarotonga are self-governing.

Fitness, 2018). Samoan citizens arriving in greater numbers than the specified 1,100 immigration quota for Samoans of the early 1970s was initially disregarded while Aotearoa required the workers (Kerslake, 2010). While Pacific migrants contributed much to Aotearoa's economy at a time when they were most needed (Hau'ofa, 1994), being situated as a minority migrant group also meant that Pacific peoples were subject to the political and social mores of the period and seen as dispensable when hardship struck (Havea et al., 2021).

Most notable were the 1974 Dawn Raids (Fraenkel, 2012); named for the gestapo-style visits from armed Police with sniffer dogs, who demanded to see Pacific peoples' immigration papers during the early hours when they were sure to be home and defenceless (Anae, 2020; Kerslake, 2010). These on-the-spot visa checks, which also occurred in the street during daylight hours, were aimed at revealing anyone overstaying their visitors' visas or work permits and to deport them back to the islands (Fraenkel, 2012). Samoans and Tongans in particular were easy targets while non-Pacific foreigners were largely ignored (Havea et al., 2021). The term 'overstayers' was used to good political effect to encourage the public to alert authorities of potential-lawbreakers (Anae, 2020). This breach of the Samoa-New Zealand Treaty of Friendship 1962 was tried by the Privy Council and resulted in the 1982 Protocol to the Treaty of Friendship between the two countries, which set out agreements relating to immigration and citizenship (Devere & Ligaliga, 2013). At the turning of the millennium, both 'Dawn Raid' and 'Overstayer' were terms reclaimed by Pacific peoples through pop culture (Dawn Raid, and Overstayer clothing: Dix, 2019; Dawn Raid Entertainment: Henderson, 2016). Further reclaimed terms included FOB (fresh off the boat), fresh/ies, islanders, Pls, poly, and nesian (Dunlop-Bennett, 2019). The institutionalised racism, and unwarranted harassment and arraignment remain dark spots on New Zealand's history with the Pacific, and a source of mistrust and scepticism from Pacific peoples toward New Zealand governments past and present (Anae, 2020; Havea et al., 2021). In 2021, Prime Minister Right Honourable Jacinda Ardern apologised on behalf of the New Zealand Government for the harm caused to Pacific communities during the racist immigration policies of the 1970s which led to the Dawn Raids (Beehive.govt.nz, 2021). This history of Pacific-Indigenous peoples as diasporic settler communities in Aotearoa and as ethnic minorities, is illustrative.

The most recent 2018 Census enumerated the Pacific population in Aotearoa at 381,642 people or 8.1% of the population at the time of 4.7 million, and still the fourth largest ethnic group (Census, 2018). Comprising fifty percent of Aotearoa's Pacific peoples, Samoan people represent the largest Pacific group (182,721). In numerical order, the remaining six largest Pacific populations in Aotearoa are: Tongan (82,389), Rarotongan/Cook Islands Māori (80,532),

Niuean (30,867), Fijian (19,722), Tokelauan (8,676), and Tuvaluan (4,653; Census, 2018). The “Other” Polynesian, Melanesian, and Micronesian groups have smaller numbers (collectively 17,763) within Aotearoa, but remain an important part of the Aotearoa Pacific population (Census, 2018). Interestingly, owing to their special status as protectorates with NZ citizenship and therefore ease of mobility, the Niue, Cook Island, and Tokelau populations living in Aotearoa outnumber populations in their respective islands in the Pacific (Census, 2006). Furthermore, 62% (235,086) of Pacific people live in Auckland, Aotearoa’s largest city (Census, 2018). This explains why Auckland is often called “the Polynesian capital of the world” (Kirkwood, 2021). In contrast with the general population, Aotearoa Pacific peoples are young, with median age 23.4 years and 35% under 14 years old, the highest percentage of any sub-population group (Census, 2018). Aotearoa Pacific peoples are also overwhelmingly NZ-born (more than 62%), cementing their ‘place’ firmly in Aotearoa; this is home, now (Census, 2013; Dunlop-Bennett, 2019). By 2026, with the highest population growth-rate, Pacific peoples are forecasted to reach 10% of Aotearoa’s population, and 14% of Aotearoa’s youth population (Census, 2018). An increasing percentage of Pacific peoples also claim NZ European/Pākehā/Kiwi, Māori, and/or multiple Pacific heritage in addition to their main Pacific identity (Tukuitonga, 2013). At the last Census, those who acknowledged what may be called ‘Pacific plus’ identities comprised 28% of the Auckland Pacific population (Census, 2018).

Pacific peoples contribute significantly to Aotearoa’s faith landscape with 77.1% reporting being people of faith, compared with 46.5% of Māori and 45% of NZ European/Pākehā (Census, 2018). For many Pacific peoples, faith and church remain a significant part of daily life, including influencing attitudes to health, wellbeing, mental distress, disability, support, and so on (Gibson et al., 2019; Te Pou, 2010; Tukuitonga, 2013). Matapo and Enari explicate the importance of faith to Pacific people, “from a Samoan view, the spiritual gives rise to meanings, thoughts and compassion through acts of love—expression of *alofa* that nurture both life and the genesis of ideas. Spiritual knowing offers insight to what is both within us and beyond, outside the constraints of mortality” (2021, p. 82-83). Faith is often poorly understood, overlooked, and poorly integrated, if at all, despite a growing literature stating its positive effects on climate action, wellbeing, mental health, cessation of substance abuse, psychological treatment outcomes (Bennett et al., 2016; Fa’alogo-Lilo & Cartwright, 2021; Florence & Mikahere-Hall, 2019; Foulis et al., 2022; Havea et al., 2021; Lee et al., 2019; Tu’itahi et al., 2021), and coping with a child’s autism diagnosis (Pearson et al., 2022). Health care professionals may struggle to understand the influence of faith and may miscategorise it as fatalism in regard to health and disability views (Tukuitonga, 2013). Similarly, Pacific people’s use of silence as a concept of relational ethics is poorly understood (Matapo & Teisina, 2021). Such

mismatches in beliefs between health professionals and clients can lead to 'clinic-hopping' and seeking clergy, friends and family, and traditional healers in adjunct to, or instead of, health professionals (Paterson et al., 2018; Tamasese et al., 2005; Tukuitonga, 2013). It is important to note, however, that an increasing number of Pacific young people do not adhere to any particular faith or spirituality (17.5%; Census, 2013). Furthermore, most of Aotearoa's Pacific young people were born in Aotearoa (Census, 2018), and many have never visited the islands, therefore, their beliefs and attitudes to health, mental health, and disability are likely to be less traditional and include more aspects of New Zealand culture compared with older generations (Mila-Schaaf, 2013; MoH/MoE, 2016; Tukuitonga, 2013).

Pacific peoples continue to endure the most significant unmet health needs of all groups in Aotearoa across several indicators, including higher mortality, lower life expectancy, higher incidence of long-term conditions and non-communicable diseases, obesity, and co-occurring conditions (MoH, 2020; MoH, 2022a). Research shows that 90% of Pacific people live in areas of relative social and economic deprivation (Fa'alogo-Lilo & Cartwright, 2021; Tukuitonga, 2013). Patterns of ill-health within Pacific communities continue to reveal that socioeconomic factors and particularly deprivation are major obstacles to good health outcomes (Tukuitonga, 2013), in particular, chronically low incomes, a lack of potential reached in work and education, and inaccessible housing costs (Fa'alogo-Lilo & Cartwright, 2021). A recent study showed that health indicators of Pacific children improved significantly if their parents undertook additional educational development between the child's ages of nought to six years (Schluter et al., 2022). Importantly, however, while the disproportionality in health outcomes is not solely due to deprivation, Pacific cultures and protocols per se do not lead to poor health (Tukuitonga, 2013). Rather, some approaches to health, illness, and treatment can delay help-seeking which causes poorer outcomes (Paterson et al., 2016; Tukuitonga, 2013 - discussed in Barriers to Seeking Support). Overall, some of the most difficult external factors to overcome in accessing adequate healthcare consistently include: low health literacy; cold and damp housing; overcrowding; food insecurity; inequitable healthcare access (use of jargon, inaccessible appointment times, cost/inaccessibility of transport, cost of GP consults and prescriptions, inability to take time off work); lower quality healthcare in areas of deprivation/non-urban areas; a lack of culturally safe healthcare; and prejudice, bias and racism within the health system—all of these being factors which are avoidable (Fa'alogo-Lilo & Cartwright, 2021; Gossage et al., 2002; MoH, 2020, 2021; Tukuitonga, 2013).

In addition, diasporic Pacific families are more commonly becoming disconnected from their close-knit family and traditional community networks (Mila-Schaaf, 2013). Pacific churches are community structures which provide comfort to

their congregations and reflect traditional village structures in the diaspora (Alefaio, 2018). Disconnection from these structures, which are self-monitoring, increases the need for external support and can contribute to mental distress (Tamasese et al., 2005; Tukuitonga, 2013). Twelve-month prevalence rates of mental distress in Pacific-born peoples living in Aotearoa are half that of New Zealand-born Pacific peoples (MoH, 2008a). The authors credited traditional Pacific family and community structures and their inherent social support networks for the decrease in experienced mental distress, but cautioned that increased acculturation could weaken this protective factor for Pacific peoples. Indeed, Su'a-Tavila stated that “one of the coping mechanisms that sustains us in the new environment is our cultural and collective approach” (2019, p. 11). Unable to rely on existing familial and geographically near networks as in the islands, diasporic communities have to create their own relationships and networks across diverse new communities (Mila-Schaaf, 2013).

Findings from a recent longitudinal study with a South Auckland Aotearoa birth cohort revealed higher rates of depression in Pacific young people (25%) compared with the general adolescent population (20%; Fleming et al., 2020). For Pacific young people, depression is gendered and ableist, with 33% of Pacific females experiencing depression compared with 15% of Pacific males (Fleming et al., 2020; c.f. Gossage et al., 2022), and those with a disability impacted twice as much (42%) as those without (21%; Tiatia-Seath et al., 2021). For Aotearoa Pacific young people, relationships continue to be crucial for mental wellness (Gossage et al., 2022). The authors found that a poor relationship between Pacific young people and their mothers or friends, perceiving “bad things about their looks” (due to self-assessed weight), and low school connectedness were the highest predictors of depression symptoms and severity (p. 375). In addition, poor relationships with peers and not feeling a part of school both led to more severe depressive symptoms and having less friends (Gossage et al., 2022). Interestingly, the authors noted that spending seven or more hours online per day—which could be seen as a marker of social approval- or relationship-seeking—was positively correlated with self-hatred in this sample.

For a sub-sample of Pacific young people with disabilities, findings included that while Pacific young people with a disability experienced less wellbeing, greater housing and food insecurity, more unmet health needs and discrimination, greater depression and suicidality, and less safety at school, more of them were engaged in volunteering and service compared with both Pākehā with a disability, and Pacific and Pākehā young people with no disability (Tiatia-Seath et al., 2021). These findings could be seen as markers of resilience and service within Pacific young people, but could also be considered as a cry for help and equitable conditions or as coping mechanisms in navigating hostile environments. To

explain further, one Pacific young person with a disability from the study stated “[the biggest issues facing young people today are] Racial Dysphoria, Mental wellbeing, the societal pressures to live up to the expectations of those around us, peer pressure” (Tiatia-Seath et al., 2021, p. 6). Pacific young people are living in an increasingly individualistic culture and technologically advanced world, yet are chastised for acting in ways seen to be individualistic compared with the *vā*-based socio-cultural context they come from (Mila-Schaaf, 2013). Another explanation for these dichotomous findings could be Pacific young people’s felt sense of intergenerational responsibility for fulfilling family aspirations through becoming exemplary young Pacific leaders, despite any challenges such as disability, they may face (Cammock et al., 2021; Dunlop, 2019).

Diasporic Pacific peoples are constantly adapting to the shifting socio-economic, socio-political, and societal climate they live within. In addition, Pacific young people are a fast-growing group in Aotearoa, are more ethnically and culturally diverse thus having differing needs and approaches to health and wellbeing, and are our future adults, community leaders, and general working force. As traditional values such as *faith* adapt and change over time, it is imperative to explore the lived experiences of Pacific families of autistic children now. Against a backdrop of many challenges, Pacific peoples’ overwhelming resilience, faith, determination, and resourcefulness are key assets which have facilitated their adaptation and flourishing in Aotearoa. The following section describes the Pacific-Indigenous worldview where these strengths originate from, in closer detail.

The Pacific-Indigenous Worldview

Indigenous worldviews including the Pacific-Indigenous worldview have typically been excluded from psychiatric or psychological literature (Kopua et al., 2019; Macfarlane et al., 2014; Tamasese et al., 2005; Tuitea, 2006). There is a perceived incompatibility of the spiritual realm, which is important to many Pacific peoples (Census, 2018; Havea et al., 2021), with scientific explanation (Botha et al., 2021; Tuitea, 2006) although the two need not be mutually exclusive. Macfarlane et al. (2014) reminded us that “the unique philosophical, pedagogical and epistemological characteristics that define Indigenous cultures are regularly in conflict with those of the dominant culture” (p. 259). Additionally, the oral transmission of knowledge and traditions over time common to Indigenous cultures is consistently undermined and justified away as being unscientific, inferior to text-based cultures, and unreliable as an accurate source (Adds, 2012; Janke, 1999; Smith, 2021). This has contributed to the valuing of one knowledge tradition (Western) over all Indigenous knowledge traditions (Kopua et al., 2019; Smith, 2021). Theorising a cultural worldview as a knowledge tradition is helpful in restoring

Indigenous epistemology to its rightful valued place with all knowledge systems (Chiu et al., 2021). As “the worldview lies at the heart of the culture, touching, interacting with and strongly influencing every aspect of the culture” (Marsden & Henare, 1992, p. 3), there is an identified need to examine in more detail the Pacific-Indigenous worldview. In areas where there has been a “disembodiment of practice from Pacific Indigenous epistemology”, social problems have resulted (e.g. mental health: Foliaki et al., 2006; youth offending: Ioane & Lambie, 2016; education: Matapo & Teisina, 2021, p. 498; physical health: MoH, 2020). How Pacific-Indigenous knowledge and clinical psychology are integrated through the ontological and epistemological stance of this project, is described further in the Method section.

Features that make the Pacific-Indigenous worldview inherently different to Western worldviews include differing perceptions of the self and the collective, increased value and sacred status placed on relationships, the centrality of faith, and more holistic views of health and wellbeing (Mo’a, 2014). Pacific-Indigenous world views (plural) are situated, and localised to the Pacific culture in question, rejecting standardisation (Matapo & Teisina, 2021). At the same time, the Pacific-Indigenous worldview (singular) is gaining momentum internationally as a “transnational Pacific paradigm” with utility in re-privileging the Pacific way and Pacific ways of knowing (Matapo & Teisina, 2021, p. 499; Mila-Schaaf, 2010). Here, an ethnic-specific paradigm, the *fa’aSamoa* (Samoan culture and worldview) provides a vehicle through which to explain and understand a little of the pan-Pacific-Indigenous worldview. While researchers have noted that the following views and values are broadly relevant to Pacific-Indigenous cultures (Fa’alogo-Lilo & Cartwright, 2021; Le Va, 2019; Matapo & Teisina, 2021; Pulotu-Endemann & Faleafa, 2017; Su’a-Tavila, 2019; Tamasese et al., 2014; Tuitea, 2006; Tukuitonga, 2013), it is noted that the following explanations and views will not apply wholesale to all Pacific-Indigenous peoples and will apply to varying degrees even within the Samoan culture.

For Samoan people, the cosmos, environments, lands, seas, genealogy, positions, roles, identity, place, belonging, and the physical person are all inextricably, physically, and spiritually linked, and cannot easily be separated or looked at in isolation (Mo’a, 2014; MoH, 1995; Ravulo et al., 2019; Tamasese, 2002). All humans and non-human things could be traced back through genealogy to a god, therefore every living and non-living thing is sacred by a matter of degree, and all things divinely and cyclically linked (Addis, 2012; Tamasese Taisi Efi, 2005). In regard to human interconnectivity, the Samoan ‘self’ is a relational self and is “selfless”, where one is only able to describe themselves in relation to others, both living, past, and ancestral (Anae, 2016; Cammock et al., 2021; Tamasese, 2002; Tamasese et al., 2014). “I” does not exist. ‘I’ is always ‘we’” (Figiel, 1996, p. 135). These ‘we’ relations extends a person’s connections to

specific villages, districts, and motherland, as well as their genealogically defined societal and cultural roles, and their nuclear familial-defined roles and positions (Tamasese, 2002). Taken together, one is positioned as a Samoan of specific defined status, with specific defined societal, cultural, and familial roles; sacred identity and heritage are bound within these formations of self in relation to others. In contrast with Indigenous cultures which are relational, the self as an individual is an imported Western Christian ideal (Botha et al., 2021; Tamasese, 2002; Tamasese et al., 2014).

In addition to an interpersonal relational self, Samoans like many Pacific peoples are also inseparable from their land and sea connections; land is inherited and connected to family titles and lineage (Cammock et al., 2021). In many instances, *fanua*, land was passed down from the inception of the motherland until now along genealogical lines and so an unbroken spiritual connection to the land exists (Mo'a, 2014); not just in part due to the literal sustenance of the people by the land and its water features for multiple generations (Matapo & Teisina, 2021). There is a reciprocal relationship between *fanua* and Samoan people; the *fanua* nourishes the people, and the people *tausi fanua* (steward the land; Lilomaiaava-Doktor, 2009). Many Pacific-Indigenous people are now separated from their original homelands due to migration and the settling of diaspora (Mila-Schaaf, 2013). However, in recounting the identity of the self, Pacific-Indigenous peoples generally acknowledge their island origins, their genealogical and geographical connections, then state their individual identities (Cammock et al., 2021). It is not just relationships and physical assets that are seen as communally held resources, as Macfarlane and colleagues (2014) explained: "in the same way that Indigenous people consider their lands and resources to be collective assets, they see their languages, cultural values, beliefs and practices as a function of the group, not individuals" (p. 259). Cammock and colleagues concurred, stating "for Pacific people, their beliefs and values are often expressed through cultural practices and traditions, and their spoken language. Enacting cultural practices and obligations helps Pacific people connect with their identity and foster feelings of belonging through connecting past and future generations in respectful and safe ways" (2021, p. 121). Thus, the relational self situated within a communal Indigenous setting confers a sense of collective responsibility and solidifies group cohesion (Macfarlane et al., 2014).

In a cyclical fashion, the Samoan worldview sees life as "relational, reciprocal, interconnected, and interdependent" (Mo'a, 2014, p. 50). *Tā-vā*—time and space continuums—are also seen this way (Mo'a, 2014; Kalavite, 2019; Matapo & McFall-McCaffery, 2022). The Pacific-Indigenous conceptualisation of '*vā*' demonstrates the sacredness and value placed on the interdependency of relationships (Mo'a, 2014). *Vā* simply means "the space between", the relational space or social space (Anae, 2016; Lilomaiaava-Doktor, 2009, p. 12), however, the epistemological underpinnings

of the *vā* and its various facets are by no means simplistic. *Vā* is not an empty space, but a connecting space that receives, contains, and reacts to whatever is put into the space (Lilomaiva-Doktor, 2009; Mila-Schaaf, 2013). Ioane and Tudor aptly describe the *vā* as “the space that we ‘feel’” (p. 291). *Vā* is an acknowledgement that relationships between all living things are important, sacred, connected, and reciprocal. Mo’a stated “care for the personal and relational components of the spirit and soul of the human person is vital to the Samoans” (2015, p. 5). Tongan, Hawai’ian, Māori, Japanese, and Fijian cultures, as examples, also share this concept (Lilomaiva-Doktor, 2009; Matapo & McFall-McCaffery, 2022). To ‘*teu le vā*’ is to look after, cherish, tidy, and take care of the sacred spaces between people (Anae, 2016; Lilomaiva-Doktor, 2009). In the *fa’aSamoa* or ‘the Samoan way’, “care for the *vā* ensures healthy co-existence” (Mo’a, 2015, p. 5).

Vā, then, informs what is culturally appropriate or inappropriate behaviour (Anae, 2016). Anae explained, “*teu le vā* is significant because not only does it infer protocols, cultural etiquette, both physical and sacred, and *tapu*, it implies both proscribed and prescribed behaviour and the concomitant moral and ethical underpinnings of behaviour. It insists that direct action must follow to correct the relationship and/or the relational arrangement if a breach of the *tapu* in the *vā* has occurred” (p. 121). The importance to Samoans of honouring the equilibrium of *vā* relationships is captured in *talanoaga* (discussions) with Samoan elders: “great care is taken to ensure that relationships between people, villages, the land and the spirit world remain in good order. When these relationships are disrespected, or crossed in culturally inappropriate ways, there are serious repercussions” (Tamasese, 2002, p. 65). For example, at the highest level of *vā*, *vā tapuia* describe sacred relationships, usually relationships between sociocultural and spiritual hierarchies (God to parishioners or chief to a lower-ranked person; Matapo & McFall-McCaffery, 2022). Transgressing these relationships through unsolicited touch or foul language, for example, amounts to a breach of the *vā tapuia*. *Vā fealoaloa’i* describes shared protocols and respect between people, and separately between people and their environment (Matapo & McFall-McCaffery, 2022). The stewarding of the natural environment is an example of taking care of the *vā fealoaloa’i*. There are other facets to the *vā*, which are reviewed more thoroughly in other works (Fuluifaga, 2017; Lilomaiva-Doktor, 2009). Pacific relational ethics could be said to be underpinned and held to a higher ethical standard through the philosophy of the *vā* (Matapo & McFall-McCaffery, 2022).

Within the *fa’aSamoa* several key concepts find their meaning, including: *alofa* (love/compassion), *tautua* (service/to serve), *fa’aaloalo* (respect), *feagaiga* (covenant and protocols between brothers and sisters), *gafa* (genealogy), *lotu* (prayer/church), *fa’alavelave* (familial obligations), and the chiefly and natural justice system of *fa’amatai* which are

explicated elsewhere (for example: Anae, 2016; Fairbairn-Dunlop, 1991a; Fuluifaga, 2017; Lilomaiava-Doktor, 2009; Taleni et al., 2018). Each of these concepts can only have its full meaning within the context outlined above. All of these things together make up the fa'aSamoa and have variations or parallels within each of the Pacific-Indigenous cultures. Hence, pan-Pacific values (i.e., those that are presumed to be shared across all Pacific cultures) have been proffered: “family, reciprocity, culture, love, spirituality, respect” (Le Va, 2022a). In knowing more about who Pacific peoples are within Aotearoa, and more about the values which they live by, some questions may remain unanswered. Including, what happens when individuals from within a collective are treated in health settings as individuals (Esera, 2001)? And, if individualism is a Western Christian ideal yet there is wide uptake of Christianity across the collectivist Pacific, what does this mean for our young people? Further, how can we better serve Pacific peoples within health and disability contexts? The common denominator to answer these questions may be cultural competency. One aspect of cultural competency is understanding how Pacific peoples communicate, which is briefly highlighted in the following section.

Use of Metaphor

Many Indigenous cultures use metaphor to discuss issues of sensitivity and importance, thus practitioners need to be cognisant of the indirect, and “round-about” ways that information may be shared (Bennett et al., 2016; Te Pou, 2010, p. 30). Within Pacific cultures, key information is often conveyed through conversation, body language, and use of metaphor (Te Pou, 2010). Therefore, use of respectful and genuine verbal and non-verbal language is critical in building effective rapport with Pacific people (Le Va, 2020a). Metaphor, simile, and symbol are used “so that sometimes the heart understands long before the head does” (Culbertson et al., 2007, p. xiv). Therefore, if one is not listening through all of these modes, one might not catch what is being thrown out. Pacific researchers (Goodyear-Smith & 'Ofanoa, 2022, p. 41) discuss use of metaphor further, stating:

Metaphors structure our understandings about our experiences; they influence our thoughts and actions without us noticing them. They allow us to use what we know about our physical and social experiences to understand and make meaning of our world (Lakoff & Johnson, 2003). Conceptual metaphors occur in language in our everyday lives, shaping not only our communications but also our perceptions and our behaviors. Metaphors are not merely language and literary devices; they are embodied in our cognition grounded on bodily experience. Conceptual in nature, they are physically represented in the brain and can affect the way we behave.

In this way, metaphor are grounded in the knowledge traditions they come from, and include values, beliefs, and protocols inherent to their culture of origin (Tualaulelei & McFall-McCaffery, 2019). Pacific metaphor can be ethnic-specific, such as the Rarotongan education research model based on the process of creating a *Tivaevae* (Maua-Hodges, 2000), or relevant across Pacific cultures such as the metaphor of navigation or wayfinding (Sanga & Reynolds, 2017).

Many Māori and Pacific models of health and education are based on metaphor (Bennett et al., 2016). For example, Te Whare Tapa Whā (Durie, 1994), Te Wheke (Pere, 1997), the Hui Process and Meihana Model (Pitama et al., 2007), Seitapu (Pulotu-Endemann et al., 2007), Fonofale (MoH, 1995), Fonua (Tu'itahi, 2007), Vanua (Nabobo-Baba, 2006). Aotearoa psychologists have suggested the use of metaphor with Indigenous clients, stating that this has been very effective for those with Māori and Pacific clients (Bennett et al., 2016; Kopua et al., 2019; Makasiale, 2007). Further, metaphor was used by Fijian participants in research *talanoa*, which allowed them to tell their own stories (Meo-Sewabu, 2014). Metaphor also works well with technology, as Le Va used metaphor in their recent social media campaigns to good effect (Kingi-'Ulu'ave & Mati, 2020). The use of metaphor and symbol must be understood in the context of the Pacific worldview so that working with Pacific families does not become a "performance", but rather renders a genuineness and usefulness to both the therapist and family seeking help (Makasiale, 2007, p. 121).

Child Development from a Pacific Perspective

Literature regarding Pacific conceptualisations of child development are scant. However, concepts which are discussed are holistic and value interconnected relationships including spirituality, the ultimate relationship (Makasiale, 2013). One salient aspect to Pacific cultures (although common to Indigenous cultures), is the idea that "Pacific peoples individuate by remaining whole and attached" (Makasiale, 2013, p. 282). This is in contrast with Western cultures where individuation/differentiation and independence are prized stages of development, and autonomy means acting independently of external influences (Dumont, 2021; Patall & Hooper, 2017). Attachment from a Pacific perspective concurs with a te Āo Māori perspective, where attachment relationships may be seen as continuous across multiple, horizontal relationships, and inseparable from Indigenous knowledge, the spiritual realm (wairua), land connections (whenua), and wider family groupings (equivalent to whānau, hapu, iwi; Fleming, 2018). Therefore, within collective cultures including Pacific cultures, autonomy is better conceptualised as self-determination or volitional or self-endorsed functioning as alternative terms for agentic action by individuals (Soenens et al., 2017; Zimmer-Gembeck et al., 2017). These terms are inclusive of individuals' values and preferences when part of a collective group where a "group ideal ego"

is formed rather than an individualistic ego (Makasiale, 2007, p. 113). Soenens and colleagues concur, “when autonomy is defined as volitional functioning, autonomy is relevant and essential for well-being *across cultures*” (2017, p. 23, emphasis added). Research shows that children with parents supportive of developing self-endorsed functioning, experience greater wellbeing and a range of positive behavioural and academic outcomes (Zimmer-Gembeck et al., 2017).

Within the *fakaTonga* or Tongan cultural paradigm, children develop a sense of *tangata* or personhood where they come to understand the self in relationship to the expansive cosmos: “life for the child is affirmed within tangata through ancestral and natural connections to the fonua, moana, language and culture. The cultural collective and social upbringing contribute to identity formation as an intersubjective being within tangata” (Matapo & Teisina, 2021, p. 500). A uniquely whole Pacific person develops and makes sense of itself through being in reciprocal relationship with family, community, and collective (Matapo & Teisina, 2021, p. 500).

Similarly, from a Samoan perspective, children are viewed as divinely bestowed treasures and sacred from inception (Dunlop-Bennett, 2019). A Samoan proverb describing how children are ‘fed’ with words (Dunlop-Bennett, 2019) denotes both mindfulness of caregiver’s tongues, but also an oral form of early learning. Research with Samoan primary school principals revealed this fundamental way of learning that is subsumed within the *fa’aSamoa* (Alefaio, 2008, as cited in Alefaio-Tugia, 2015).

Va’ai, fa’alogo ma tautala is a holistic process which involves learning through observing (seeing/watching and learning from the environment) at the same time listening (for appropriate ways to respond in situations, contexts, everyday living practices) culminating in the ability to *Tautala* (p. 115, italics in original).

The author stated that the resultant learning is assessed by one’s ability to *tautala* or verbally reproduce the learning. The child’s ability to *tautala* was reflective of their socio-cultural context and the competency of the *‘āiga* or family (Alefaio-Tugia, 2015).

A further Pacific perspective, shared by Fijian-raised Tongan psychotherapist Dr Makasiale is that throughout child development in the Pacific setting, an “externally referenced personality emerges” (2007, p. 112) owing to multiple authority figures in a Pacific child’s life. In the beginning, mother and God are indistinguishable and the baby is totally dependent for all of its needs (Makasiale, 2007). Pacific parents are initially very attentive, responsive, and intimately

involved in the child's life, however, as the child ages, Makasiale purports that a distant form of parenting ensues, characterised by a lack of intimacy or praise. The author discusses the importance of health professionals understanding the Pacific client self in relation to the social hierarchies, authority figures, and cohesive belonging that have moulded them. Therefore, within the health setting, there occurs a transfer of the authority from God, parental figures, family collective, and community voice to the clinician, who should be aware of such power relationships and moderate their words and conduct accordingly so as not to enact shame presentations and identity threats (Makasiale, 2007).

These four perspectives offer interesting insights into ways of viewing child development which are unique to Pacific peoples. While naturalistic and largely effective, oral models of child development would struggle to accurately capture the extent of autistic children's learning through tautala as many autistic children have reduced speech or are nonspeaking. However, these perspectives can inform how to approach Pacific parents about their child's development, and can also inform the therapeutic relationship with parents.

Pacific-Indigenous Conceptualisation of Autism

As in many cultures, there is no widely used term for autism in any Pacific-Indigenous language²⁴ (Bernier et al., 2010). Therefore, understanding autism from a Pacific-Indigenous lens requires triangulation. Disability is conceptualised variously depending on a cultural group's "values, beliefs, and sociohistorical context" (Gaines, 1991; Shochet et al., 2020, p. 2). In addition:

Folk and professional notions of sickness evolve historically, in association with other aspects of culture, [so] that individuals' understanding and experience of illness are patterned on this accumulated social knowledge. In this way, cultural concepts of distress may reflect distinct cultural histories of societies (Lewis-Fernández et al., 2017, p. 4535).

Thus a cultural group's experience of illness and disability throughout their history informs their contemporary conceptualisations of it (Macpherson & Macpherson, 1990). Accordingly, Pacific-Indigenous peoples have conceptualisations of disability, health, illness, and mental distress which differ from Western conceptualisations

²⁴ The Ministry of Health (2012) published a term "Amioga e mafua o le ma'i o le mafaufau", however, this is not well-recognised or understood.

(Tamasese, et al., 2005; Te Pou, 2010). Understanding more about the interconnected *vā* nature of the Samoan worldview mentioned earlier provides some context as to how Samoan people view health and disability.

Pacific notions of wellness are understood in reference to the essential and sacred relationships between both human and non-human entities, including deities and spirits (Macpherson & Macpherson, 1990; Matapo & Teisina, 2021; Mo'a, 2014; Te Pou, 2010). This key difference in views is highlighted by the following statement: “when we [Samoans, Pacific-Indigenous people] talk about mental health, it is not seen as a separate category of health. It is a part of the total health and wellbeing of people, land, and sea” (Tamasese, 2002, p. 68). Tu'itahi (2020) adds, “we are the fonua [land], and the fonua is us”. Further, within Pacific knowledge traditions, mind and body, psyche and spirit have never been disconnected as in the Western dualist mind-body worldview (Hopner & Liu, 2021; Makasiale, 2007, 2013; Mo'a, 2014). Total health and wellbeing when conceptualised through a Pacific-Indigenous lens is more holistic than Western conceptualisations, incorporating the spiritual, physical, mental, familial, cultural, environmental, and other contextual factors, for example, as stated in the Fonofale model (MoH, 1995; Te Pou, 2010). Indeed, Tukuitonga described the Pacific-Indigenous health lens as “socioecological” (2013, p. 68) to explain its comprehensiveness. Other expansive Pacific-Indigenous and Māori models of health and wellbeing include Fonua (Tu'itahi, 2007), Fa'afaletui (Tamasese et al., 2005), Vanua (Nabobo-Baba, 2006), Te Wheke (Pere, 1997), the Meihana Model (Pitama et al., 2007), and Te Whare Tapa Whā (Durie, 1994) to name a few, and all follow a more comprehensive, interconnected approach to health and well-being.

The term *ma'i-aitu* is a Samoan-specific term used to refer to what is most closely recognised as mental distress, being curses, spirit visitation, and all illnesses of the mind (Esera, 2001; Mo'a, 2015; MoH, 1995; Tukuitonga, 2013). Other Pacific nations, for example Rarotonga, Tonga, and Fiji have similar terminology for mental distress, being *neneva*, *āvea āvanga*, and *lilia*, respectively (MoH, 1995; Tuitea, 2006; Vaka, 2016). In Pacific-Indigenous cultures pre-European contact, mental distress was most well-understood as brief or transitory visitations from the spirit realm from early gods and deities of which there were up to 120 of such identified, with either positive or negative connotations (Macpherson & Macpherson, 1990). When one of these beings was offended, a *Taulāitu* would be consulted to act as a conduit between the community and the relevant *aitu* (spirits), to learn of the offence and how to appease them (Macpherson & Macpherson, 1990; Mo'a, 2015). Before Christianity, sudden illness, pain, or spirit visitations were understood as the consequences (punishment) of transgressions against cultural protocols and customs, particularly against genealogical traditions, or against familial and village roles and responsibilities (Esera, 2001; Te Pou, 2010; Mauigoa-Tekene et al., 2013; Tamasese,

2002). The former Samoan Head of State proposed that the transgressions themselves were also seen to have a more serious, spiritual element, as in Samoan culture, roles and responsibilities are accepted as a person's *fa'asinomaga* or divinely bestowed designation and inheritance (Tamasese Taisi Efi, 2007). Tuitea separated *ma'i-aitu* from the Western understanding of psychosis, articulating: "Mai Aitu has been clearly identified in the Samoan culture as a mental illness caused by spirits as a result of the individual breaking Samoan traditions or rules. It is a well-known fact and philosophy" (2006, p. 40, c.f. "*fasia*" in Mo'a, 2015).

Within the *fa'aSamoa*, the "multiple worlds" of the cosmos are considered equal and in their natural state, in harmony (Dunlop-Bennett, 2019, p. 50; Tamasese Taisi Efi, 2005). A further path to unwellness within the Pacific-Indigenous worldview therefore was through the imbalance of harmony, the disintegration of social relationships, and offence caused toward others (MoH, 1995). Disharmony could occur between people, between people and their environments, and between people and early *atua* (Tamasese, 2002; Tukuitonga, 2013). Ways of life, cultural ritual, and daily acknowledgements and prayers sought to maintain or to restore imbalanced harmony in Pacific-Indigenous peoples' lives across all key areas (Macpherson & Macpherson, 1990; Mo'a, 2015). Socio-cultural rule-breaking and actions that led to the breakdown of relationships would most often have been perpetrated by the person affected by the disturbance of wellbeing. However, there was also a belief that the health and wellbeing of children was affected as a result of their parents' misdeeds or omissions, particularly the mother's (Birkin et al., 2008; Mauigoa-Tekene et al., 2013; Tuitea, 2006), or at times those of extended family members (Te Pou, 2010).

The Samoan term *ma'i-aitu* is made up of two words: *ma'i*, meaning sick, ill, or with child, and *aitu*; meaning spirit, which includes that of deceased relatives (Tukuitonga, 2013). Other terms in Samoan used for mental conditions or disorders include *ma'i o le mafau* (MoH, 2012; Alefaio-Tugia, 2015), and *ma'i-leaga-le-ulu* (Mo'a, 2015, p. 4) both meaning illness of the mind, however, less kind in tone. There are other more denigrating terms which in the Samoan culture convey a distaste for the affected due to their or their family's perceived wrongdoing (Macpherson & Macpherson, 1990). Over time the Samoan conceptualisation of illness and the number and types of known illnesses have expanded to meet new variants introduced to the islands of Samoa (Macpherson & Macpherson, 1990). Now, in everyday parlance Samoan illness terms are often shortened to *ma'i*, which is widely understood to mean that one is either physically, mentally/emotionally, or spiritually unwell, therefore requiring context to distinguish which of these meanings is intended (Mo'a, 2015). Mo'a explained:

Ma'i, as the Samoans understand it, is *anything* that alters and modifies the balance and equilibrium of the person. This can come through the body in its physicality, the spirit, the mind or the emotions.

Ma'i is induced from within the person or from without or both (2015, p. 4, emphasis added).

Thus, we understand ma'i to refer to the full gamut of human conditions produced by either internal or external causes. Ma'i is therefore inclusive of the neurodevelopmental condition of autism.

It may have been an easy transition for Pacific-Indigenous people to transform their view of unwellness arising from transgression against protocols and early gods, to a view of the same arising from punishment for sin against the commandments of Atua, the Christian God (Esera, 2001; Te Pou, 2010; Mauigoa-Tekene et al., 2013). Esera stated that Pacific peoples tended to eschew their ancient culture in favour of the missionaries' brand of worship, and willingly adopted biblical rules and regulations. Hau'ofa (1994) commented:

The wholesale condemnation by Christian missionaries of Oceanic cultures as savage, lascivious, and barbaric has had a lasting and negative effect on people's views of their histories and traditions. In a number of Pacific societies people still divide their history into two parts: the era of darkness associated with savagery and barbarism; and the era of light and civilization ushered in by Christianity (p. 149).

Largely due to the gospel being used as a tool of colonisation such was the case across the Pacific region (Salesa, 2012). Indeed, the explanation of unwellness arising from sinfulness derives from the Western Puritan tradition (Gray, 2001).

However, Samoa refutes religious colonisation as goddess Nafanua is purported to have prophesied the coming of Christianity herself (Tuisuga-le-Taua, 2009, as cited in Alefaio, 2018). Instead of total replacement of traditional religion, Samoa effectively indigenised Christianity and in doing so, strengthened already present cultural values of *alofa* and peace, among others (Alefaio, 2018; Mo'a, 2015). The absorption of the gospel into Samoan culture may have also been assisted by the heavy focus on moral conduct between both ideologies (Macpherson & Macpherson, 1990). In Tonga also, Christianity was blended into the existing *fakaTonga* until the two are now described as inseparable (Matapo & Teisina, 2021). Pacific peoples with more traditional beliefs still remain cognisant of the *aitu* spirits and early gods they knew before God, who could bring blessing or curses upon humans (Anae, 2016; Fa'alogo-Lilo & Cartwright, 2021; Mauigoa-Tekene et al., 2013). This fundamental tendency to understand psychological phenomena in terms of punishment and retribution

leads to significant anxiety for Pacific elders in particular who seek to 'live right' to avoid negative consequences, and must be understood for its impact on Pacific peoples' reticence to attend health services due to stigma and shame (Macpherson & Macpherson, 1990; Pulotu-Endemann & Faleafa, 2017; Te Pou, 2010).

In the Pacific-Indigenous conceptualisation of unwellness, a traditional etiology requires a traditional treatment response (Te Pou, 2010). Mo'a stated that recognised "inter-connected shifts" in wellbeing required a similarly "inter-connected realignment for restoration of balanced wellness" (2015, p. 4). For example, the development of *ma'i aitu* stimulated an integrated physical, cultural, and spiritual response to restore the balance of the transgressed elements or protocols (Fa'alogu-Lilo & Cartwright, 2021; Tuitea, 2006). That is, when a loved one had been affected by *ma'i aitu*, the traditional response was to treat the family member at home with traditional healing and spiritual practices, and if possible, not by Western medical practitioners (Tuitea, 2006). Where a condition had arisen from transgressing the *vā* in some way, the family may have sought mercy from the offended for their wrongdoing, in anxious anticipation that the condition may be resolved before common recognition of it (Macpherson & Macpherson, 1990). Only if after following this type of remedy and the condition persisted would it be disclosed for treatment. Importantly, it would be against a Pacific cultural response to treat a family member as an individual in a clinical setting without regard to their family's concerns, or to their community's typical healing practices (Fa'alogu-Lilo & Cartwright, 2021; Te Pou, 2010).

Moreover, a further cause of stigma with regard to help-seeking for Pacific peoples is a perception that despite the strength of the interconnected familial structure with pooled resources and love for family members, it was not enough and one is affected, needing help (Te Pou, 2010). This can lead to familial guilt for not being able to provide sufficient care for the family member, and for needing to seek help from strangers (Te Pou, 2010) which goes against Pacific beliefs of dealing with things in-house (Pulotu-Endemann et al., 2004, as cited in Fa'alogu-Lilo & Cartwright, 2021). Therefore, within more traditional Aotearoa Pacific communities, private healers including *taulasea* (spirit healers), *fofō* (masseuses), and those mixing natural medicinal remedies continue to be engaged with regularly, often before or in place of primary and public health services (Cammock et al., 2021; Tamasese et al., 2005; Te Pou, 2010; Tukuitonga, 2013). Overall, due to the Pacific conceptualisation of unwellness arising from erroneous conduct or spiritual means—not biologically-based with an associated quick diagnosis and resolution—Pacific people are less likely to report illness and seek a biomedical solution, because they are less likely to believe that there is one (Macpherson & Macpherson, 1990).

With the introduction of te Reo Hāpai: the language of enrichment, a Māori strengths-based health and disability terms glossary in Aotearoa in 2020, the term *Tangata Whaikaha* (person determined to do well; www.manawhaikaha.co.nz) to refer to a person with a disability, was developed. Following this, a Samoan equivalent, *Tagata Sa'ilimalo* meaning person or people in search of success was developed and is distinguished from the te Reo Māori term by its reference to both the disabled person and their immediate community (www.tofamamao.com). The establishment of Aotearoa's first government ministry charged with the wellbeing of disabled people, officially occurred on the first of July, 2022. In alignment with strengths-based language and the preferences, centrality, and ownership of the disability community within Aotearoa the name of the new ministry is Whaikaha – Ministry of Disabled People (www.whaikaha.govt.nz). This language concurs with a Māori perspective of tangata whaikaha as “having value and mana as of right” (Bevan-Brown, 2013, p. 573). As can be seen through these examples, overall, the Indigenous understanding of disability is shifting towards a more inclusive, less stigmatised conceptualisation and towards a more valued and celebrated position. However, the introduction of a new term or new knowledge unless well-accepted by a community will do little to change belief systems which have served people over time (Macpherson & Macpherson, 1990). It is not known to what degree Aotearoa Pacific peoples subscribe to traditional beliefs around health, disability, and restorative healing practices, or how or if their beliefs have evolved in their contemporary contexts (Te Pou, 2010). It is well-established however, that significant barriers are in place which stop Pacific peoples accessing health services when they make the decision to do so.

Barriers to Seeking Autism Support for Pacific Peoples in Aotearoa

Having no Pacific term for autism makes conceptualisation of the condition and acceptance of it more difficult for Pacific peoples (Lewis-Fernández & Kirmayer, 2019; Lilley et al., 2020; Shochet et al., 2020; Simpson, 2021). Pacific cultures have traditionally attributed conditions of all kinds to transgressions against cultural protocols and customs, particularly against genealogical traditions, roles, and responsibilities (Fa'alogo-Lilo & Cartwright, 2021; Tuitea, 2006). As well, unwellness could result from an imbalance of harmony in relationships with others, with God or pre-Christian gods, and with the environment (Fa'alogo-Lilo & Cartwright, 2021; Tukuitonga, 2013). A child's disability could also reflect the parents' perceived incompetency or involvement in sinful behaviour (Te Pou, 2010). Given these facts, it is understandable that disability or neurodiversity such as autism, would be met with stigma, fear, and negative beliefs and attitudes in Pacific cultures (Fa'alogo-Lilo & Cartwright, 2021; Paterson et al., 2016). Stigma and negative attitudes regarding conditions or

illnesses of the mind still remain in contemporary Pacific cultures within Aotearoa (Fa'alogo-Lilo & Cartwright, 2021). This significantly impacts when people will choose to seek help (Macpherson & Macpherson, 1990). Fears of being incriminated for their child's disability, discriminated against, of receiving poor service and treatment by others within the family and community, and fear of the potential limiters on future options that autism could bring, are very real, and can delay or preclude help-seeking and diagnosis (Bernier et al., 2010; Crane et al., 2018, 2019; Macpherson & Macpherson, 1990; Paterson et al., 2016). Furthermore, these barriers could strengthen resolve to access traditional interventions and avoid primary and public health services (Fa'alogo-Lilo & Cartwright, 2021; Tukuitonga, 2013).

Strongly maintained connections with family in the Pacific are also said to impact health beliefs and engagement with health services in Aotearoa (Paterson et al., 2016). Traditional remedies may partially account for Pacific peoples' tendency to avoid primary and public health systems, and why service-access rates continue to be low despite efforts to increase the Pacific workforce and the acceptability of health services for Pacific peoples (Foliaki et al., 2006; Tamasese et al., 2005; Tukuitonga, 2013). Tamasese (2002) and colleagues (Tamasese et al., 2005) found several additional cultural factors that contribute to psychological distress for Pacific peoples. These included both internal and external factors, such as: weakened traditional relational arrangements due to decreased contact between extended families and their communities; Western values being viewed negatively by Pacific people; Western values not being inclusive of, or directly conflicting with Pacific worldviews; perceived failure to meet extended family obligations causing isolation and fear; and, reduced access to traditional healing forms and restoration of relationships leading to delays in help-seeking and a sense of few available options for families (Bathgate & Pulotu-Endemann, 1997; Fa'alogo-Lilo & Cartwright, 2021; Paterson et al., 2016; Tamasese, 2002; Tamasese et al., 2005). Low health literacy also persists, with Pacific peoples having little knowledge of symptomology, of where to go in times of heightened distress, and of available services and supports (Ataera-Minster & Trowland, 2018; Fa'alogo-Lilo & Cartwright, 2021; MoH/MoE, 2008). This meant that Pacific people still felt that family, friends, and clergy were the most trustworthy and such were still the most sought-after advisors when people were help-seeking (Paterson et al., 2018; Tukuitonga, 2013). When Pacific people do seek supports, before beginning any interventions, the most important task for Pacific people is to build a trusting relationship with health professionals (Birkin et al., 2008). Coincidentally, where lack of relationship, trust, and other options are issues, Pacific people often will not present to a mental health service until they or their family member is at crisis point (Pulotu-Endemann & Faleafa, 2017; Tukuitonga, 2013).

Aotearoa Pacific adults reported 1.5 times the rate of psychological distress over the preceding month as the general population (9.6% for the total population and 15.7% for Pacific peoples; MoH, 2021), with some increased distress attributed to COVID-19 (Gasteiger et al., 2021). In addition, 15.2% of Pacific peoples did not attend a doctor's visit due to cost (MoH, 2021). Transport was also twice as hindering for Pacific peoples visiting the doctor (4.8%) than the general population (2.4%; MoH, 2021). The rate of unfilled prescriptions for Pacific peoples (6.6%) was also double that of the general population (3.1%; MoH, 2021). When adults are unable to access health care for themselves due to costs, lack of transport, and COVID-19-related restrictions or anxiety, they are also likely to be less inclined to refer their child for neurodevelopmental assessment. In addition, even if they were to refer their child/ren, families would have experienced extra delays associated with COVID-19-related restrictions including cessation of face-to-face assessment, which due to the observational necessities, is required for autism diagnosis (Jang et al., 2022). Only one study had reported on barriers to Pacific families accessing autism supports. An Aotearoa government-funded psychoeducational programme for parents of a newly diagnosed autistic child (EarlyBird; Birkin et al., 2008) revealed barriers to attendance for parents, including Pacific parents. These included: intervention programmes being scheduled during the day and requiring both parents' attendance, video-taped sessions of their child being shown to the group leading to feelings of exposure and judgement, jargon/language barriers, distance of the programme, learning about the programme/being offered the programme too late to be helpful, long wait times for the programme and delays in diagnosis leading to programme ineligibility due to the child's age, and irregularity in the offering of the programme especially in all locations (Birkin et al., 2008).

Despite the many barriers for Pacific people in accessing health services in Aotearoa, there are pockets of innovation, dedication and passion, and a small Pacific workforce (5%) who absorb the burden for the community in seeking to provide top-quality, culturally relevant, and clinically safe health and disability services and support (Pulotu-Endemann & Faleafa, 2017). Su'a-Tavila contended that the success of this group of Pacific practitioners is owed to traditional Pacific values, applied contemporarily:

Our traditional practice and how it informs our contemporary approach to professional practice is crucial (Ravulo, 2016; Sua-Tavila, 2010). ...traditional practice is a cultural-based practice where the service provided is founded on cultural norms that are appropriate when working alongside individuals, families, communities and societies (2019, p. 12).

Traditional practice, or cultural competency, is recognised as critical to the reduction of disparities in health outcomes for Pacific peoples, due to its combating of racialised prejudice, bias, and health discrimination ingrained within Aotearoa's public health systems (Fa'alogo-Lilo & Cartwright, 2021; Paterson et al., 2016; Su'a-Tavila, 2019). Now, culturally appropriate assessment and treatment are required to be provided by all health practitioners, and a minimum standard of cultural competency is expected (Le Va, 2022b). In reality, culturally valid autism assessment for Māori and Pacific families remains elusive. Given that 95% of the mental health workforce is non-Pacific, Pacific families seeking diagnosis or intervention for their autistic child will likely see a non-Pacific health practitioner (Pulotu-Endemann & Faleafa, 2017). Therein lies a dire need for capacity building in the health workforce to achieve culturally competent health professionals in Aotearoa.

Existing Research on Pacific Autistic People

There is currently no peer-reviewed, published research with Pacific families of autistic children surveying their experiences, support needs, and language and culture maintenance (MoH/MoE, 2016; Whaikaha, 2022). Internationally, within the small amount of US autism experimental studies that do mention Pacific peoples, accurate numbers and outcomes for Pacific cases are difficult to ascertain. This is due to masking of potential Pacific cases with labels such as 'Asian or Pacific Islander', 'Native American/Pacific Islander', and 'Asian/Pacific Islander'. Quite apart from the diversity hidden beneath the term "Pacific Islander", addition of the term "Asian/Asian Islander/Native American" significantly increases the possibility of non-Pacific ethnicities being included within the cases. In addition, in some studies, just single cases are included under these umbrella terms with no results, perhaps due to attrition or other outcomes, and in others the rationale for non-reporting of small case numbers is to protect anonymity (Christensen et al., 2016; Dyches et al., 2004; Fountain & Bearman, 2011; Pituch et al., 2010; Swensen et al., 2007). Ironically, one US study looking at ethnic disparity labelled 1,871 cases 'Native American/Pacific Islander' with no further derivation, making the reading of results in regard to both the Native American and Pacific cases futile (Bilaver et al., 2021). In all of these cases, it is impossible to obtain the experiences of Pacific families of autistic children with any clarity.

In Aotearoa, the total of eight available documents that mention Pacific families of autistic children include: a social network analysis of co-occurring conditions within Aotearoa autistic participants (Virués-Ortega et al., 2017); a small-scale prevalence study limited to the Hutt Valley area (Drysdale & van der Meer, 2020); a government evaluation report of an autism parents' psychoeducational programme (EarlyBird; Anderson et al., 2006); an associated article on access

to early intervention in Aotearoa (Birkin et al., 2008); a book chapter written for teaching professionals on the development of a Samoan Makaton sign language resource (Polson, 2016); a further chapter in the previous book about the role of culture in autism (Bevan-Brown & Moldovanu, 2016); the NZ Autism Spectrum Disorder Guideline which noted the need for Pacific families of autistic children's experiences and perspectives to be collected (Broadstock, 2014); and, a study which compared child age at parents' first developmental concerns with latency to autism diagnosis (Waddington et al., 2022a). Virués-Ortega and colleagues (2017) created a combined Māori/Pacific ethnicity category for any participant who was either of those ethnicities or both (n=115), and Waddington and colleagues (2022a) aggregated their five 'Māori or Pacific Islander' participants, so deducing Pacific outcomes from the published literature was elusive. No other peer-reviewed, published research on Pacific families of autistic children in Aotearoa could be found. It remains that the holistic lived experiences of Aotearoa Pacific families of autistic children are unresearched.

The Pasifika Autism Support Group

The Pasifika Autism Support Group (PASG), Auckland, Aotearoa, was birthed out of a desire to gather together like-minded parents who could share experiences and support each other and their autistic children, from the particular viewpoint of shared Pacific cultures. The PASG founders, Brian and Betty Pulefolau, are of Niuean and Samoan descent respectively and established the group after being frustrated at the lack of culturally relevant support available to them when their son, Roman was diagnosed autistic at four years old. The PASG website (www.asdpasifika.org.nz) states: "Pasifika Autism Support Group is a new initiative for Pasifika parents and carers to meet with others who support and share similar experiences, gain new information, and to bring awareness of autism to the Pasifika community". The PASG story foregrounds narratives of resilience, navigation, and creativity which are relevant to Pacific parents of autistic children. The PASG parents' network brings together over 2,300 parents, family members, and supporters mostly in Auckland but also across Aotearoa and other areas of Oceania. Members share a broad commonality of experience anchored through being of Pacific descent and a family member of a Pacific autistic person whom they support. The following section outlines the research questions for this project.

Research Questions

This exploratory research provides the first literature detailing the narratives of Pacific families of autistic children while highlighting the specific Aotearoa context. The first contribution of this research to the field of autism literature lies in

the differing ways that being a Pacific family of autistic children is holistically experienced on a daily basis. Accordingly, the first focus of this research is to explore the holistic lived experiences of Pacific families of autistic children. The research question associated with this aim is: *What are the holistic lived experiences of Pacific parents raising an autistic child in Aotearoa?*

Secondly, it is well-supported in research that adequate support and early intervention is critical to long-term health and education outcomes for autistic individuals, therefore, the investigation of important values for Pacific peoples will be instructive for support services aiming to assist Pacific families of autistic children. This study will illuminate the myriad of barriers to health and disability service access, whether they are internal to the families, or present externally. The narratives of the families will highlight these barriers, and therefore opportunities to intervene effectively. The collated information will further provide insights to inform agencies such as disability support services and Learning Support and assist them in developing their own practical guidance for supporting Pacific families of autistic children. This focus will be answered by investigating the research question: *What available supports are Pacific parents raising an autistic child accessing or not accessing, and what supports do they need that are not there?*

The third focus of this research examines how traditional language and culture maintenance occurs within Pacific families of autistic children. The links between traditional language and cultural embeddedness, and identity and wellbeing are well-established. However, there is no research on how Pacific families of autistic children pass their traditional language and culture on to their autistic child, given the unique communication challenges of autism. These success stories could be shared to help other Pacific families of autistic children facing the same challenges. The final research question to be answered is: *How is language and culture maintained within Pacific families of autistic children in Aotearoa?* The following chapter outlines the method used to answer these research questions.

Chapter 5: Method

The Broad Ontological and Epistemological Position From a Western Perspective

Overall, the preceding literature review demonstrated that the Pacific-Indigenous worldview and conceptualisations of health, wellbeing, and disability are nuanced and holistic. Pacific peoples' lived experiences of raising autistic children will therefore be gainfully explored if the research methodology matches the paradigm and worldview of the participants (Fa'avae et al., 2016). As Pacific people view their spirituality, environments, and relationships as interconnected and reciprocal (Mo'a, 2014), then Pacific people will likely articulate their experiences referencing each of these aspects. Accordingly, Pacific peoples' lived experiences of disability need to be investigated holistically also, using these same parameters which Pacific people equate with health and wellbeing. It seems obvious that if Pacific experiences and views are sought through a Western paradigm and guided by a Western (and therefore a constricted) conceptualisation, there will be several poles of the fale (Fonofale) that will remain inaccessible to empirical research evidence, and untouchable by Western treatment approaches. Pacific-Indigenous methodologies and research methods are therefore employed in this study as they provide the most appropriate conditions to study the lived experiences of Pacific families of autistic children whose experiences continue to be shaped by their Pacific-Indigenous paradigm, and their current diasporic context.

The methodologies chosen for this exploratory study are most akin to experiential and participatory action research methodologies (Braun & Clarke, 2022; Cammock et al., 2021; Goodyear-Smith & 'Ofanoa, 2022). Qualitative research methodologies share an "affinity" with Indigenous methodologies due to their shared aspirations of authentic representation and solutions for participating communities (Alefaio-Tugia, 2015, p. 100; Vaoleti, 2006). Within a quantitative research frame, which seeks to "project a sense of objectivity, control, and authority" through distance from the data, qualitative research appears biased and loose (Patton, 2015, p. 72). By contrast, qualitative research methodologies acknowledge the researcher-context-research influential cycle and the value of the reflexive "self as the instrument" when conducting research (Patton, 2015, p. 73). Like all socially constructed activities, research is influenced by the knowledge, experiences, values, and beliefs of the researcher (Holmes, 2020). Holmes continued that rather than to ignore the inevitable effects of bias on the research design, data collection, data analysis, and research outcomes, it is critical to acknowledge and understand these within the current research as part of a process of reflexivity. To not do so would render such research unethical. Research in social realms is rarely value-free (Holmes, 2020). It could be argued

that qualitative methodologies produce less biased studies than quantitative methodologies, due to the overtly rigorous and systematic processes of decision-making key to these approaches (Braun & Clarke, 2022; Patton, 2015). Qualitative research methodologies are then an appropriate starting point from which to build the research design.

The experiences which are true and valid for the participants will vary across the families, across geographical location, across time, and across the socio-cultural contexts in which the families live. Therefore, the underlying ontological position of the research must take a relativist stance (Braun & Clarke, 2022; Patton, 2015). The relativist approach claims that there are many 'truths' or realities that can be communicated through the surveying of participants' lived experiences, and that knowledge is relative to the time and place in which the research occurs (Patton, 2015). A relativist stance rejects the idea of a singular universal truth existing or being able to be uncovered through undertaking more rigorous research, rather, the description of all categories and variation within the data is the goal (Braun & Clarke, 2022; Holmes, 2020). Accordingly, some of the parents' lived realities may be replicated, may overlap, or may contradict with other parents' realities, however, each family's truth will be a direct reflection and their own interpretation of their realities as Pacific parents (Braun & Clarke, 2022). The resulting analysis is therefore inductive, with the acknowledgement that any interpretations are through the lens of the situated researcher and reflect the time-period and wider context of the research (Braun & Clarke, 2022; Patton, 2015).

In addition, this research arises from a constructionist epistemological perspective where participants' knowledge and ways of knowing are rooted in their context and their social world (Patton, 2015). Patton distinguishes a *constructivist* viewpoint (relating to *an individual's* meaning-making) from a *constructionist* viewpoint relating to *collectively decided and transmitted* meanings. A constructionist position therefore supports the valuing of Pacific-Indigenous knowledges which are traditionally collective, oral, experiential, constructed, and involve contextual factors including the physical environment (Patton, 2015; Matapo & Enari, 2021). Consistent with a Pacific-Indigenous worldview of cyclical interconnectedness and the centrality of relationships, constructionists explore the numerous realities created by groups and the real-world implications of these interpersonally and in their lives (Patton, 2015). This further concurs with the emphasis within Pacific research on the resulting implications for Pacific communities (Fa'avae et al., 2016).

In the current study, the researcher was involved in the co-construction of the data with participants through shared language (English, the "default cross-Pacific language"), so the researcher position is emic, and interpretivist involving symbolic interaction rather than purely phenomenological (Moon & Blackman, 2014; Tualaulelei & McFall-

McCaffery, 2019, p. 198). An emic perspective not only influences the design of the study but also the practical considerations. For example, a cultural relativist constructionist approach:

Recogniz[es] behavior and actions as being relative to the person's culture and the context in which that behavior or action is both rational and meaningful within that culture. It uses terminology that is meaningful to and from the perspective of a person from within the culture whose beliefs and behaviors are being studied. So, for example, interview transcriptions would include verbatim colloquial language, spelling, and grammar. Prior theories and assumptions are discarded or disregarded so that the true 'voice' of the research participants may be heard (Holmes, 2020, p. 5).

The insider/outsider binary is unhelpful as positionality can change over time and researchers often occupy more than one role at a time (Fa'avae et al., 2016; Holmes, 2020). The current research data were therefore interpreted through the researcher's own socio-cultural context and experience at the time, as well as through the specific research context (Braun & Clarke, 2022).

Interestingly, this research could also be described as having a critical realist/contextualism leaning (Patton, 2015). This is because while acknowledging all the tenets of a relative constructionist viewpoint, there are some truths that will emerge from the data whether some participants or the researcher have experienced them personally or not. These might include the autism-related supports that are available across different geographical regions of Aotearoa, the particular socio-cultural climate in a given area or towards given peoples, and indeed the government's health agency's policies on disability services, learning support, and funding distribution which affect Pacific families. These truths will be verifiable as facts, although their effects and level of influence will be experienced subjectively across the participating families. To summarise, from a Western ontological and epistemological perspective, the research design of this study is relativist-constructionist, with an interpretivist-interactionist philosophical position. However, this study was not designed with Western notions of ontology and epistemology in mind. The following sections will outline this study's research design in the way in which it was conceptualised, through a Pacific-Indigenous methodological frame.

Whose Knowledge Matters?

In relation to the health and wellbeing of humanity, Tu'itahi contended that *all* knowledge systems contribute to our advancement, including Indigenous knowledge systems (2020). Yet, the Indigenous experience has largely been excluded from knowledge development and research evidence as the Western academy has been content to sustain their default rank of supreme knowledge authority (Alefaio-Tugia, 2015; Botha et al., 2021; Gaines, 1991; Hopner & Liu, 2021; Macfarlane et al., 2014; Matapo & Enari, 2021; Patton, 2015). The unfortunate result is that empirical research has limited relevance and applicability to the socio-cultural contexts, the “lived realities”, and the hopes and dreams of Indigenous peoples (Bennett et al., 2014; Gaines, 1991; Macfarlane et al., 2014; Vaoleti, 2006, p. 22). Even the language of publication limits thought as Smith (2021) emphasised, “there are realities which can only be found, as self-evident concepts, in the Indigenous language; they can never be captured by another language” (p. 179). Of dire consequences, research that denies diversity of thought, upholding the “dominant cultural hegemony”, continues to perpetuate disparities for Indigenous peoples and falsely renders Indigenous knowledge to be of no value (Anae, 2010, 2016; Bennett et al., 2014; Gaines, 1991; Macfarlane et al., 2014, p. 259; Vaoleti, 2006). The reality is, to solve the social and health problems of the world, we need Indigenous knowledge systems present and contributing (Hopner & Liu, 2021; Matapo & McFall-McCaffery, 2022).

Consequently, Indigenous researchers have emphasised the importance of research approaches that esteem methods developed from concepts Indigenous to the cultures of the research participants (Anae, 2010; Fa'avae et al., 2016; Kleinman, 1987, as cited in Tamasese et al., 2005). In other words, decolonising and indigenising research (Matapo & Enari, 2021; Suaalii Sauni & Fulu-Aiolupotea, 2014; Thaman, 2014). Indigenous knowledge development must move forward, while deftly reviewing the efforts of those before us to avoid redundant or weak iterations of previously articulated knowledge (Sanga & Reynolds, 2017). It is pertinent to recall that “methodology did not arrive with the coloniser”; that Indigenous peoples for millennia have been involved in processes of discovering, naming, describing, and investigating their worlds (Smith & Wolfgramm-Foliaki, 2022, p. 31). Smith (2021) testified that Indigenous methodologies often comprise a mix of non-Indigenous methodologies and Indigenous concepts and protocols. This arises from the fact that Indigenous-descendant researchers can currently only gain qualifications in fields such as clinical psychology within the Western academic fraternity, and this methodological mixing reflects their knowledge *whakapapa* (genealogy; Smith, 2021).

It is critical to the continued development of knowledge generally and the wellbeing of humanity that Indigenous knowledges are ‘brought into the fold’ and given the platform and recognition they deserve (Alefaio-Tugia, 2015; Botha et al., 2021; Thaman, 2014; Tualaulelei & McFall-McCaffery, 2019; Tu’itahi, 2020). Sanga and Reynolds (2017) asserted, “a Pacific research paradigm is equal to all others or nothing at all” (p. 202). Pacific researchers are therefore called to interrogate and disrupt the status quo of Eurocentric methodologies used within research and to re-privilege our ways of knowing and knowledge (Cammock et al., 2021; Thaman, 2014; Tualaulelei & McFall-McCaffery, 2019; Tuia & Cobb, 2021). Indeed, re-privileging Indigenous ways of knowing and knowledge is “urgent work” (Botha et al., 2021, p. 52). Fortunately, there is now a proliferation of research methodologies available to select from, including: “Pacific-Indigenous research approaches, non-Indigenous research approaches, Pacific-inspired approaches or a blend of various approaches” (Tualaulelei & McFall-McCaffery, 2019, p. 189). As the authors explain, the advents of globalisation and technological advances have led to increasing accessibility and participation by Pacific researchers. As a result, through adaptation and significant effort there is a new hybridity and eclecticism to Pacific research approaches (Sanga & Reynolds, 2017; Tualaulelei & McFall-McCaffery, 2019). In answering the call to trouble existing structures, this study seeks to indigenise the autism research space by leaving behind systems of the academy which marginalise Indigenous experiences and knowledges, through esteeming instead “Pacific-centric” methodologies (Cammock et al., 2021, p. 120; Matapo & Enari, 2021).

Valuing Pacific-Indigenous Knowledge through Ethical Research

Before discussing further the methodological frameworks used in this study, it is important to underscore the Pacific-Indigenous ethical position within this research. Although research ethics are not unique to research undertaken by Pacific researchers, they do present differences to Western-principled research salient enough that they are important to distinguish. For example, psychological ethics evolved out of the legalistic ethics of the medical field, and are inherently individualistic, authoritarian, and normative (Hopner & Liu, 2021). The rationale for attending to a higher standard of research ethics within Pacific-focused research is that when ethical relationships are appropriately attended to within collective societies and in Pacific research, positive outcomes and transformative change result for Pacific communities (Anae, 2016; Fa’avae et al., 2016). Massey University sets out Pacific Research Principles in its guidelines for Pacific researchers as follows: Respect for relationships, Respect for knowledge holders, Reciprocity, Holism, and Using your research to do good (2017, p. 3). Adherence to these ethical principles of research is intended to decrease the likelihood

of further “epistemological violence” (Hopner & Liu, p. 180) being perpetrated within minority research communities and to increase the likelihood of good emerging research.

There is an unfortunate history of Pacific peoples being exploited through extractive research (Alefaio, 2018; Anae, 2016; Hopner & Liu, 2021; Vaioleti, 2006) and previously “outsiders looking from the outside [has been] the norm for Western researchers doing research on Pacific people” (Fa’avae et al., 2016, p. 139). As successive government priorities shifted, the voices of Pacific people in research became (financially) important to government and funding agencies (Alefaio, 2018). In response, non-Pacific researchers proliferated research on Pacific peoples (Alefaio, 2018; Aporosa et al., 2021; Kapeli et al., 2020; Tualaulelei & McFall-McCaffery, 2019) in exchange for a small incentive or no reciprocal gesture. Even the choice of incentive reflected attitudes of beneficence on the part of the researchers. Notwithstanding this strained research setting, Pacific peoples obligingly participated in research being done ‘on’, ‘to’, or ‘about’ them, with sometimes little explanation, autonomy throughout the process, or control over the way that their perspectives and themselves were portrayed in the final dissertation (Vaioleti, 2006). This has led to the underrepresentation or partial representation of Pacific peoples and their voices at best, and the blatant misrepresentation and outright damage of their reputation at worst (Alefaio, 2018). As examples, recall anthropologist Margaret Mead’s conclusions about sexuality in Samoa (Vaioleti, 2006), and the mythical “warrior gene” purported to be responsible for violent behaviour in Māori (Wensley & King, 2008). Due to these and many other instances of historical exploitation, negative consequences such as ‘research fatigue’, scepticism, and concerns over data sovereignty²⁵ have arisen (Moana Research, 2021; Vaioleti, 2006).

One way this study seeks to ‘*teu le vā*’ (care for relationships) is to recognise and value the sacred knowledge shared within research relationships. That is, acknowledging the responsibility of the researcher while essentially exposing sacred Pacific-Indigenous conceptualisations to the purview of others, the gravity of which should not be understated (Tamasese, 2002). Pacific peoples have always been mindful of what they share of their culture and their history, and particularly who they share it with (e.g.: Hau’ofa, 1994; “secret knowledge” Sanga & Reynolds, 2017; “knowledge politics” Tualaulelei & McFall-McCaffery, 2019). The idea of responsibility in the sharing of sacred knowledge concurs with *kaitiakitanga* (stewardship) around sharing of Māori “cultural traditions and knowledge” (Macfarlane et al., 2014). The Samoan-authored book ‘*Whispers and Vanities*’ elegantly captures some of the history and Indigenous perspectives

²⁵ See Pacific Data Sovereignty Network (Moana Research, 2021).

behind this protective position (Suaalii Sauni et al., 2014). Tamasese (2002) shared this explanation from Samoan cultural knowledge experts during her focus groups around mental health:

Do you realise the significance of what you are asking us to speak about? To speak about what you call conceptions of mental health, involves exposing all that we believe about life and about persons, about selves, about spirit. This kind of knowledge, in our culture, is not public knowledge. It is not to be shared openly with young people (non-elders) like yourselves, because we do not know how you'll handle this type of knowledge. You are asking us to articulate ourselves in relation to our world of spirituality. In matters like this we take great care. There are only particular people who speak about these things and particular places and times when these sorts of conversations take place (p. 65).

While the Western perspective of knowledge-sharing is to improve understanding, Pacific-Indigenous knowledges are patient; safeguarded until the appropriate purpose, time, place, and receiver presents (Lefale, 2010).

Essentially, these words were both intended to acknowledge the weight of the wisdom that the facilitators were receiving, and to impart responsibility for its proper representation and care. Alefaio-Tugia (2015) concurred, stating that Pacific researchers “[carry] a greater ethical responsibility to ‘care’ for the knowledge” gained through research with Pacific peoples” (2015, p. 168). What overrode the elders’ instincts to protect and preserve their sacred and hard-acquired wisdom was a desire for the wisdom shared to help not only Samoan people, but other people as well (Tamasese, 2002). Similarly, Vaiotele explains that within Pacific research, “the effect of reciprocity is such that when people give *koloa* (in this case, time and knowledge) they will expect it to be respected and honoured, and to be used well” (2006, p. 26, italics in original). The elders’ crucial need to protect and preserve sacred, privileged knowledge underpins the desire in this research for wisdom shared during *talanoaga* (discussions) to be truly represented and passed on in ways that will keep it safe while ultimately helping others (Tamasese, 2002). Moreover, within interconnected Pacific communities, the consequences of a lack of cultural discernment within research relationships will impact the researcher and potentially their family long past the life of the study (Meo-Sewabu, 2014). Vaka (2014) agreed, warning that Pacific researchers risked all credibility within their communities if they did not report accurate and true reflections of participants’ experiences. Maintaining harmonious relationships within our communities is key to Pacific flourishing (Tualaulelei & McFall-McCaffery, 2019).

Further ways in which a higher ethical standard is met within this study include through following Pacific protocols. Pacific protocols of engagement facilitate the honouring of relationships, the acknowledgement of genealogy, and appropriate respect for the sacred (Cammock et al., 2021). Previously within research, attendance to these necessities were dismissed as mere customary tradition (Tualaulelei & McFall-McCaffery, 2019). Moreover, families participating within this study were viewed as self-determining yet socially connected agents (Matapo & McFall-McCaffery, 2022; Mila-Schaaf, 2013), and were valued appropriately for their time, generosity, and expertise. Families were viewed as knowledge holders and solution sources, with answers that could inform others (Alefaio-Tugia, 2015; Mila-Schaaf, 2013). This project honoured *tōfā saili* (the search for wisdom; Alefaio-Tugia, 2015; collaborative wisdom; Taleni et al., 2018) by privileging Indigenous knowledge and experiences, and the ultimate belief that solutions lie within the families engaged in this study. Overall, this project sought to engage, appropriately care for, and bring together wisdom from the participating families, to enable that collective wisdom to be shared for the benefit of others. In these ways and throughout the research design decision-making process, the author submits that this project adheres to the principles of Pacific ethical research.

Pacific Methodology: “A Triple-Braided Cord is not Easily Broken”²⁶

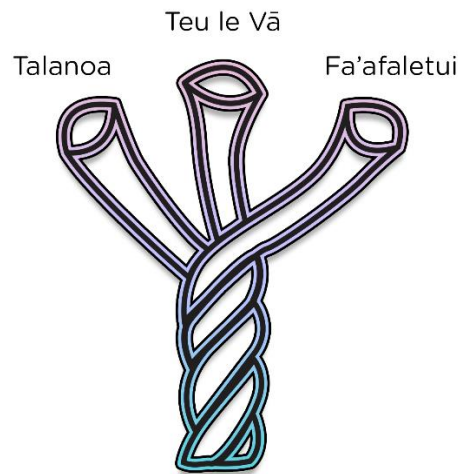
As alluded to earlier, no one paradigm or approach is sufficient to explain all phenomena and all knowledges have something to offer the research design process (Tualaulelei & McFall-McCaffery, 2019). Accordingly, this research project brings together complementary Pacific-Indigenous methodological frameworks; *Teu le vā* (Anae, 2016), *Talanoa* (Fa’avae et al., 2016; Vaioleti, 2006, 2013; Vaka, 2014), and *Fa’afaletui* (Alefaio-Tugia, 2015; Suaalii Sauni & Fulu-Aiolupotea, 2014). To the researcher’s knowledge, these three frameworks have not been combined before. However, due to the flexibility and clear synergies between them they are argued to dovetail neatly. Both *Talanoa* and *Fa’afaletui* have been combined with non-Indigenous approaches before, something Tuia and Cobb described as “an uncomfortable coupling” (2021, p. 275). By contrast, similarly to *He Awa Whiria*—a braided river approach—the researcher submits that when the three Pacific frameworks are bound together as if each was a strand within a triple-braided cord, each lends its best to the research design (Macfarlane & Macfarlane, 2014; Martel et al., 2022). Just as in a triple-braided cord such as in Figure 1, the strands are not off-set at different times and no one strand holds more prominence. Instead, the three strands of the methodological braid begin together and contribute equally to the overall research design in a coordinated and considered way, where ultimately the braid is worth more as a whole than as the sum of its parts (Macfarlane et al.,

²⁶ Ecclesiastes 4:12 (Holy Bible, NLT, 1996/2021).

2015). The combining of methodologies and philosophical standpoints in creative ways is also called the bricoleur approach (Nord, 2022).

Figure 1

The Three Pacific Research Frameworks forming a Triple-Braided Cord



Teu le Vā: Relationships as Central to the Research

This research takes a “radical” approach (Airini et al., 2010, p. 9) where relationships, both established and new, are centred as the foundation of the project methodology (Fa’avae et al., 2016). Relationships are also the recruitment strategy, the vehicle for data collection, and importantly, relationships formed or strengthened during this research will not end when the research thesis is finalised. For example, Anae opined, “the role of the Pacific researcher is to facilitate continued dialogue between research participants, colleagues in the research team, funders, policymakers, and communities to ensure debate and continued dialogue over time” (2016, p. 122). Further, Pacific researchers report the dynamic interaction within their research projects: “we respected these relational protocols throughout the data collection process up until the final stage of disseminating our findings back to [participants] face to face” (Suaalii Sauni & Fulu-Aiolupotea, 2014), and, “[research] developments will be followed with interest. Because of the relationship that has been developed, quality will be added to the research. The researcher will not want to let down participants with whom he or she has developed a relationship” (Vaiioleti, 2006, p. 26). Holmes also discusses how the psychological distance between researcher and participants minimises across research time spent together (2020). These extracts suggest a dyadic process that occurs throughout Pacific research, where communication continues in the form of participants following

updates to the projects, and participants receive findings through in-person dissemination events. The extracts also allude to relationships formed adding incremental research quality, and participants' expectations of the usefulness of the research for their communities.

In line with the Samoan concept of appropriately tending to and cherishing relationships discussed earlier, Anae's *Teu le vā* collective approach outlines how researchers can create 'ethical moments' within Pacific-Indigenous research (Airini et al., 2010; Anae, 2016). Matapo and McFall-McCaffery describe the approach, thus: "teu le vā positions Pasifika peoples as fully engaged, self-determining agentic partners within the research and policy process" (2022, p. 125). Anae contended that Pacific-Indigenous ethical research includes three key components: 1) "optimal relationships" to encourage a collaborative approach; 2) the co-construction of knowledge; and, 3) a research focus on producing optimal outcomes for Pacific peoples (p. 123). Anae's 'optimal relationships' refer to relationships which are reciprocal, which honour the genealogy of vā partners, which demonstrate respect, and which *teu le vā* or sensitively tend to the various vā relationships created within research (2016). Together with appropriate attention to relationships, an appreciation of the sacred and the search for wisdom further provide the parameters for ethical research within Indigenous contexts (Tamasese Taisi Efi, 2009). The key focus of the *teu le vā* research approach is to achieve optimal outcomes for all involved through the appropriate valuing of stakeholder relationships (Airini et al., 2010).

Hypotheses and surveys do not require a relationship between the researcher and the participant (Vaiotei, 2006). For the Pacific researcher, however, methods which allow space for the enactment of spiritual and cultural protocols encouraging warmth and edification, and which recognise the importance of relationships within research, are methods which *teu le vā* in appropriate ways, and which lead to valid research evidence (Anae, 2016; Vaiotei, 2013). Hopner and Liu argue that a continual dialogical relationship between relational ethics and epistemological considerations leads to a more comprehensive psychological science and philosophy of practice (2021). More importantly perhaps, such methods allow for the *fatu* or 'heart' to be present and valued within an otherwise controlled research environment (Fa'avae et al., 2016; Farrelly & Nabobo-Baba, 2012; Hopner & Liu, 2021; Vaiotei, 2006; Vaka, 2014). The attention to appropriate cultural protocols within research relationships is not just a feel-good concept, however, for only if and when participants feel that timing and context are appropriate will they share intimate disclosures with the researcher (Vaiotei, 2006). *Teu le vā* fits well with the *talanoa* framework, which is flexible enough to allow the informing of its execution by cultural protocols appropriate to the time and context of the research (Cammock et al., 2021).

Talanoa: the Data Gathering Framework

Talanoa (Vaiotei, 2006) was deemed appropriate as a methodological conceptual framework and method of data collection for use in this study. The *talanoa* framework in the research context was originally articulated by Tongan academic Dr Timote Vaiotei, although it has earlier roots in diplomatic conflict resolution and Vaiotei credits Professor Konai Helu Thaman with much of the knowledge development (Suaalii Sauni & Fulu-Aiolupotea, 2014). Several Pacific researchers have since adapted the *talanoa* framework into methods which suit their Pacific research ethics and purposes (e.g. Fa'avae et al., 2016; Fuluifaga, 2017; Halapua, 2008; Mila-Schaaf, 2010; Prescott, 2016; Vaka, 2014, 2016). Pacific researchers consider that the *talanoa* concept, while acknowledging local variation, is natural and basically “the same” across Pacific peoples (Vaiotei, 2006, p. 25; Vaka, 2014); some researchers refer to *talanoa* as a “Tongan and Samoan dialogic concept” (Matapo & McFall-McCaffery, 2022, p. 130). The word *talanoa* itself is found in many Pacific-Indigenous languages often pertaining to dialogue, discussion, or talk (Meo-Sewabu, 2014; Mo'a, 2014; Suaalii Sauni & Fulu-Aiolupotea, 2014; Vaka, 2014). The excitement of utilising Pacific research methods is not only that the families' subjective realities can be elicited and gathered through the medium of language via *talanoa*, but the resultant *talanoa* data can be analysed, interpreted through a cultural reading, and expressed as research evidence (Meo-Sewabu, 2014; Suaalii Sauni & Fulu-Aiolupotea, 2014; Vaiotei, 2013). A further advantage of the *talanoa* concept is that it is “premised on intergenerational ethical understanding”, as such, *talanoa* allow for appropriate Pacific protocols to be carried out within ethical Pacific research (Matapo & Enari, 2021, p. 79).

Talanoa as a framework provides the appropriate conditions to facilitate the sharing of Pacific people's stories and narratives as experienced by them—that is, their lived experiences—through trust, respect, and mutual relationship (Vaiotei, 2006). A *talanoa* is viewed as: “a personal encounter where people story their issues, their realities and aspirations” (Vaiotei, 2006, p. 21). Vaiotei explicated the concept of the *talanoa* method as follows:

Superficially, *Talanoa* can be referred to as a conversation, a talk, an exchange of ideas or thinking, whether formal or informal. It is almost always carried out face-to-face. *Tala* means to inform, tell, relate and command, as well as to ask or apply. *Noa* means of any kind, ordinary, nothing in particular, purely imaginary or void. Churchward (1959)...described *Talanoa* as to talk (in an informal way), to tell stories or relate experience (p. 447). *Tala* also means to command, tell, relate, inform and announce, and *noa* means common, old, of no value, without thought, without

exertion...Talanoa, then, literally means talking about nothing in particular, and interacting without a rigid framework” (2006, p. 23, emphasis in original).

In Fiji and Samoa, talanoa are held to gain consensus and are used for both serious and “free conversations”, involving layered social positions and purposes, and can involve commercial or diplomatic agenda (Vaiotei, 2013, p. 192; Matapo & Enari, 2021; Mo’a, 2015). Vaiotei explained how talanoa ‘work’:

In a good Talanoa encounter, noa creates the space and conditions. Tala holistically intermingles researchers' and participants' emotions, knowing and experiences. This synergy leads to an energising and uplifting of the spirits, and to a positive state of connectedness and enlightenment (Vaiotei, 2006, p. 24).

In the research context, two key concepts which the talanoa method are predicated upon include ‘mālie’ and ‘māfana’ (Fa’avae et al., 2016). Fa’avae and colleagues describe these concepts in relation to their Tongan meanings as “upliftedness” and “inwardly warm feelings” (p. 140-141). However, these concepts also reside in and have similarly recognisable outworking in other Pacific-Indigenous languages and cultures (Vaiotei, 2013). In addition, these concepts share elements with the psychological concept of rapport-building which has an emphatic empirical basis within clinical psychology (Sommers-Flanagan & Sommers-Flanagan, 2013). Of note is that these concepts have influenced relational interaction for millennia within Pacific-Indigenous societies (Vaiotei, 2013). The researcher considers mālie and māfana to be critical concepts in the forming and maintenance of relationships at all levels and important to the protocols and processes of *teu le vā* within this study. As an example, in contrast with research interviews, talanoa have no fixed end time (Cammock et al., 2021; Vaka, 2014). Instead, talanoa come to a natural end when mālie and māfana dissipate, the participants arrive at a state of harmony, and discussion of the agreed topics has concluded (Fa’avae et al., 2016; Meo-Sewabu, 2014; Vaka, 2014).

As a method, talanoa shares likeness with other phenomenological and narrative interview methodologies, however, is distinguished by the requirement of cultural connectedness between the researcher and participants, and the co-construction of knowledge that results in talanoa (Vaiotei, 2006, 2013). Vaiotei asserts that talanoa is collaborative, subjective, and resists outsider control of both data collection, and of the ensuing narrative (Vaiotei, 2006). Although talanoa has been described literally as talking about nothing in particular, the ultimate purpose of talanoa is to “produce

relevant knowledge and possibilities for addressing Pacific issues” (Vaiotei, 2006, p. 21). Vaiotei stated that the value of talanoa “is more than just potentiality” for new knowledge and helpful solutions, however, that these are the likely products of facilitating “the new knowing that has been missed by most traditional research approaches” (Vaiotei, 2006, p. 24). Fa’avae and colleagues concurred, stating that talanoa which did not lead to change or positive actions for Pacific peoples were pointless (2016).

In the pan-Pacific research context, talanoa should be explicated in terms of its applied meaning within the specific research context (Suaalii Sauni & Fulu-Aiolupotea, 2014). Within this project, the purpose of talanoa was to meet face-to-face, to relate with each other, to deepen existing or establish new relationships, to ‘talk story’, to share mostly ordinary experiences and co-create new knowledge, and to do all of this in a safe, autonomous environment founded on shared connections, warmth and uplifting, while potentially providing relief for the participants (Fa’avae, et al., 2016; Sanga & Reynolds, 2017; Vaiotei, 2006; Vaka, 2014). The researcher’s position as a Pacific person (sharing a Pacific cultural background) and as a parent of an autistic child within PASG where the parents were recruited from (shared experiences), provided the foundation for a talanoa relationship. This relational and cultural foundation was hypothesised to contribute significantly to the vā relationship with participants and enhance the likelihood that deep and “*mo’oni* (pure, real, authentic)” experiences were shared, further validating talanoa data (Vaiotei, 2006, p. 21, italics in original).

The key distinguishing feature of talanoa relative to other qualitative methods is the “cultural synthesis of the information, stories, emotions and theorising...[which] will produce relevant knowledge and possibilities for addressing Pacific issues” (Vaiotei, 2006, p. 21). The type of cultural synthesis Vaiotei refers to here alludes to the specialised lens that a Pacific researcher holds, and which necessarily influences their analysis of the data (Suaalii Sauni & Fulu-Aiolupotea, 2014). Only a Pacific researcher could recognise the nuanced intricacies of interactions with participants (including non-verbal cues; Vaka, 2014) and their critical implications, which are partially dependant on the language proficiency, approachability, personality, “age, gender, cultural rank or community standing of the researcher” (Aanae, 2016; Meo-Sewabu, 2014; Vaiotei, p. 22; Vaka, 2014). Non-Pacific researchers are “unlikely to have values and lived realities that allow understanding of issues pertaining to knowledge and ways of being” from the Pacific, therefore Pacific researchers are best-placed to interpret data derived from Pacific research methods including talanoa (Aanae, 2016; Meo-Sewabu, 2014; Vaiotei, p. 22).

Talanoa, being held in-person, acknowledging of participants in their context, allowing for spiritual acknowledgement and cultural protocols, and involving the lifting of the spirits and edifying of the participants (Fa'avae et al., 2016; Vaioleti, 2006), could be said to be engaging of the whole person. Indeed, Farrelly and Nabobo-Baba explain talanoa discussions as an “embodied expression” (2012, p. 1) and Halapua (2002, p.1) stated that talanoa “embodies our understanding...as members of a shared community” (as cited in Vaka, 2014). Matapo and Enari (2021) allude to talanoa as an act of decolonisation because traditionally Pacific knowledge and stories have always been passed down through cultural and ceremonial embodied performative acts. This embodied sharing of knowledge is in stark contrast to the objective research interview or survey, which is often devoid of spirit, lacking in relationship, and lacking validation of the participants and their contextual factors. As embodied Pacific researchers, enacting data collection sessions as talanoa facilitates keeping “on top of our minds the Pacific values...central to [talanoa]; we [think] of our Polynesian/Samoan codes of respect, the need for turn sharing when speaking, the need for symbolic gestures of reciprocity and gratitude, and so on” (Suaalii Sauni & Fulu-Aiolupotea, 2014, p. 337). By interacting with Pacific participants in-person and through using appropriate Pacific research methods, relational and respect protocols are given space to be enacted appropriately and participants are fully engaged with and also benefit from the research process and its resultant solutions (Meo-Sewabu, 2014; Vaka, 2014).

Fa'afaletui: the Data Weaving and Analysis Framework

This research sought to go one step further than just cataloguing the Pacific autism parent experience, although this holds inherent value. Indigenous researchers discuss the importance of research that captures and interrogates “new ways of knowing” (Vaioleti, 2006, p. 24). The Samoan *Fa'afaletui* approach (Alefaio-Tugia, 2015; Suaalii Sauni & Fulu-Aiolupotea, 2014; Tamasese et al., 1997, 2002, 2005) adds further richness and validity to the research design due to the synergy of the methodological approaches, despite their differing origins. *Fa'afaletui* describes a process of gathering collective wisdom from various *fale* (houses) and weaving these together to achieve consensus (Goodyear-Smith & 'Ofanoa, 2022), and can also refer to “the houses of collected wisdom” (Alefaio-Tugia, 2015, p. 159). *Fa'afaletui* is a Samoan relational and dialogic framework which values Pacific-Indigenous epistemology by engaging cultural knowledge-holders and leaders in discussion for the purpose of gathering their expertise and experience and esteems that knowledge and expertise as the highest authority in Pacific-Indigenous research data (Alefaio-Tugia, 2015; Suaalii Sauni & Fulu-Aiolupotea, 2014). In the fa'aSamoa, issues of importance are always discussed collectively (Mo'a, 2014). *Fa'afaletui* is

often used with more formal groups, and/or for a deeper level of cultural or ideological inquiry (Alefaio-Tugia, 2015; Tamasese et al., 1997; Tamasese, 2002, 2005). Some reserve it for more “serious” matters (Suaalii Sauni & Fulu-Aiolupotea, 2014, p. 334). The esteemed knowledge-holders in this study are the Pacific parents of autistic children and the resultant gathered cultural and experiential knowledge is new knowledge to the greater field of autism literature.

Advantages of both talanoa and fa’afaletui methodologies are their ability to provide participants with an autonomous and mutually beneficial experience, to create and/or strengthen relationships, to uphold Pacific-Indigenous knowledge, to allow space for Pacific-Indigenous protocols, to provide a vehicle for new knowledge to be co-constructed, and to allow for culture and context to be valid threads within the data analysis (Vaiotei, 2006; Suaalii Sauni & Fulu-Aiolupotea, 2014). Generally in a fa’afaletui discussion, participants share their experiences and narratives on agreed topics with the facilitator and together they co-construct their story, reach a decision, and/or generate consensus together (Suaalii Sauni & Fulu-Aiolupotea, 2014). These processes within fa’afaletui are clearly dependent on the researcher’s capacity to *teu le vā* including the embodiment of love, respect, and humility (Goodyear-Smith & ‘Ofanoa, 2022). Within the fa’afaletui paradigm in this study, talanoa, rather than fa’afaletui sessions were first held with participants. This was because talanoa provided the open-ended and circular structure required to enact such cultural and spiritual protocols as fit the individual talanoa and reduced the pressure dynamics of status—as researcher and participants were all on the same level (Vaka, 2014). Each talanoa with Pacific parents symbolised a *fale* or ‘house’ representing one Pacific family. Fa’afaletui methodology is fit-for-purpose in this research, and subsumes a Pacific-Indigenous method producing new knowledge that is true to Pacific-Indigenous ways of thinking, being, and doing without the amendment or erasure of a Western lens (Alefaio-Tugia, 2015). Fa’afaletui as a method is descriptive of a process that facilitates the collation and examination of knowledge and/or experiences of the participant group ultimately in search of *tōfā saili* (the search for wisdom; Alefaio-Tugia, 2015). Fa’afaletui also describes the process of *tui* (weaving) together the various understandings and pearls of wisdom from across participant groups (Goodyear-Smith & ‘Ofanoa, 2022; Tamasese et al., 2014).

Fa’afaletui was implemented as a guiding framework in illuminating the knowledge and experiences collated from the talanoa transcripts while respecting the transcripts’ many layers and facets (Alefaio-Tugia, 2015). This process involved a:

‘Cultural synthesising’, which describes “the bringing together, as in the act of weaving together...the various strands of ‘talk’ that emerge from the talanoa session[s], and making sense

of these through a cultural reading. The emphasis on ethno-cultural referencing as a key reference point for making sense of the information gathered and of the emotions and behaviours associated with collecting and reporting that information is what is suggested to be unique to the methodological design of both the talanoa and the fa'afaletui (Suaalii Sauni & Fulu-Aiolupotea, 2014, p. 334).

During data analysis, the knowledge and experiences from each of the 'houses' were reviewed separately and then systematically and rigorously woven together and critically validated as to where consensus was reached and where variation occurred (Braun & Clarke, 2022; Goodyear-Smith & 'Ofanoa, 2022). Where the experiences were representative of the larger group, these were later drawn together and labelled as recurrent themes of the data. This process culminated in a collective representation of Pacific parents' experiences of raising an autistic child (Tamasese, 2002; Tamasese et al., 2005). The methods followed during data collection and data analysis are explained further in the subsections that follow.

Procedure

Participants

Eight Pacific families of autistic children were recruited for talanoa. A wide definition of 'parents' was taken in this study as Pacific families tend towards a higher proportion of multi-generational and extended family groupings under one household (Suaalii Sauni et al., 2009), and because in Pacific cultures important matters and those requiring solutions are generally discussed collectively (Meo-Sewabu, 2014; Tamasese et al., 1997). For example, parents within a Pacific community setting would typically comprise a heterosexual couple, either de facto or married, but may also include sole parents, grandparents raising the child, parents and grandparent/s together raising the child, or older sibling/s of the child or aunts and uncles with significant caregiving responsibilities where parents are absent (such as child migration for educational purposes, or the work schedules of parents). Across the parent sets, attempts were made to gain as much representation across Pacific ethnicities as possible. Due to the effects of COVID-19 alert level restrictions in Aotearoa around the time of data collection, the final participant group was less diverse than that originally recruited. Demographic information for the final participant group is displayed in Table 1. This project was evaluated by peer review and judged to be low risk (Notification number: 4000020645). Consequently, it was not reviewed by one of Te Kūhanga ki Pūrehuroa Massey University's Human Ethics Committees. The researcher and supervisors named in this document were and are responsible for the ethical conduct of this research.

Table 1*Talanoa 'Āiga/Family Demographic Information*

Talanoa 'Āiga	Parent Participant	Gender Identity	Age	Country of Origin	Ethnic Identity	Autistic Children	Total Children
1	1	F	47	Aotearoa	Māori	2	4
	2	M	49	Aotearoa	Samoan		
2	3	F	43	Aotearoa	Niuean/Samoan	1	3
	4	F	69	Niue	Niuean		
	5	F	67	Niue	Niuean		
	6	F	46	Aotearoa	Niuean		
3	7	F	39	Tonga	Tongan	2	3
	8	M	41	Aotearoa	Tagata Niue/New Zealand		
4	9	F	40	Aotearoa	Samoan	1	3
	10	M	40	Aotearoa	Samoan		
5	11	F	42	Samoa	Samoan	2	2
	12*	M	47	Aotearoa	Samoan		
6	13	F	34	Aotearoa	Samoan	2	3
	14*	M	32	Aotearoa	Samoan		
7	15	F	39	Aotearoa	Māori/Samoan	1	3
	16	M	44	Aotearoa	Samoan		
8	17	F	35	Kiribati	i-Kiribati	1	4
Total						12	25

Note. *Did not attend talanoa on the day.

Recruitment

All participants, except one, were group members of the Pasifika Autism Support Group (PASG; a parent-led support group for Pacific parents raising autistic children) in Auckland. Permission was granted by the PASG Founders to

launch the study at the Term 4, 2019 PASG network meeting through a short presentation. The study was described during the formal part of the meeting with an invitation for interested families to talk further with the researcher and/or complete the sign-up sheet during the informal part of the meeting, or make contact following the meeting directly with the researcher or through the PASG Leaders. Parents were also approached directly by the researcher where there were existing relationships. Where relationships were not yet established, the Pacific process of *sāvali* was enacted, where a cultural and/or status-level conduit (in this case, a local community worker) facilitated the beginning of a relationship between the researcher and one parent participant who did not belong to PASG (Alefaio-Tugia, 2015). The researcher then contacted those families who indicated that they were interested by email in March 2020 to offer a participant information sheet and further logistic information. Once their interest in participating was re-confirmed, the researcher arranged a suitable time and place where the parents were most comfortable to meet and *talanoa*.

One *talanoa* was held at a local community venue, but in most cases, the researcher travelled to the families' homes to engage in *talanoa*. After greetings and small talk, parent participants were each given a copy of the participant information sheet and research consent form in English, and given appropriate time to read through these and ask any questions. The parents' informed consent was recorded once the study parameters and protocols were clearly stated, and the participants had read through the information to their satisfaction. Copies of the consent form were offered to the participants, and the original copy of the consent forms were kept with the researcher and stored securely. Participants were not aware that there was a *mea'alofa/koha* for them as part of the project. Following the approval of the transcripts by participants, families were gifted \$500 as a token in recognition of their generosity, expertise, and willingness to be part of the study to help others. This was intended to assist the families with something that would benefit their autistic child, for example, purchasing assistive technology, equipment, or media, supporting attendance at an autism-related conference or workshop, or to assist with household expenses throughout the COVID-19 period. One family chose to donate their *mea'alofa* to PASG, and one family did not respond to accept the *mea'alofa*.

Data Collection

Talanoa guiding questions were developed which were focused to bring out information on the desired topics (the families' lived experiences), while allowing participants to remain in control of the conversation and what was shared; in effect, enabling co-construction of the data (Vaiolleti, 2006). For example, an open, guiding question might be: "Would you share a little bit about your journey to diagnosis for your child?" This question encouraged both answers that describe the

holistic lived experiences of parents, as well as their level of engagement with available supports, without leading the participants towards particular perspectives, or being able to be answered with a 'yes' or a 'no' answer. The final guiding questions used in the study are reproduced in Appendix A. Talanoa sessions were voice-recorded with the prior permission of all participants to allow the researcher to participate fully in the talanoa while remaining unhindered by the intrusion and perception of explicit notetaking (Fa'avae et al., 2016). Recordings were recorded using the recording function on the researcher's secure personal mobile device, then transferred (and deleted from the mobile device) to the researcher's secure laptop for transcription and backed up using Google Drive cloud service.

Pacific processes of engagement and relational connection underpinning the *teu le vā* concept and approach were adhered to throughout the research project including before, during, and following talanoa, through practising *fesuiaga* (reciprocity), *alofa* (love), *fa'aaloalo* (respect), *tautua* (service), and *feagaiga* (relational covenant between people; Fuluifaga, 2017). The *vā fealoa'i* or respect for relationships "extends beyond consent forms" and data collection (Fuluifaga, 2017, p. 66). These protocols included the researcher using greetings and other phrases in the family's Pacific language from the point of the introductory and participant information emails, continuing throughout contact with the family. During talanoa, as is Pacific custom, the researcher offered for the parent participants, or the most senior family member present, to begin and end talanoa sessions with a *lotu* (prayer) in the family's preferred language. Where preferred by the family, the researcher offered a *lotu* in English. Usually before the *lotu*, the researcher facilitated the sharing of humour and small talk, and the drawing of genealogical and geographical connections between those in the room, as well as reiterating the connections with PASG and any shared memories. The reciprocal act of a food offering was engaged in at each talanoa with the presentation of quality Pacific baking²⁷ to the family at the start of the talanoa. There are many aspects to this tradition in the Pacific way, including: reciprocal honouring of the hosts for opening their space, to facilitate relationship-building over the informal sharing of food, relieving of tapu and status barriers between researcher and family, and physical sustenance. Food was later shared at a natural point in the talanoa at the family's direction, or left with the family to share.

According to talanoa protocol, once it was clear that feelings of *māfana* (warmth) and *mālie* (upliftedness) were established or sustained, the talanoa session was commenced. A decorated Samoan *tānoa fai'ava* (commonly used ceremonially for kava mixing, also a symbol for an important discussion) was placed on the floor in the space between

²⁷ iTaukei Fijian-owned 'Sweet and Me' provided the baking for talanoa due to the existing *vā* with the researcher.

researcher and participants to signify the shifting of the discussion into the beginning of the talanoa. Similarly to Vaka (2014), it was important to situate the researcher with the families as a talanoa conversation partner, rather than person of expert knowledge and to explain the talanoa as an informal conversation. This was to ameliorate any presupposed status dynamics and to facilitate sharing as equals. It was also stated that the researcher may share personal experiences, but that the talanoa was focused on the family's story and what they wanted to share. The researcher would start by recounting their brief 'migration to diagnosis story' which is the story of how one's Pacific relatives came to Aotearoa and brief life story to the current time, thus relaying and situating the researcher in relation to their and their children's cultural identities and journey to autism diagnosis. This set the model for participants to share their 'migration to diagnosis' stories.

Discussions then naturally progressed into deeper levels of talanoa loosely following the topics of the guiding questions, where sharing, with personal narrative elaboration and co-creation of shared stories and experiences, occurred. In talanoa, topics are covered in a circular rather than linear fashion (Cammock et al., 2021), where topics can be revisited for depth or clarification, metaphor or personal experience can be added to elicit participant sharing, and once sufficient detail is gathered conversation is moved on (or abandoned if the researcher sensed discomfort). The talanoa word sheets, reproduced in Appendix B, generally reminded participants of experiences and stories relevant to talanoa topics. Spaces on the sheets were available for participants to record terms not already captured, for example, during the pilot talanoa a participant wrote down 'passion'. It was not uncommon for talanoa sessions to extend past the typical 1-hour interview session timeframe to allow sufficient time for the covering of Pacific cultural protocols, the surveying of key topic areas, and to allow all participants to contribute as they felt comfortable. In this study, talanoa continued until the sessions came to a natural place of rest (Fa'avae et al., 2016). Typically, this was found to be between 1-3 hours: closer to the one-hour mark for one parent participant, and around the three-hour mark for larger family groups. Level of relationship was also found to affect the talanoa duration, where deeper relationship lengthened talanoa and new relationships shortened the duration.

A Note on Information Power

It is generally accepted within the qualitative research field that 'saturation' as a target for sample size in non-Grounded Theory projects is unwieldy and unhelpful (Braun & Clarke, 2022; Malterud et al., 2016). Instead, researchers proffer information power as a concept with which qualitative researchers can engage to consider the reliability and validity of their research data (Braun & Clarke, 2022; Malterud et al., 2016; Patton, 2015). Malterud and colleagues set out five

dimensions on which to judge the information power needed for a study, including: study aim, sample specificity, level of applied theory, dialogue quality, and cross-case or in-depth analysis (2016). The authors explained the five aspects as dimensions rather than continuums, as positioning on a given dimension is dynamic and should be re-assessed across the study. Malterud and colleagues opined, “research with social constructivist roots, where knowledge is considered partial, intermediate, and dependent of the situated view of the researcher, does not support an idea that qualitative studies ideally should comprise a “total” amount of facts” (2016, p. 1759). Saturation, therefore, is not a well-aligned strategy with a qualitative relativist, constructionist approach. The present study is concerned with the representation and privileging of Pacific parents’ voices as the experts within the specific context of raising autistic children in Aotearoa. This study is therefore exploratory, with dense specificity, having high quality data, and prioritising depth over breadth (Malterud et al., 2016; Patton, 2015). In addition, the research goals are not comparison nor generalisation (Braun & Clarke, 2022; Patton, 2015), but rather the description of variation within categories (Malterud et al., 2016) within and across the historically- and culturally-situated cases of the parents within the study (Bazeley, 2021).

Data Analysis

The analysis of talanoa data in this study was carried out with reference to the Fa’afaletui framework while utilising a systematic, staged approach and tool for data analysis as outlined in Braun and Clarke (2022)’s reflexive thematic analysis. Initially, talanoa audio recordings were manually transcribed by the researcher using the ExpressScribe v 8.26 software package. The transcriptions were transcribed using participants’ initials only. Transcripts were proof-read and checked against audio recordings for accuracy. In line with processes of *teu le vā*, transcripts were returned to the participants to check, add to, or otherwise amend to ensure their intent was fully captured and any Pacific language terms were accurate before entering into further data analysis. Then, transcribed talanoa were stored and analysed following the phases of reflexive thematic analysis within NVivo12 software. These phases comprised: 1) Familiarising yourself with the dataset; 2) Coding; 3) Generating initial themes; 4) Developing and reviewing themes; 5) Refining, defining and naming themes; and 6) Writing up (Braun & Clarke, 2022). In line with Pacific research methods and Fa’afaletui methodology the current analysis was aligned with inductive and experiential treatment of the data. While interesting process and analytic features of the data were illuminated through the process of data-weaving—for example, the use of Pacific humour to discuss topics of a sensitive nature—these will not be focused on within this thesis in lieu of a more situated, interpretive, and cultural reading of the data.

A key focus of Fa'afaletui analysis was on the emergence of cultural nuance and explanation, the meanings of participants' experiences, and knowledge creation where concepts were envisioned and verbalised or alluded to (Tamasese et al., 2014). As a result, the iterative, yet rigorous and systematic process of reflexive thematic analysis was deemed appropriate as a tool of analysis to sit within the Fa'afaletui framework and metaphorically be the 'hands and feet' of Fa'afaletui in facilitating the data weaving (Braun & Clarke, 2022). Indeed, the authors state that reflexive thematic analysis is not a singular method, but a framework to guide decision-making and a broad phasic process of analysis to consider within a researcher's specific theoretical and methodological approach. Accordingly, the six phases of the Braun and Clarke process were used as a guide while considering the applicability of these concepts to data collected within a Pacific context. For example, within reflexive thematic analysis coding generally parses out distinct experiences so that positive and negative experiences of education would be coded separately (Braun & Clarke, 2022). However, within a Pacific-Indigenous context where health is holistic and there are already many automatic coding topics, separating out positive or negative experiences under each of these would become unwieldy. It was decided that the careful interpreting and reporting of the themes and outliers could make sense of these disparate experiences if they were indeed salient or representative enough to be present at further stages of analysis (Braun & Clarke, 2022). Further, the sixth phase of writing up and data weaving was enacted with specific reference to Pacific methodology and Fa'afaletui which may have in parts represented a departure from the outlined reflexive thematic analysis process.

In addition to these adaptations of the coding and analysis process, themes were considered in relation to the data and in reference to Pacific concepts and motifs that might help to explain the themes from a Pacific perspective without forcing the data into structures which did not fit. This cyclical, iterative process formed part of the data weaving and interpretation processes for the researcher, as resulting analysis means nothing if it does not return to inform the communities it has come from (Fa'avae et al., 2016). Resulting themes should have the capacity to stand alone as well as form a coherent picture together with other themes (Braun & Clarke, 2022). The primary supervisor further reviewed the codebook and themes before finalisation, with no amendments. Finally, resultant themes were interpreted according to a snapshot in time and are influenced by the socio-environmental context of the research and the situated researcher (Patton, 2015). Accordingly, there will exist various ways in which to interpret the same data when viewed with differing lenses and over time (Braun & Clarke, 2022).

Limitations

The findings and implications of this study must be understood within a context which includes the following limitations. The term 'parents' took a wide meaning within this study to accommodate for common Pacific intergenerational and diasporic family configurations. Participants included sole parents, parents together with grandparents and aunts and cousins, spousal couples, and mothers on behalf of spousal couples. Further, despite the convenience sample drawing participants almost exclusively from PASG, some consideration was given to Pacific ethnic diversity within the sample. Regrettably, Covid-19 restrictions meant that the final participating group was less diverse than intended (only including four Pacific groups in Aotearoa). It would be beneficial to canvas the experiences of Rarotongan, Fijian, Tokelauan, and Tuvaluan parents, as well as members from the smaller island groups within Aotearoa due to the inherent diversity within and across Pacific peoples. While this is acknowledged as a limitation, descriptive studies do not intend to be generalisable, and as an exploratory study the importance lies in including Pacific experiences within the wider autism literature. Future research should look to undertake larger studies that are representative of the Pacific population in Aotearoa.

Further, while every effort was made to include fathers in talanoa, at times fathers did not attend talanoa on the day. When fathers are not recruited into studies about autism, mothers' experiences are often generalised as the parental experience, giving an incomplete picture (Downes et al., 2021). There is reason to suspect that fathers experience raising autistic children differently to mothers. For example, fathers experience more denial of their child's autism diagnosis and less coping and social support than mothers (Grebe et al., 2022). While this study did manage to include four fathers within the eight talanoa, it would have been beneficial to hear from all present fathers.

Additionally, there was no coverage of LGBTQIA+/MVPFAFF+ perspectives within this study. This resulted from the convenience sample and the lack of diverse parents within the current PASG membership. This is a limitation due to the multiplicative effects of intersectionality arising from sex, gender, and sexuality-diversity, neurodiversity, and ethnic minority on raising an autistic child (Simpson, 2021). While many Pacific cultures have terms which describe sex, gender, and sexuality-diversity (Fraser, 2019), for example, fa'afafine/fa'afatama (Samoa), fakaleiti (Tonga), and vakasalewalewa (Fiji) hinting to Pacific cultures' acceptance of this diversity, discrimination and conditional acceptance within these communities is still rampant (Le Va, 2020b) and may account for the limited membership of diverse parents within PASG.

Taken together, further exploration of the experiences of both Pacific fathers, and more diverse Pacific parents, as well as remote and rurally based parents, would be beneficial in future research.

This study covered a wide range of Pacific parents' experiences and included valuable information in good detail. While it was important and culturally appropriate to survey the holistic experiences of Pacific parents, this led to limited feasible depth on each topic discussed. At times there were follow-up questions which could have been asked to further elucidate parents' experiences which were not asked due to perceived time restraints and the range of topics to survey, for example, more information on the 'how' of language and culture maintenance within these families. Further, attunement tempered the in-depth exploration of some issues when the researcher felt it was important to prioritise the relationship with the participants and their comfort within the talanoa over data collection.

The effects of Covid-19 restrictions in Aotearoa caused some attrition and lengthy delays in meeting with Pacific parents due to community anxiety regarding the pandemic. Planned focus groups were abandoned due to sequential lockdowns. Virtual talanoa were offered to families but most declined, consistent with a Pacific preference for in-person talanoa (Vaiote, 2013). Attrition was reflective of the increased stress that families were under (Jang et al., 2022), particularly Pacific families, many of whom were essential workers. However, due to high interest, intended family numbers were achieved and data collection was completed within nine months of the original timeline. The results are presented in the following section according to the high-level themes that were woven together across all talanoa. Direct quotations from parent participants demonstrate the nuanced themes and their meanings for clinicians and for the Pacific autism community in Aotearoa.

Chapter 6: Results and Discussion

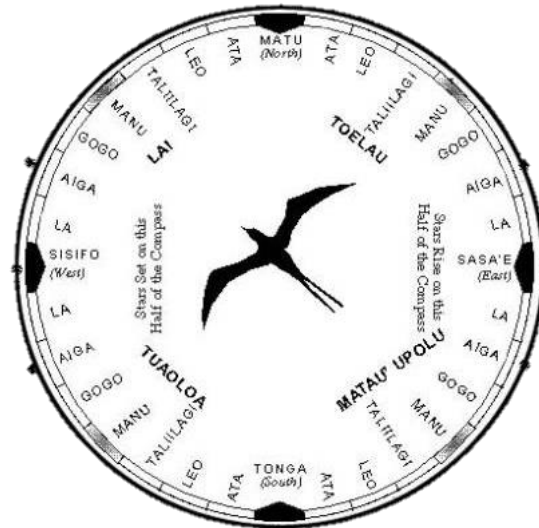
Introduction

Fifteen parent participants representing 17 adults and 25 children from eight Pacific families recruited from the Pasifika Autism Support Group (PASG) and Auckland Pacific community, discussed their experiences of raising autistic children with the researcher during eight talanoa. Discussions included the holistic lived experiences of these parents, their current use of supports and what is missing, and how heritage language and culture are maintained within these families. The Samoan star compass in Figure 2 is used as a metaphor for understanding the resulting themes. The Samoan star compass being a traditional Pacific instrument of navigation²⁸ is broadly relevant to the journey of raising autistic children according to the shared views of Pacific parents. The journey metaphor was reflected in participants' use of traditional and seafaring themes, including navigation, ancestors, journey, future, horizon, connection, and is mentioned in prior autism research (Lutz et al., 2012). Additionally, within the star compass, stars are said to rise and fall within one of the same seven 'houses' on opposing sides of the compass over a 24-hour period (Evans, 2021; Taonui, 2005). These celestial houses are reminiscent of the houses of fa'afaletui, wherein each 'āiga (family) represents an individual fale or 'house' within an overall collective from which knowledge and expertise are weaved together across the houses (Alefaio-Tugia, 2015). The knowledge represented by the various houses of the fa'afaletui (the 'āiga represented in this study) has thus been transformed and represented as knowledge across the houses of the Samoan star compass, which can then be used for navigating the experiences of Pacific parents of autistic children within Aotearoa.

²⁸ The star compass has been adapted for many Oceanic environments, including Aotearoa with Te Kāpehu Whetū, the Māori star compass (Evans, 2021; Taonui, 2005).

Figure 2

Samoa Star Compass



Note: A simplified reproduction of the Samoan star compass from the Samoa Voyaging Society (SVS; 2012). This image was adapted by SVS with Samoan translations from Charles Nainoa Thompson's original Hawaiian Star Compass <https://www.hokulea.com/education-at-sea/polynesian-navigation/the-star-compass/> (permission requested).

Further relevance of the star compass for elucidating the experience of Pacific families of autistic children is the link to ancestors who reside in the realm of lagi (the heavens) and are said to form constellations which guide the contemporary living (Mo'a, 2014). Here we see the ancestors illuminating a path of light which health professionals could follow when working with Pacific families. Furthermore, when considering how the experiences of Pacific families might be different to those of non-Pacific families raising autistic children, the star compass may again reveal insight. In the celestial example, the viewer's orientation to the celestial poles, whether they are situated in the northern or southern hemisphere, which time period (decade, millennium) they are in, the time of day, and the climatic environment they are situated in (contextual factors), all influence which constellations are available for stargazing or navigation. Similarly, lived experience of raising an autistic child depends on which knowledge traditions have influenced one's experience, what socio-historic-politico-economic-cultural-spiritual backgrounds have been the lived reality, experiences within health systems to date, the daily practical realities of raising an autistic child, and the parents' responses to these (contextual factors). So while a Pacific family living in Auckland, Aotearoa may experience many of the same experiences as similarly matched non-Pacific

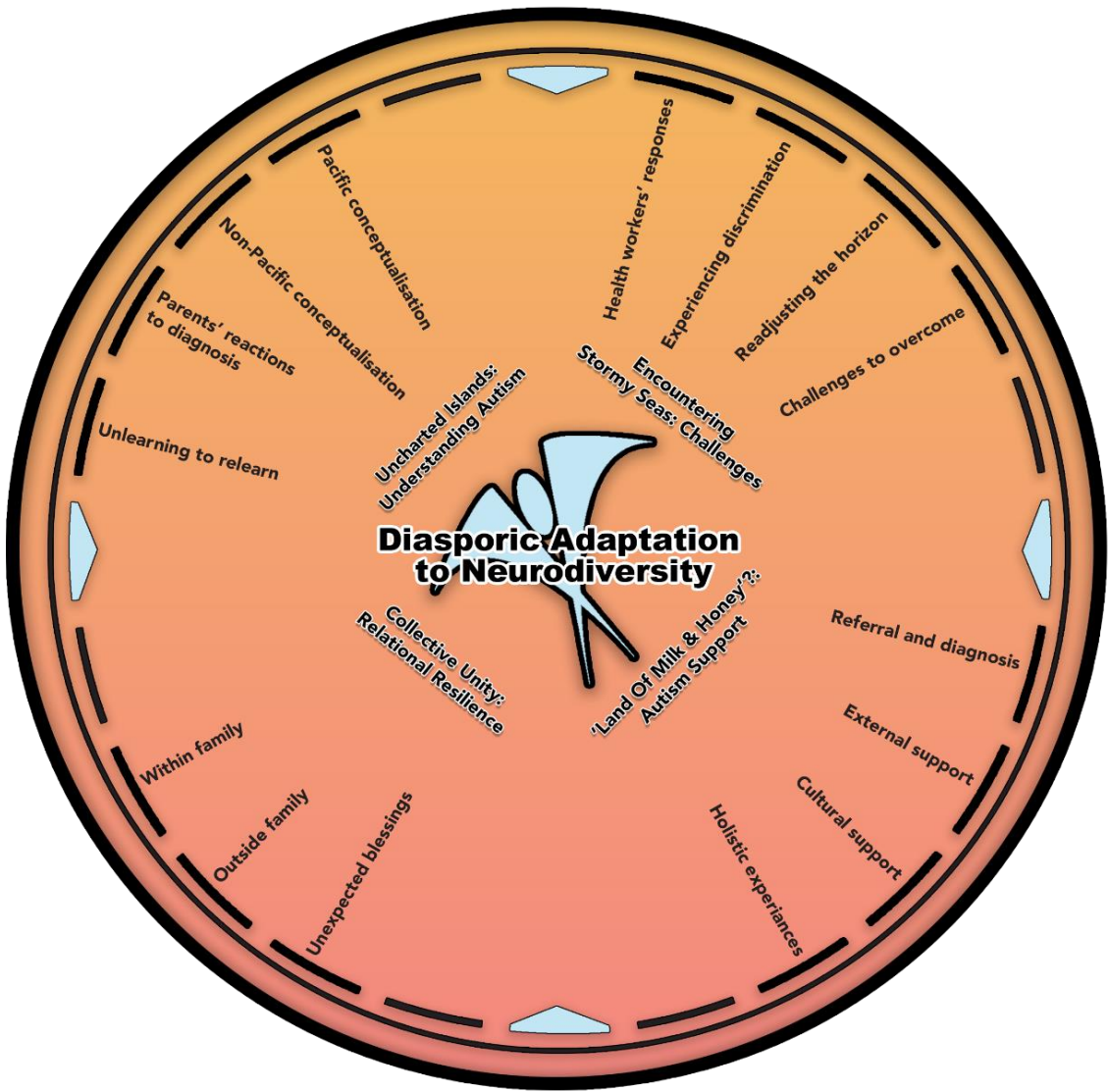
parents of autistic children in other Western countries, they may also experience added challenges and benefits which are important for health professionals to understand.

Finally, a star compass is adapted for the specific environment it exists within (Evans, 2021). A Satawalese star compass from the Caroline Islands in the northern hemisphere will be of little use to a navigator departing from the Chatham Islands in the southern hemisphere, as star alignment differs according to latitudinal and longitudinal position on the earth (Te Tai Tokerau Tarai Waka Inc., n.d.). Similarly, a clinician attempting to journey alongside a Pacific family seeking or having just received an autism diagnosis will have little understanding or direction in how to advise the family without some prior knowledge of lived experiences relating to Pacific families. It is important to note that not every Pacific family have the same experiences or the same worldview, and experiences or beliefs can be diverse, even contradictory, within Pacific cultures (Pulotu-Endemann & Faleafa, 2017). Notwithstanding, the Samoan star compass can be adapted to provide a navigational tool that would present lived experience and knowledge for use as a guide to be mindful of the potential for similar experiences across Pacific families raising autistic children.

To this end, the *Tapasā a Tagata Sa'ilimalo* presented in Figure 3 comprises four nautical quadrants plus a centre point on which the themes of this study's data can be mapped. On the star compass, a star cannot rise and set without encountering the centre point, represented here with a tuli bird. In the findings of this study, the centre point of the *Tapasā a Tagata Sa'ilimalo* is hypothesised to be a super-ordinate category called *Diasporic Adaptation to Neurodiversity*. The resulting knowledge gained is that parents cannot adjust to raising neurodiverse children without adaptation. Beneath *Diasporic Adaptation* were interpreted to be four important themes: (1) Uncharted Islands: Understanding Autism, (2) Encountering Stormy Seas: Challenges (3) Collective Unity: Relational resilience, and (4) 'Land of Milk and Honey'? Autism Support. These five total themes and their associated sub-themes will be elucidated with reference to the original research questions throughout this chapter. Importantly, many parental experiences reported in the general autism literature were reflected throughout talanoa with Pacific parents in this study. The reporting of the following results will therefore concentrate on highlighting the new knowledge and differences or salient experiences gathered from the parents within this study, particularly where there was majority consensus. Where possible and relevant, solutions to issues raised will be suggested.

Figure 3

Tapasā a Tagata Sa'ilimalo



Research Question 1: What are the Holistic Lived Experiences of Pacific Parents of Autistic Children in Aotearoa?

An overwhelming thread that came through talanoa held with parents in this study was that of adaptation. All parent participants had adapted and were in the process of adapting to the journey of raising autistic children in Aotearoa. Adaptations vary widely and are highly specific to the child but could be described as changes, support, and/or accommodations that are different than that required by, or of an increased intensity and provided for longer, compared with same-aged neurotypical peers. A common and smaller example might include practical adaptations at bath time to accommodate the sensory and learning needs for the autistic child, such as fragrance-free products, bath aids to avoid water on the face, and singing to embed the washing process. Others may require significant home support for washing due to sensory aversions and/or external support such as washing hair at a salon. Additionally, all parents in the study were either migrants themselves or first or second-generation children of migrants to Aotearoa; that is, study participants are the Aotearoa Pacific diaspora. Whether discussion centred around referral, diagnosis, support seeking, education, faith, work, or parenting, adaptations were made in these areas and many more to recognise and appropriately accommodate the autistic child/ren's needs and preferences. To these diasporic study participants, neurodiversity was largely unknown before having their children and so the plethora of small adaptations made along the journey could be perceived as adapting to parenting a neurodiverse child, or adapting to neurodiversity itself. The culmination of these experiences together led to the super-ordinate theme of Diasporic Adaptation to Neurodiversity.

Diasporic Adaptation to Neurodiversity



Parents discussed adapting to changes across their family and personal lives following becoming aware that their child was neurodiverse. Adaptation has also been described as a coping mechanism of both mothers and parents of

autistic children which includes accommodations, alterations, and adjustments made to meet the autistic child's needs (Higgins et al., 2022; Lutz et al., 2012). When presented with a range of life domains including work, financial, physical health, mental health, family relationships, faith, leisure, spousal relationship (full list in Appendix B), Vasa responded: "I'm saying yes to all of it, it's affected everything. Everything, every single thing". Lanuola further described that the parenting goals and focus changed once their two children were diagnosed autistic with the implication that they would require support longer than that of other children:

Researcher: What do you think has changed for you guys?

Lanuola: I guess our direction...now we are gonna have to support and guide for a long time, and so just that direction for us.

Katalina explained a time where she found change uncomfortable:

Katalina: I definitely felt like I could [inspire others] in the beginning... [Couples] came to us when they were first diagnosed... but I definitely don't feel like that person now... in fact it's me searching for someone for me, for help, for answers, for guidance.

Mikaele realised that it was up to him and Salote to accommodate their son's learning and communication needs while allowing him to grow. This led to adapted parenting practices and raised expectations:

For me, I started adopting that and adapting, and I was thinking you know what? Just because my son has this condition he's not gonna settle for less, we're not gonna accept that he's gonna be here [gesturing low]. We're going to push, push, push and like, I started changing my attitude and started actually going yep, we're going to push him just a little bit at a time and, you know, no excuses. So if he plays up like every other kid, treat him like every other, [kid] ...it's just how we communicate to him... was the only difference. But everything was just chip, chip, chip and then I noticed in doing that, we no longer feel sorry for him, it's like nah, this is, you know, this is about our boy pushing to be the best that he can be at his pace, at his level.

Change and adaptation was considered critical to families following diagnosis. Pania described with a sense of urgency: "You have to carry on! Like you have to, like, do the best for your family which, which is what every parent wants to do, and you just have to find a way to do it". Ofania agreed: "it's always adjusting to what he wants or, you know, not

even that—cos you know he doesn't get what he wants all the time cos it's just impossible". Problems could arise, however, when parents resisted change, tried to maintain their previous lifestyle, or went too far in changing, as Mareko explained:

You have to, like, give yourself 100% to the kid so that the kid is safe, but then the problem is the parents become part of the kid and not themselves. And so another problem is the parent that doesn't want to give that 100% is gonna stress out more because they're trying to be themselves, but they know they can't. I think that's where problems can happen when the parent is trying to be cool or something and then the kid runs off and then they don't come out of that vibe they're in, and the kid will go off and maybe the parent keeps talking to someone trying to be up to date and cool with them. But they totally forget... they'll stress out more if they just try to hold on to what they, who they are. ...it is cool when you can just switch between those and not try and hold on to one.

Mareko highlights the importance of reaching a state of flexibility of adaptation, in not losing who you are as a parent, but also in ensuring that the needs and preferences of your autistic child are met well.

It was also understood that change within the family was ongoing, due to autistic presentations and idiosyncratic behaviours changing across time, most challenging through early childhood, adolescence, and puberty (Carr, 2016a, Grebe et al., 2022). Pania and Mareko remarked:

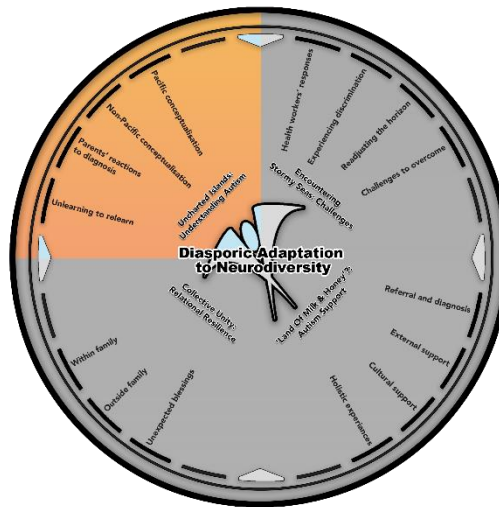
Pania: I mean we still don't know everything what to do...

Mareko: Yeah, you never know what to do!

Pania: ...and every different stage presents something new that we have to learn, or like, we have to "OK, family meeting, let's try and suss this out".

Lanuola agreed: "you just have to deal with change the best you can until the next change, the next thing". To summarise, parents found adaptation challenging at times, but a necessary aspect of parenting autistic children. Areas in which Pacific families adapted included, but were not limited to, the major areas outlined throughout the following subthemes of the key themes.

Theme 1: Uncharted Islands: Understanding Autism



The first major theme which came out of talanoa with Pacific parents in this study was *Uncharted Islands: Understanding Autism*. This theme describes parents' understanding of autism at diagnosis, which varied as to whether the understanding was of Pacific or other origins. At times, there was no awareness of autism prior to diagnosis. Understanding autism as a diagnostic label for their child is the first task of parenting an autistic child (Bernier et al., 2010). Understandings of autism etiology and of autism itself in turn influenced parents' reactions to their child/ren's diagnosis. Following diagnosis, unlearning previously accepted life knowledge and experience occurred to make way for understanding the neurodiverse child and the child's support needs and preferences. 'Uncharted Islands: Understanding Autism' is therefore comprised of four sub-themes: Pacific Conceptualisation, Non-Pacific Conceptualisation, Parents' Reactions to Diagnosis, and Unlearning to Relearn which will be elucidated further below.

Pacific Conceptualisation. For those with more traditional beliefs the Pacific understanding of autism relies on an understanding of any condition or disability within Pacific knowledge traditions, such as *ma'i* (Mo'a 2015). As discussed earlier, the Pacific conceptualisation of ill-health in any sense—*ma'i*—is often attributed to the consequences of biblical sin, breaching relational boundaries, a lack of care of relationships and familial duties, and other causes of disharmony within the community (Pulotu-Endemann & Faleafa, 2017). When Pacific peoples subscribe to these conceptualisations, first-line treatments and sources of information also tend toward the traditional, including engaging healers of the perceived spiritual and physical contributors (Tukuitonga, 2013). Pacific parents within this study spoke of traditional Pacific conceptualisations of conditions including autism:

Akanesi: With the [Pacific] culture it goes back to myths and, you know, what you hear from your mum. What you hear from your aunty and your family. Mental illness is something like a curse that's been brought down generations of family. And a lot of [Pacific people] believe it's more of a spiritual thing as well.

Higano: I think the word curse, yeah. The family has done something in the past and so you're gonna pay for it now.

Pania: Aw shucks, and they're still in the God's punishing me zone.

Salote: Usually people ...don't know the first thing about [autism] and it just sounds like a sickness. You know, 'cos that's what ma'i is.

Although some did, most Pacific parents in this study did not subscribe to the above beliefs and attitudes towards autism. Their understanding was more informed by non-Pacific conceptualisations and are discussed in the following subtheme section.

Having no term for autism in Pacific languages increases the difficulty for Pacific peoples in grasping the condition. Salote reported that her experience with her son's autism did not match up with the available translated information about autism:

I knew that there were not enough words that would define autism very well, like the word ma'i, and then even when I started to read up information that was translated about autism and translated in Samoan I was kind of disappointed to see that it's still called ma'i, ma'i o le mafafau. ...that's like brain damage to me when I translate it.

Describing autism as being akin to "brain damage" may make acceptance difficult, and impact adjustment to the condition due to missing and incorrect information about autism itself (Higgins et al., 2022). Further, undershooting goal setting may be more likely as the term "brain damage" implies permanent disability while autism is a neurotype which with early intervention and supported learning often achieves positive results (Downes et al., 2021). Akanesi concurred, speaking about raising expectations for their children: "you know, there was a time we accepted that's how it is".

Pacific community knowledge of etiology and symptomology of conditions tended to be low (Fa'alogo-Lilo & Cartwright, 2021). Although a lack of general knowledge about autism is not uncommon, and was also found with Torres Strait Islander communities (Lilley et al., 2020) and non-Pacific rural communities of the US (Barber et al., 2022). Within Pacific conceptualisations, etiological factors of autism were often related to omissions or commissions of behaviour, and therefore were inherently stigmatised, as Salote reported: "it's kind of funny, but not really, not when you're talking about my kid, you know, having this condition because of whatever reasons, because I was facing the sun on this particular day or not". Salote clearly did not agree with these understandings. Akanesi's response showed that while being influenced by the conceptualisations of her family and community, experience meant that her conceptualisation was beginning to change: "to be honest, I believe it's genetic. I don't really know at this stage about the spiritual thing, or the curse thing, but to me I just believe it's passed down by family through genetics".

Education was hypothesised by Pacific parents as the key to overcoming the lack of awareness, and increasing autism acceptance within Pacific communities. Indeed, Pacific organisations within Aotearoa have been targeting destigmatisation in the disability space for some time (<https://www.leva.co.nz/our-work/disability-support/resources-and-tools/>), although this is yet to include information about unseen disabilities such as autism. Mikaele's personal story of telling his parents about his son's autism diagnosis perfectly illustrated an educational strategy in action, shared with alofa:

They were like 'Aw kalofa e, ma'i le kama' and they used the word 'ma'i' a lot and it really got to me.

The way I approached that was, I said 'Mum, you know, Mum, Dad it's too bad that the Samoan language doesn't have better words'. And then they were like 'Oh what do you mean?' And I go 'Oh you know the word ma'i, it's such a bad word to describe my son'. ...It's such a bad word, a? There should be better words than that'. And then my parents were like 'Aw yeah, OK'. And it's about, like, educating them and it's, like, I wish we had better words. Since that time, they didn't use the word ma'i.

Although Mikaele cites education as being pivotal in shifting his parents' understanding and use of language terms for autism, it is clear from Mikaele's approach that relationship was both the prerequisite and the critical conditions for such a positive exchange to occur.

Overall, awareness within Pacific communities of autism is increasing as higher numbers of Aotearoa Pacific children are being diagnosed with autism (MoH, 2021). Parents within this study had increasingly less traditional Pacific conceptualisations of autism. This was hypothesised to be due to most parents being born in Aotearoa, and through increased exposure and awareness to autism through their wider families and communities. While Pacific parents are less likely to adhere to traditional beliefs around conditions such as autism, it is important to note that Pacific communities are largely gerontocratic and the elders largely set the tone and environment of those communities. This means that within churches and other communal environments there is likely to be stigma and judgment present, and likely a conflict of beliefs between the older and younger generations about autism. This is important to be mindful of, as while contemporary generations of Pacific parents hold different beliefs about autism and its etiology, they are still regularly exposed to the stigma and judgement of elder society members who hold more traditional beliefs. To demonstrate, Akanesi commented:

When you're dealing with Pacific Islanders you get this sort of judgement? ...Like when I go to meetings, not meetings but anything to do with, I don't know, with your kids, with your family, you just kind of tense up a bit and it's almost, you don't wanna, I don't know. You don't wanna air your dirty laundry, that's exactly it, you don't want them to, I don't know, say something to you that you don't wanna hear.

Non-Pacific Conceptualisation. Parents in this study further described how any understandings of autism they had prior to direct experience of it were heavily influenced by non-Pacific media, including television, news articles, and movies. For example, when asked if she had heard of autism before their children were diagnosed, Lanuola replied:

I had, mostly through the media or through work when I've had to attend [Police] jobs for, you know, kids on the spectrum who have taken off from home. ...I guess even working in the Police and that, I was still learning about mental illness and everything, and so autism was sort of grouped in everything else like schizophrenia, and bipolar, all those things that were almost viewed as quite scary cos it's so unpredictable.

Akanesi and Higano's understanding had also been influenced negatively by movie portrayals of autism:

Akanesi: We always picture a person who's completely vegetable, or, you know? I thought maybe someone who has some sort of physical disability. But that's how ignorant I was, you know, I didn't

know anything much, nah, pretty much the answer is nah, I had no idea what autism was. I'd heard the term, different ideas. Just from watching TV.

Higano: There's a few movies ay.

Conversely, movies which highlighted support needs or savant-like traits had influenced Mareko and Pania's conceptualisations of autism:

Mareko: I didn't know much about autism in college, and I could say even before that I only kind of saw stuff on TV when they would highlight ...special needs, or a kid that's amazing.

Pania: Yeah, like a prodigy.

Mareko: Because they've got a condition, but they've got this amazing talent that goes with it. ...It's always either a news article or some programme.

Importantly within the Western psychiatric system, until recently a diagnosis of autism meant institutionalisation for autistic family members where families did not have the knowledge or resources to appropriately care for their child/ren within their community. Pania and Mareko explained:

Pania: When [our son] got diagnosed [in approximately 2006], we heard from my mother's friend who had a way older son. He was only in his twenties but they said he was, like, diagnosed and put on psychotic, like, medication and pretty much put in a psych ward, you know, things like that...

Mareko: It's archaic ay.

Pania: ...in that one generation it was still like, that was an autism diagnosis, and like, kind of, like, a care plan for him, and our son was only like a decade later.

Real-life stories such as Pania's family friend's story, can cause fear and worry within Pacific communities, leading to less help-seeking behaviour in general but particularly around diagnosis of conditions of the mind (Fa'alogo-Lilo & Cartwright, 2021).

Within the wider autism literature, knowledge of the etiology and varying presentations of autism remain limited. While previously pathologised according to the biomedical model, evolutionary theories perceive autism as a retained

variation for its particular strengths conferred in non-verbal intelligence, and superior skill in attention to detail, computer coding, reading complex patterns, and operation of highly systematised and mechanised processes (Armstrong, 2015; Shpigler et al., 2017). Internationally, understandings of etiology influenced parents' conceptualisation of autism, including whether they felt positively or negatively about autism (Grebe et al., 2022). Many non-Pacific parents reported not knowing how autism developed, and of those who reported an etiology, most attributed autism to genetics, environmental factors, and interactions between these (Barber et al., 2022). Within the current study, most parents did not have an understanding of the etiology of autism prior to diagnosis. For example, Pania described some of the purported etiologies that she had been exposed to:

The reasoning ay, how did this happen. We don't even know how this happened! ...it's not your fault, you know you didn't eat something, you didn't drink something, you didn't have something. ...because, you know, as a mum you're like 'OMG, what happened?!' and as a first-time mum you're trying to scan 'what did I do', but we don't even drink or smoke, so it's like, what else could we have done then, gees?! Too much seafood, I dunno? Too much soft cheese that I still ate?

However, it was clear from parent talanoa that personal experience changed people's conceptualisations and acceptance of autism, through both education and relationship. As Higano reported: "I had a narrow sort of view of what it was, and in amongst that was Asperger's, it was ADHD... I learnt a lot through teaching. For the better". Vasa recalled that at the time when her children were separately diagnosed autistic:

I was OK because I had experienced it with my nephews. ...So deep down for me I was just like, 'Cool, that's all good'. I was absolutely fine. But I guess, with my sister's boys, that that had a lot to do with my prep. Because yeah, nah, I really had a huge hand in helping to raise those boys and I'd seen their, how they were, and I'd seen how my sister would handle it, and I saw that it worked for her so that kind of like lessened the fear, I guess.

This is interesting for clinicians as there are direct ways in which non-positive myths, biases, and mindsets about autism can be influenced towards more positive perceptions through real-life situations that work for parents and others.

Parents' Reactions to Diagnosis. Gray contended that parents' experience of autism is "reconciled to his or her central values" (2001, p. 1248). Accordingly, Pacific parents' reactions to their child/ren's diagnoses in this study were

reflective of diverse emotional reactions. Reactions could be broadly categorised into reactions of acceptance or denial. For Pacific parents, notwithstanding their reaction at the time of their child's diagnosis, an important part of adaptation to parenting a neurodiverse child was processing acceptance of the diagnosis and of their neurodiverse child. Previous research shows that parental resistance to their child's autism diagnosis is not uncommon (Boshoff et al., 2019). Additionally, fathers may experience more denial than mothers following an autism diagnosis (Grebe et al., 2022). These facts are important for clinicians to understand when supporting families towards, through, and following an autism diagnosis as those with more denial and negative reactions will need more tailored support post-diagnosis. Denial was present for a minority of parents in this study also, for example, Mikaele recounted:

I'd been listening but, I was, I guess secretly hoping that it wasn't gonna be true that he had the condition. And then when he finally got diagnosed, then I thought, OK, now I really gotta just accept that this is what, you know, God has, I guess, blessed us with.

It is understandable that parents who held more negative perspectives of autism would find acceptance more difficult, as Lanuola explained:

From a [Pacific] perspective I always thought mental illness was really a negative and not well-supported, you know, like almost like hide that person, that person's not normal... [When our second child was diagnosed] it was so devastating, we just cried and cried, and we still do, every now and then, just at the struggles that they walk, that they may face, but we feel for them.

Similarly for Heirava, who had negative perceptions based on the conceptualisation of conditions of the mind within her community. She stated "we call them back in the islands kind of slow and mental". She continued "[it's] lucky, you know, [my husband] he can see... for me it's hard and I don't want to know that he's autistic".

Conversely, often within Pacific families acceptance was natural and unconditional. This was not often discussed by Pacific parents within this study and this is hypothesised to be because it is an assumed aspect of Pacific traditional values. Indeed, Dunlop-Bennett explains the child's acceptance, place, and belonging as a birth right, no matter how the child comes to its 'āiga, as the child's *fa'asinomaga* (2019, p. 53). When the researcher highlighted this acceptance to parents, they always agreed. Ofania and Lagi (Ofania's Mum) explained further:

Ofania: I try not to make him any different than how I treat the other kids, you know, my nieces and nephews. He's just [our son].

Lagi: We don't treat him as he's not same with the other kids. We treat him as all the same.

Overall, clinicians should be cognisant that the factors which affect Pacific parents' acceptance of a child's diagnosis of autism, both positively and negatively, are multifaceted and involve both Pacific and non-Pacific influences. Therefore, clinicians should spend time with parents following diagnosis to understand the parents' reactions to diagnosis and which factors are relevant for each family. This will guide how to help parents more effectively with their acceptance and adaptation journey. This strategy concurs with prior research that stated that parents often felt rushed and unsupported at diagnosis, which had negative impacts on their post-diagnosis journey through the support system (Boshoff et al., 2019). Researchers stated that clinicians' emotional support for parents during and post-diagnosis was critical to their adjustment and positive outcomes (Boshoff et al., 2019; Legg & Tickle, 2019).

Unlearning to Relearn. An important aspect of parents' adaptation to change was in unlearning accepted life experience and knowledge to learn new knowledge that would help parents appropriately understand and care for their neurodiverse children and teach them daily living skills. Autism requires continual learning and adaptation as children change with each developmental stage (Boshoff et al., 2019). The process of unlearning to relearn for Pacific parents included rethinking education and learning for their neurodiverse child, setting appropriate expectations, letting go of unhelpful or unrealistic ideals, and adapting typical or learned parenting approaches and strategies. Higano opined: "you have to take time to teach yourself and unlearn some things. And then relearn some things".

Effectively educating a neurodiverse child often required changes in approach such as viewing autism and other differences as neurodiversity and natural variation rather than as disorders to be fixed, and further, valuing and developing their strengths while attending helpfully to any weaknesses (Armstrong, 2015). The neurodiversity model leads to a strengths-based focus on what the child can do, rather than the challenges they may face (Mirfin-Veitch et al., 2020). Several Pacific parents found specific learning strategies based on increasing communication using behavioural principles were useful. These successful learning strategies included child-led play, use of visuals, repetition, extension, routine, incentives and rewards, and increased preparation and warnings before transitions. The addition of naturalistic strategies such as prayer, singing, dancing, and other cultural activities were also included by most Pacific parents. For instance,

Salote recalled how proud she was that their children could recite grace in the family's Pacific language. Pania explained how they turned their son's special interests into successful adaptive skill learning tools within their family:

He likes trains? OK, let's build trains, let's make trains, let's go on trains, let's go to Wellington on a train! We were like trains, let's do this. And from there, his reading, his writing—cos we always just did it through his passion. That's what we were like. OK, whatever he's into we'll use that for things he's not so much into. That's how he kind of picked up that, I mean that was then when he was young and he liked watching Dora [the Explorer]. Dora was on so we did everything at home in 'threes' like Dora, so OK. it's like 'Get undressed, go to the toilet, get in the bath—Yay we did it, we did it!' We'd just do the song and everything. And then it's like 'OK, let's eat, let's brush our teeth', everything was in threes, just like Dora. And then he'd get to watch a little Dora thing if that's what he wanted.

Importantly, research has demonstrated that neurodiversity strategies are effective for all students, and not only those students with neurological differences (Mirfin-Veitch et al., 2020).

In rethinking the best learning setting for their son, Pania and Mareko realised there were various experiences throughout the education system for autistic children in Aotearoa, for example: "some people have gone to school, done home-school, gone to another school, not been allowed to go to school". They decided that the right environment for their son was the bilingual te Reo Māori/English unit at their local primary school. Pania relayed:

I asked if he could go into the Māori bilingual unit. I said 'He's not coming from kohanga and we don't speak Māori at home, but I want him to be in a whānau environment because that's how he thrives'. ...And also I thought in the Māori unit they would be more accepting of having me come in. And I would just help out in the class any way I can.

In Pania's case, home to school communication was strong. At times, communication between home and school required strengthening which led to different strategies being effective in different contexts. Ofania explained:

I want to know what they're teaching him so if it's something that's good I can teach it at home and then I'll show [the family], you know, 'This is what they're doing at his school'. Yeah, but for some reason, what they teach at the school does not work here at home.

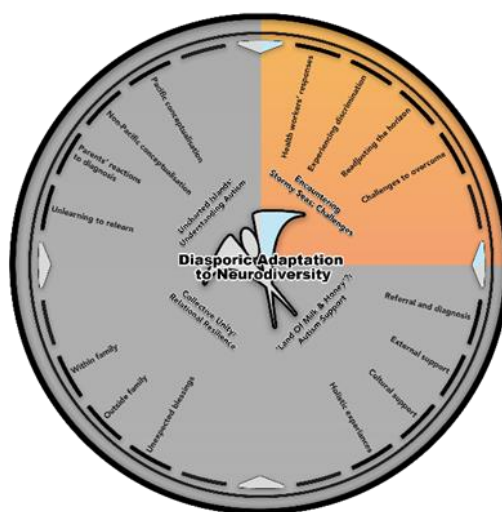
Clinicians can assist families in identifying goals for their child and the type of school environment that they believe their child will benefit the most from. Where necessary and appropriate and in conjunction with parents, clinicians could also act as a conduit between parents and school staff, such as Special Education Needs Coordinators (SENCOs) and classroom teachers to increase effective communication and agreement on shared goals for the child. This could be either through directly attending Individual Education Plan (IEP) meetings and advising in relation to their specific knowledge of the child and their learning potential, and/or through assessment information and recommendations tailored to the child's teaching staff.

Overall, Pacific parents in this study fought hard to ensure that their children had the same learning opportunities as other children in Aotearoa. While not widely advertised, school exclusion was a reality for some autistic children in Aotearoa who for various reasons could not access adequate learning support or had challenging behavioural needs (Echeita et al., 2021). As an example of working to prevent negative outcomes for her child, Ofania stated that she rang every preschool in her region to enquire as to their experience with teaching autistic children. At one preschool, her mother Lagi had told her that a neurodiverse child was given a broom to use all day as they were perceived to enjoy sweeping:

He may be sweeping but give him something else to use, a, I dunno, where he can learn something while he's sweeping or...once I heard what they do at the preschool I'm, like, 'OK, no, we won't be going there.' He's not gonna learn there.

In this example, it is possible to see that through the preschool's low expectations of the neurodiverse child's capacity and a perceived following of the child's interests (but lacking extension), a ceiling is being placed over the child's learning potential and instead a form of educational exclusion through inclusion is occurring. It is therefore important that following assessment families are given accurate information on the cognitive potential of their child and encouraged to give the child learning opportunities commensurate with their capacities and interests (Mirfin-Veitch et al., 2020). This will increase the likelihood that the adults involved in the child's life are not mis-assigning and prematurely curtailing the child's potential.

Theme 2: Encountering Stormy Seas: Challenges



The theme *Encountering Stormy Seas: Challenges* relates to the difficulties and challenges experienced by Pacific families in raising autistic children following diagnosis. Some of these experiences are the same as those of non-Pacific parents of autistic children, whereas others are unique to Pacific parents. The four sub-themes under this major theme include: Health Workers' Responses, Experiencing Discrimination, Readjusting the Horizon, and Challenges to Overcome.

Health Workers' Responses. One set of difficulties which Pacific parents in this study faced were those arising from interactions with health professionals across the health system who had a lack of understanding of autism itself, as well as low cultural sensitivity in working with Pacific peoples. As Pacific relational ethics is underpinned by *fa'aaloalo* and *ava*—humility and respect—for authority figures, which discourages questioning elders and those perceived to be in positions of expertise or of higher status such as health professionals (Ioane & Tudor, 2017; Matapo & Teisina, 2021), often health professionals went unchallenged in their approach. Mareko and Pania explained from their perspective:

Mareko: As Māori and Pacific we're trained

Pania: Trained, forced

Mareko: Trained, trained to obey our elders and people of importance, say like, doctors

Pania: Yeah, that's right, specialists

Mareko: So when someone says something to us we believe it.

Salote concurred, adding:

I was like that as well where, you know, listen to the doctor because they know what they're talking about, listen to the specialist, you know, the experience, the experts and all of that, you know, and I'd just be taking it all like wow, wow, wow.

Mateo also had a similar experience:

I also brought up the question about the vaccine and he shut, and that's where I got shut down, and that's where I could see his stance straight away was, like, quite negative towards me questioning. So it was like, OK... stay calm.

Research shows that autistic young people consistently experience inadequate health care and as a result evince greater unmet health needs than non-autistic young people (Menezes et al., 2021). The above extracts demonstrate that even when concerns are present, Pacific parents may be perceived as acquiescing to those who are advising them in their capacity as a health professional through their silence or implicit agreement. In Pacific relational ethics these responses are conceptualised as respect and humility for the health professional (Health Research Council, 2004). In other Indigenous communities also, "acquiescence" has been described as a strategy of making space for everybody, rather than a political tool or example of deference (Musharbash, 2019, p. 23). To restore self-determination within this situation, health professionals are advised to check parents' understanding and offer further discussion if desired (Pitama et al., 2017). Rather than asking "Do you understand/Do you have any questions?" which is more likely to lead to agreeable answers, a simple language change to "What questions do you still have/What are your thoughts about what I've just said/What would *you* like to talk about?" may produce more helpful discussion.

Parents in the current study also reported difficult experiences with health professionals in attempting to access routine public health care, such as hearing tests, for their children. Health professionals often had little understanding or strategies for working with neurodiverse children. For example, Ofania retold how it took significant courage for her to be firm with professionals and to assist them, but stated that this was not always appreciated:

"If you've gone through his medical notes he is diagnosed with autism and, you know, I've tried to do, I've done my part, can you, you know, do your part?" - and that's me always telling them beforehand. And they're like "Oh, we can't do that". Well, then, this is the result. You can't get any

results without, you know. But they're like "Oh what do you know? I'm the eye specialist, I'm the ear specialist, I'm the dental technician", blah blah... And that made me feel real stink because I'm like, I'm not telling you to do, how to do your job, but you know, to make it easier on me, on yourself, and my baby who's standing there crying the house down, you know, you just have to do it this way.

Pania had a similar experience, which led her to enacting greater advocacy for her son:

When we went for his hearing test I was so, like, upset about the people who work there. Cos I said 'OK, he's very sensitive around his ears and his neck' and then she just tried to shove this thing in his ear and he was like [jerked away], like that and I said 'Aw I told you he's really sensitive' and then she goes 'Aw but it's so soft, it doesn't hurt!' And I was like, I'm trying to help you. At that time, I wasn't ready to talk to professionals like that, like school them. But then, after that one time, I learnt that, no, they are professionals at what they do but I'm the professional about my son. And I'm trying to help them out, so you better listen lady!

Health professionals should be cognisant of and sensitive to the needs of neurodiverse patients/clients and be supported to engage in further professional development focused on knowledge of autism, and strategies and clinical adjustments that may smooth out potential challenges during consultations (Erwin et al., 2022; Holingue et al., 2021). Practical measures, such as a flagged note in the system for neurodiverse children would prompt health staff booking appointments to ask about any accommodations required for sensory or other needs, either prior to or at the beginning of the appointment. These accommodations could then be considered and planned for, or alternative recommendations made to families.

Parents further felt empowered and a sense of satisfaction in successfully advocating for their children, and this was particularly true when parents perceived better outcomes arising out of their advocacy (Boshoff et al., 2019). For example, Salote reported regarding "the first time I felt I disagreed with an expert", that while sharing her concerns with the Speech and Language Therapist was uncomfortable for her, it was ultimately "really beneficial for all of us, especially for [our son]". Pania and Mareko agreed, stating:

Pania: It was...because of our experience that we were like, we're not gonna go out and be disrespectful

Mareko: It's a compromise

Pania: But you have to respect, you know we're trying to help you out, too, because we know how he functions and that. And so now I'm really always like 'So OK he's really like..', you know, like I always, if I need to help him out I will say it, or if they need to stop then I will say that too. I think it's really empowering.

Prior studies have found that parental advocacy is more common when parents initially have a negative or denial reaction to their child's diagnosis (Boshoff et al., 2019). Boshoff and colleagues found that advocacy not only helped with parental coping, but often improved the child's situation in gaining relevant resources and support, and gave parents a sense of empowerment that they were able to effectively help their children.

In this study, clinician bias interacting with Pacific relational ethics together led to Pacific parents being prone to experiencing dismissal of their developmental concerns about their children, and delays in diagnosis of their children. For example, Salote reported:

So we had concerns then but we were just kind of, what's the word, the GP just sort of said that it was a phase. And I guess on top of that having a doctor just, a GP too, sort of say that, you know, not to worry about it too much, it's just a phase, not to compare him to other children. It sort of gave a slight sense of relief but sort of looking back, I just wish I sort of pushed through that, and, you know, not waited another, you know, year until the Plunket checks to sort of get things, you know, going.

He was so discouraging in saying that 'Yeah, there's long waiting lists, the chances of you getting a referral were pretty slim and it was gonna take a long time', and I mean, in hindsight why didn't I just say 'Well you're not the one doing the waiting, I am, so why is it a problem for you? Just tell us what we need to do' and then we'll, you know, sort out the whole time and waiting thing. But yeah, he wasn't very helpful or encouraging of next steps on how to get that kind of support.

Research shows that what Salote described regularly happens to ethnic minorities and Indigenous peoples in Aotearoa and other countries also, and is called dismissal (Bailey & Arciuli, 2020; Boshoff et al., 2019; Bevan-Brown, 2004; Crane et al., 2018; Legg & Tickle, 2019; Simpson, 2021; Tupou et al., 2021). Dismissal occurs when parents' developmental

concerns about their children are ignored, side-lined, and remain unanswered by biased health professionals when parents seek help (Pearson et al., 2022).

Experiencing Discrimination. Health practitioner bias leading to dismissal of concerns, delayed diagnosis, and misdiagnosis affects minority ethnicities in the US, Canada, Australia, and Aotearoa (Begeer et al., 2009; Dyches et al., 2004; Mandell & Novak, 2005; Pearson et al., 2022; Pitama et al., 2017; Simpson, 2021). Additionally, in Aotearoa, both Māori and Pacific people with disabilities experienced higher levels of racial discrimination than non-Pacific people with disabilities (Bevan-Brown, 2013; Roy et al., 2021). Often, clients were unaware of having experienced delays or sub-par service as they were not cognisant of best-practice (Pitama et al., 2017). Pacific parents in this study also described experiencing discrimination within the health system in trying to access diagnosis, care, and support for their autistic children. Pania and Mareko opined:

Pania: I was like 'Man, this is the [well-known clinic with a high proportion of Māori/Pacific clients], I was like how is she to other, like, brown people if this is, you know, like the kind of vibe, that she's not really embracing'...

Mareko: That's what's lacking ay, it's that cultural sensitivity, from a lot of the health industry. You know, if you're dealing with the masses of the community coming through, you've got to have that training and the onus is really on the providers ay.

Salote and Mikaele added their experience of feeling that their privacy was being compromised and feeling discriminated against after seeking support for their son:

Salote: Well, why do they need to know all our income details? If we're not asking for the money to be put into us directly, sort of thing, and she was saying, she was justifying why they do it and it just sounded like she was more of a budgeting advisor rather than anyone [who could allocate support funding].

Researcher: Oh yeah, we must have a problem with managing our money if we need help.

Mikaele: Yeah.

Salote: Exactly, so I was like nah you don't need to know all about that.

...

Salote: I would have to tell the same story over and over again and I feel like, you know, were they tryna, like, catch me out for giving them a fake story or something, like, I wasn't after their money I was just after some support because I didn't know where to go and what to do.

In addition to discrimination within the health system, prior experiences of racism and prejudice in the community led Aotearoa Pacific parents to expect negative judgements in public (Simpson, 2021). Mareko was aware that non-Pacific parents of autistic children do not experience these instances, as he retold regarding a train trip the family took as a reward for their son:

When they're approaching us it's like, because you're Polynesian, you're like, what are they gonna say to us, are they gonna put us down, or whatever, are they gonna say, 'You shouldn't be sitting here', you know, those kinds of things go through your head. You're on guard about are they gonna judge us on his autism or are they gonna judge us on our skin colour? Some baggage that... some Caucasians will go through the autism thing, and that's something that they'll share with us, but they won't share that cultural barrier. You carry it a lot, but people don't see that. Cos there's more than just the autism you're dealing with.

Mareko here raises an important truth about intersectionality, that discrimination can be additive when there is both neurodiversity and ethnic minority present, and further multiplicative when additional socio-economic disadvantages are also present (Bevan-Brown, 2013; Simpson, 2021; Tokona te Raki, 2022). Mareko believes:

Usually it's another adult that's teaching the bad behaviour to not like someone, judge someone, and they pass it onto their kid and the kid becomes the adult and the cycle continues. So that's [what we need, is] a lot more parents teach[ing] their kids to be understanding to difference in people, no matter what their neurological situation, or race is.

Similarly with Mikaele earlier, Mareko's answer to changing negative dynamics is to educate families and communities.

Antidotes to clinician bias, discrimination, and interpersonal racism include education and forming relationships or increasing connection with others (Pitama et al., 2017; Tokona te Raki, 2022). Rogerian and Indigenous psychologies understand that client outcomes and therapeutic relationships are strengthened through the establishment of rapport,

whakawhanaungatanga, and genuine positive regard, particularly when working across cultures (Hamley et al., 2022; Ioane & Tudor, 2017; Makasiale, 2013; Pitama et al., 2014, 2017; Pulotu-Endemann & Faleafa, 2017; Sommers-Flanagan & Sommers-Flanagan, 2017; Tokona te Raki, 2022). Diagnosing professionals are beginning to understand that a general lack of rapport and empathy with parents seeking an autism diagnosis for their child leads to less and lower quality assessment information being gathered from parents and affects the therapeutic relationship (Crane et al., 2018). Parents also rated how they were made to feel during their child's assessment as paramount, adding that clinician's knowledge of autism and parents' realities, and a warm and understanding interpersonal manner, aided reception of the diagnosis and led to improved relationships with further professionals in the child's early intervention sphere (Boshoff et al., 2019; Brown et al., 2021; Searing et al., 2015).

To demonstrate further, Salote explained how the rapport and demeanour of the pediatrician who diagnosed their son made all the difference to their receipt of the diagnosis:

I think we were very fortunate and blessed that the clinician, the paediatrician, that actually gave us the diagnosis is Māori. He was, I felt that he was really kind in the way that he approached us and didn't just drop the bomb on us. I think maybe he sensed that we didn't have a clue about what any of this was, we just had concerns. He very sort of kindly, and slowly got towards, you know, he didn't just say straight 'He's autistic', but he was like, you know, he talked about the tendencies, he talked about how some families support their child, so it was you know sort of building towards this is what the situation is, sort of thing, very gently did that. So I think that was very, very helpful for us to have somebody explain it in such a way.

It is likely, given the description of the pediatrician, that they were culturally competent and prioritised rapport with the parents. As Mareko stated, professional development for health professionals focusing on cultural competency is an important intervention in reducing clinician bias and racial discrimination within health interactions and autism assessment (Broadstock, 2018; Pearson et al., 2022). Indeed, this strategy has been successful in Aotearoa with health professionals who attended professional development including cultural competency components focused on working with either Māori or Pacific clients (Pitama et al., 2014; Pulotu-Endemann & Faleafa, 2017). In addition, clinicians can rectify sub-standard care through reviewing client notes and addressing areas where best-practice care was not provided (Pitama et al., 2017).

As part of its eliminating racism strategy, Aotearoa's Te Aka Whai Ora (Māori Health Authority) and Te Whatu Ora (Health New Zealand) are providing cultural competency training to health professionals (MoH, 2022c)²⁹.

These findings share the experiences of Pacific parents raising autistic children in Aotearoa, but are likely to be relevant to other Indigenous autism communities elsewhere. Research has shown that within the health system people of minority ethnicities are regularly treated in stereotypical ways which are not culturally responsive (Paterson et al., 2016; Pearson et al., 2022; Pitama et al., 2017; Simpson, 2021). Further, Simpson (2021) reviewed 22 articles which revealed that Indigenous peoples' experiences of social injustice were common across the US, Canada, Australia, and Aotearoa. While these findings cannot be generalised to all Indigenous communities or all autistic families, they provide some insight into potential experiences across both groups.

Readjusting the Horizon. Adjusting parental, child, and family expectations is a necessary and often challenging task of adaptation for all parents following receiving an autism diagnosis for their child/ren (Bernier et al., 2010). Taleni and colleagues discuss how Pacific community leaders view migration to Aotearoa as the ticket to the achievement of Pacific dreams and aspirations, therefore leading to high expectations for all Pacific young people (2018). The Pacific parents in this study were no different. Heirava commented that following her son's diagnosis she was:

Feeling sad, feeling sad, cos I know my son is not normal. Because I want to, want my child, you know, to have the normal child? The hard part for me is you can't get married, can't have a family. He's gonna be stuck with me.

Pacific parents were most concerned that their child might not find a fulfilling intimate relationship. Lanuola stated:

I guess, you know, that they might not find a, you know, their person to have a loving relationship with, you know that experience, they may not, they might. That would be so cool. That would be my dream that they do.

In addition to finding a life partner, Pacific parents wanted a good life of their child's choosing and independence for their children (being able to communicate their needs, living away from home with support, having meaningful and

²⁹ Te Whatu Ora is leading Ao Mai Te Rā | Anti-Racism Kaupapa, focused on eliminating racism in all forms from the Aotearoa health system. See: <https://www.health.govt.nz/our-work/populations/maori-health/ao-mai-te-ra-anti-racism-kaupapa>

enjoyable employment, and living a “normal” life). Mateo stated his top priorities for his son: “I just want him to be, yeah to be independent and communicate”. Lagi was emotional about her grandson’s future:

Every time I go out to the mall and I saw people you know the adults like [my grandson] or big kids like him, I cry, you know? I always cry when I saw them like that. Is that how my [grandson]’s gonna be when he grows up? Sometime I look at him over here, I cry too. Why? Why [grandson] it’s you? Why? But you know, that’s life, so what we can do? All we do is love him, look after him. As long as he does his own thing when he grows up.

Often, initial dreams for children’s futures such as becoming sport stars, were replaced with more realistic goals once the child showed no interest or proficiency in those areas (Lutz et al., 2012). Mateo had to adjust accordingly: “physically, [our son] should have been my sports man, you know, that I always wanted, but yeah”. Akanesi added: “you gotta keep on thinking that, you know, there’s something out there for them...and so much TV and videos and what not later they might become an actor!”. Lanuola also shared how her dreams for their children changed:

We would assume that our kids would just go through school, we’d give them the opportunity to go to uni if they wanted to, and then just support them to be the best and amazing, successful people. I guess, just like that dream for them has changed.

Pacific parents also had significant worries about the care of their children past the end of the parents’ lives. Katalina questioned: “that’s our biggest fear right? Mums in general but especially as autism mums, you can’t ever die ‘cos who the hell’s gonna take care of your kids?”. Vasa also held the same sentiment: “now more than ever, the feeling of Malama and I not being around anymore, and who’s gonna care for and love the kids as much as we do?”

Readjusting the horizon also related to the four Pacific families in the study who had subsequent autistic children diagnosed, and their adjustment to their future and grief. As Lanuola recalled:

That was really scary for me, I was just, like, I can’t do this again. Like, I was really, I grieved at that time—how when she was just one or one and a bit and I kinda knew that something was not right.

Akanesi and Higano had a similar experience when their second son was diagnosed:

Higano: I never cried for [our first son] because I wasn't there [at the diagnosis], so that's the problem that I've, I still kind of have to deal with

Researcher: Right, so it's almost like a double grief, in a way?

Higano: Yeah.

Akanesi: You know you've gotta go through it again. I just felt like I'm really tired, it's so, this is draining

Concurrent with the autism literature on parental experiences, almost all Pacific parents spoke about grieving the loss of a potentially neurotypical child and the classic childhood they expected. However, Katalina explained how allowing grieving led to coping action:

When he was first diagnosed I literally grieved him, like a death. It was kind of like, just getting it out, you had to be able to get it out to be able to be like, phew, OK, let's move on now.

Pania also explained what adjustment to grief looked like for their family, and what may help other families:

Yeah, no more of this 'If he just learns how to do this, then he can be normal'. But, I mean, that's all part of the whole grief thing, cos you're, like, trying to hold on, hold on. But as soon as you're like 'Oh nah, we're going down this path and that's us'. ...so I think that to help other people is just the hope, give some hope man, it's not a write-off, it's not a terminal illness, like, really!

Pania mentions hope as a key component of interactions with health professionals in helping parents adjust to their child/ren's autism diagnosis. Hope is a critically important element in all therapeutic encounters, particularly where change or adjustment is required (Sommers-Flanagan & Sommers-Flanagan, 2017). Parents opined that if there was hope given at the time of diagnosis, the inherent adjustment required would be easier to handle and there would be less anger. Higano stated: "Yeah, often a bit of hope, often a bit of hope for people, as well as the facts...I think is something that's missing".

Clinicians are uniquely placed with families to be able to furnish parents with hope at a time where they may feel disheartened, shocked, fearful, or sad. Clinical prognoses might be helpful if the child being diagnosed also has similar capacities, for example, positive prognoses for children who have at least one expressive word. Clinicians could focus

on the developing child's current assessed capacities and potential with appropriate intervention. Clinicians should consider the potential for prematurely delimiting the child's capacities through statements about what the child may/may not be able to do based on their diagnosis. It is suggested that such statements should be avoided unless: a) these statements are of absolute certainty and/or have significant evidence behind them, and, b) will be helpful for the family to know. Additionally, emotional support for parents leading to and at diagnosis is crucial and may include referral to further health professionals to address (Boshoff et al., 2019; Downes et al., 2021).

Challenges to Overcome. One of the biggest challenges faced by Pacific families following autism diagnosis was acceptance from their own families and communities. Pacific parents shared their experiences:

Katalina: We turned up [at Aunty's house] and [our son] was real happy to be jumping around in amongst everybody but your Mum being your Mum, you know, just wanted to get rid of him cos, you know, how embarrassing is that, whereas no one else cared. He was obviously kind of feeling that, then he started to play up, and so as per usual, one of us— which is usually me—had to leave, take him home and he played up even more, cos you know, I knew he wanted to be there, he was excited.

Mikaele: It's the saddest thing for me is that most of the judgey looks, like, when [my son] would be, you know, not even having a big tantrum or anything, it wasn't like those *ulavale* non-compliant ones it was just uncontrollable meltdown stuff. You know, frustration and, you know, having your own people—and it was always my own people and elderly ones who would give you that look, like *fasi*, *sasa*, whatever, sort it out—and I'm like fuck I'm not gonna resort to that, I can see your look. Like, they're looking at my son, they're looking at me, and I've seen that look. I've been out in the mall and all that and I'm like, you know what nah, I'm not gonna resort to that, I know that they want me to smack him right now. And it used to really piss me off, that feeling of being judged like that.

Salote: Everybody is judging me for that *ulavale* child on the floor.

Vasa: It was a lot more from the [Pacific] community than it was from any other community which was really, really frustrating. So yeah, at first, naturally, I just was angry, but then being angry was so exhausting. ...Nobody really knows how much work and time, tears, and, you know, we went

through with the kids, so, we're really in a much better place now. But, ... it's just a one day at a time sort of thing.

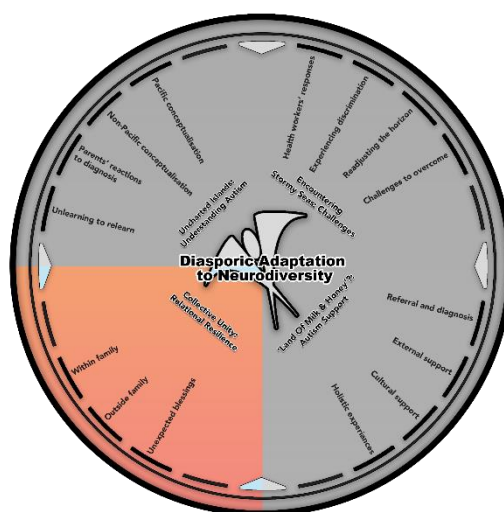
Vasa relayed her experience of judgement, felt anger, and how a decision made in humility to educate others turned her anger around:

I really can't be angry at anybody—can't be angry at the old [Pacific] ladies at church because they don't even know what autism is. So we had to make the choice to teach; teach ourselves, teach our family, teach others so that they understand, and when we did that, it all changed.

Parents in this study noted how they were more hurt by their own family's and community's responses than those of strangers. In Aotearoa, research shows Pacific people with disabilities often faced less acceptance from family compared with their non-Pacific counterparts (Roy et al., 2021). Internationally also, when minority ethnicity parents attempted to gain support with family and friends around their early concerns for their children, often they were met with doubt, a lack of understanding, placation, and even blame for their child's symptoms (Boshoff et al., 2019). Following diagnosis, parents were often isolated from their communities, and harshly judged for their children's behaviour (Bernier et al., 2010). Researchers stated that these responses were due to stigma within some cultures around disability and particularly conditions affecting intellectual capacity (e.g. Fa'alogo-Lilo & Cartwright, 2021).

Conversely, for Pacific people, felt acceptance from within Pacific communities increased mental wellness and reduced negative emotions (Mila-Schaaf, 2013). Similarly, autistic children in Torres Strait Islander communities experienced higher levels of inclusion through being accepted into the community as "cousins", although unrelated by blood. This positive identity contrasted with the non-inclusive attitudes in wider Australian communities which were "disabling" for autistic people (Lilley et al., 2020, p. 1864). Social inclusion and family and community support were critical for families raising autistic children in feeling supported and accepted within their communities (Grebe et al., 2022; Lilley et al., 2020). Therefore, clinicians are able to mitigate judgement of families through destigmatisation education and awareness activities within the communities where clinicians work. Clinicians can also support families through giving space to hear and validate families' experiences, and assisting parents in advocating for their children and teaching others where a community lack of understanding of autism exists (and parents have the capacity to do so).

Theme 3: Collective Unity: Relational Resilience



The theme, *Collective Unity: Relational Resilience* developed throughout talanoa with Pacific parents raising autistic children in Aotearoa. While adaptation to neurodiversity at times was very challenging for families, resilience was found largely to be situated within the relational networks of Pacific parents. These were either naturally present through familial lines, or created, such as acquired church and community-based networks. Sometimes, where networks did not exist, parents searched externally to create networks of support which might involve disability support services, relevant agencies and workers, for example, parents mentioned ORS-funded taxi drivers becoming part of their child's relational networks. It was through these networks, both internal and external to the families, that families found specific disability support for their child, practical help, social and emotional support, childcare, parenting knowledge, mentoring, and more. Conversely, where these networks were modest or lacked availability, parents found caring for their families particularly difficult. Relationships and relational connection as the foundation of resilience are nothing new to Indigenous peoples (Hamley et al., 2022; Makasiale, 2013) yet while best-practice, these are still not embedded widely in health and education services (Mirfin-Veitch et al., 2020; Pitama et al., 2017).

Within Family. One of the key themes discussed by Pacific parents throughout the talanoa pertained to the importance of their social relationships. Relational networks were often familial and kept tight even within these circles to sustain positive, helping relationships for parents and their children. For example, Akanesi reported “Higano’s Mum and Dad, that’s pretty much our main support at this stage”. Unity within this chosen collective was therefore critical to parental adaptation and thriving. Intergenerational living was considered the gold standard, as Ofania explained: “I love the family,

having them around you constantly, and that's why I was going 'that's how I grew up, this is the way you're gonna', you know, this is the way I want my kids to grow up".

Pania from this study earlier described Pacific families utilising family carers rather than seeking carers external to the family as "keeping it in-house". This concept is also known as accommodation in the wider health literature (Dai & Carter, 2022; Gray, 2001). Recent autism research in the US has shown that parental accommodating behaviours occur more within ethnic minority groups including Latinx, Black, Asian, and biracial families (Dai & Carter, 2022). Similarly, family members were considered by Pacific parents to be the only ones able to be trusted to care for the children appropriately and safely:

Vasa: I guess if I'm honest to myself that I would only ever feel comfortable with just having family look after the kids. ...Paid carers, we've not had any paid carers, ever. We've always had, even with our Carer Support, it's always been either my sister, or my Mum and Dad. ...We wouldn't be able to do it without the rest of, especially our, you know, our little village. We needed, cos it was, it was always gonna be heavy for me and Malama.

Heirava: I get [funding, but] it's too hard to look for someone. I don't trust people. ...trust family, yes.

Ofania: My family does support me, they take [my son] wherever. And they're always looking after him, you know, when I can't or when I'm away.

Some families received offers of care from family or friends but did not utilise these. Salote stated: "we had friends and probably extended family that have always offered to help out with babysitting, but it's that mentality that you don't really want to inconvenience anybody and also the thought of, you know, you need somebody really special". Lanuola agreed:

I didn't want to overwhelm our family with everything. Cos we're learning as well and it's our job to do, you know, 95% of getting it right for us. I wanted to try to keep [the children]'s image as just a nice, you know, as children? And not, I don't know, yeah, as not like a burden for everyone, that they have to now, you know, relearn everything.

However, not all families had family members available or suitable to care for their children. Concerns of family members not understanding their autistic child/ren, not being able to adjust to the child/ren's behaviour and needs, and concerns of

aversive disciplinary strategies stopped some Pacific parents allowing family to care for their children. Some extended families lived overseas or far away in Aotearoa, like Salote's: "neither of us have family here, you know, any of our immediate family, like, extended family".

Pacific families in this study therefore often reconfigured their work hours or left the workforce entirely to care for their autistic child/ren. Parents implemented "tag-teaming" (Lanuola) of caring responsibilities so that one parent was always present with the child/ren while the other parent was working, running errands, attending to their wider family, having a break, and so on. This approach effectively met caring needs but also meant that parents were rarely together, and also meant that autism-related workshops and support groups, social, and other development opportunities were often missed due to care arrangements taking priority. These experiences of Pacific parents are agreeable with the wider autism literature on parental experiences of autism in terms of division of roles and caring, lack of other practical help available, and toll on parents and relationships (Bernier et al., 2010; Downes et al., 2021; Lilley et al., 2020; Searing et al., 2015). The effects of a lack of family support for some families is important for clinicians to understand due to the repercussions of parental burnout and exhaustion, and the potential related effects on spousal relationships (Downes et al., 2021).

Outside Family. Although family members were considered first-line for caring and support, for Pacific parents in this study, there were a number of relational resources external to the family which were also important for them. Included in parents' wider relational networks were support people such as Teacher Aides and babysitters, other Pacific parents of autistic children, and opportunities for service and volunteering within their communities.

When talking about the kinds of supports their family was using, Higano commented about their son's teacher aide, that: "the best resource in the world is the person for him... as a teacher I believe, you know, that's the one thing and so it works. You know it works, I've seen it work". This comment was within a context of Covid-19 lockdown restrictions in Aotearoa, where while Higano was a teacher himself, he found it difficult to provide the level of support his autistic son needed for online-learning while also managing the demands of his own class. Higano recognised the relationship that had formed between his son and the teacher aide was both trusting and effective for his son's learning. Higano alludes to the fact that without a relationship, such positive outcomes for autistic children are not possible. The prioritisation and valuing of relationships is supported by best-practice evidence for supporting neurodiverse children in their learning (Mirfin-Veitch et al., 2020).

Once Pacific parents had worked up to being able to accept external help, they often found that this was helpful for them. Salote commented:

Only recently, probably in the last two, three years, we've managed to get a babysitter who is a paid babysitter to come in a couple of times to look after the kids while we've gone out. At first we just went out to do shopping cos I was like 'Let's just go out for a few hours, we can't leave for too long'.

Not taking advantage of offers of help was something that Pacific parents in this study discussed both in relation to family and non-family offers. Within these discussions were both elements of feeling a burden (Lanuola), and of others not knowing how to care for autistic children so it would be easier to stay home (Akanesi, Salote, Ofania). This was despite the Pacific value of reciprocity and five of eight Pacific families within this study specifically discussing their provision of help to others and their volunteer involvement within their communities which was in concordance with Aotearoa Pacific disabled young peoples' volunteer activity (Tiatia-Seath et al., 2021). It is likely that accepting small offers of help will lead to positive outcomes for Pacific parents and their families, as well as solidifying community networks which are highly beneficial to neurodiverse families (Higgins et al., 2022). Therefore, clinicians might explore with Pacific parents their aversions to accepting help from others and potentially temper these on an experimental graduated scale while maintaining parental self-determination and dignity.

Meeting up with other parents of autistic children proved a powerful intervention for Pacific parents, and a valuable source of information regarding support and therapies available to families. Mareko opined: "just finding other families that, you know, we can relate to our situation, it's really good, especially cos they're Pasifika". Salote agreed:

I feel so happy and privileged when people are genuinely reaching out for conversations, you know, just to even have that conversation and to know that there are other parents out there, to know that there are other children like this out there, so it's really comforting.

Ofania commented how meeting others led to information on support services she was not being given by health professionals or support agencies:

I go to a lot of the parent support groups at the [inclusive] school cos they always have family support groups. And they always have different people coming in from different places, but it's not the people when they come do their speaking, it's speaking with the parents, 'Did you know that you can get

this sort of money if you do this?' 'Oh no, I didn't know that!', you know, all these things, I'm like, wow!

Vasa enjoyed finding common ground with other families, and sharing her experiences to help others:

Whenever I come across a family I'm like *knowing look*, like, 'I know, I know!' I know everything, like I know what you're going through! So you, you know, we reach out and do whatever we can because we've been through that and we're still going through it sometimes.

Clinicians should be cognisant of the benefits of Pacific parents of autistic children being able to meet together, with the most significant benefits being a felt sense of belonging, confidence-building, and a source of support information for parents (Crane et al., 2018; Downes et al., 2021). Further benefits besides an inviting, inclusive, and fun environment include being able to help others in their journey, and increasing relational networks for both the parents and the autistic children.

Unexpected Blessings. Parent participants discussed a range of unexpected benefits or blessings associated with raising a neurodiverse or autistic child. These included becoming a team, gaining expert knowledge in autism, experiencing life lessons and wins for the child and family, witnessing and influencing generational change, and realising resilience factors. Pacific parents spoke about becoming stronger spousal partners and forming a team that was invested in doing the best for their children. As Salote said: "it was important that we were on the same page and, you know, being a team about it because, like, again, it was all so new, it was all very scary and I was depending on Mikaele getting on board". As parents learnt more about their own child's strengths and weaknesses, they began to see these in others also (Tupou et al., 2021). Mareko commented on gaining autism expertise: "we started to know about [autism]... We could even see it before we even started knowing about it, that there was something happening with a family, with a kid".

All parent participants talked about their children as being blessings to them and others. Lanuola said: "they just, they do bring lots of joy, even though they're hard work, you know, we have these moments that are just really, really beautiful and just really nice". Ofania agreed, stating: "I say blessing cos he is a blessing, not just for myself and [my partner], but for my whole family". Pania and Mareko also discussed some of the blessings that they were grateful for:

Pania: What he has given, I mean, just that insight of 'Yeah man, we roll differently and that's so cool!'

Mareko: I think it's blessings. It's original and I think that's how we are actually. We don't like thinking like mainstream a lot. When he was born we were like, he's pretty much the expression of us.

Pania: Like, so lucky to be chosen to have him and go on this journey.

Researcher: OK, so like, originality, and advocacy, and being stronger?

Pania: Yes, definitely! ...and other awesome people and their journey.

Akanesi and Higano felt similarly wondrous about their two autistic boys:

Akanesi: We're really blessed to have them actually. They've taught us a lot. A lot.

Higano: It's quite amazing, ay. When your six-year-old is your greatest ever teacher, for me that's it, he's just, yeah. He doesn't even know it.

Katalina opined how her autistic son had given her the gift of non-judgment:

The biggest blessing that I've received from having him, amongst all the hardships, amongst all the hard times, amongst all of that, you know, the way we are completely non-judgemental, you know? Of anybody or anyone's children, or any, just anyone, you know? Anything. ...Just his whole being is a blessing, I find.

At times, the blessings conferred by autistic children had generational impact. To demonstrate, Pania shared a bittersweet and emotional time around their son's diagnosis where the relationship between her father and their son influenced his understanding of neurodiversity itself:

When [our son] was diagnosed and we told [Dad] and explained a bit about autism or the spectrum... he was really, like, tears straight away, he was really upset. Because he said aw, he apologised, he apologised, because, you know, he used to take all the grandkids around the block to walk the dog kind of thing but he would leave [our son], and he'd say 'Aw, he doesn't listen, he runs out on the road'. ...And so if I wasn't there he wouldn't take him. ...So he apologised for, because he thought he was just keeping him safe. ...But, I mean, it was heart-breaking for me because, aw you know, 'he's still your moko, you know, like, just find a way, you know'. But he apologised because he said, 'You know, I just thought he was like, he didn't listen or he was

naughty'. And he just realises now the people who he grew up with, there was people like that, and he goes 'We did the same thing, we just ignored them, we don't do that with them kind of thing'. He really thought that, 'I didn't realise that sometimes it's not behavioural, it is, there's something'. And so he apologised to me and it was so meaningful to me and I just thought, 'Good on you, Dad' because he learnt straight away and he has been like [our son]'s like, real champ, he's like, 'Moko, what's happening, what chu up to?' and he really, like, engages with him and he, like, wants to know. And also, he's so, so proud of him.

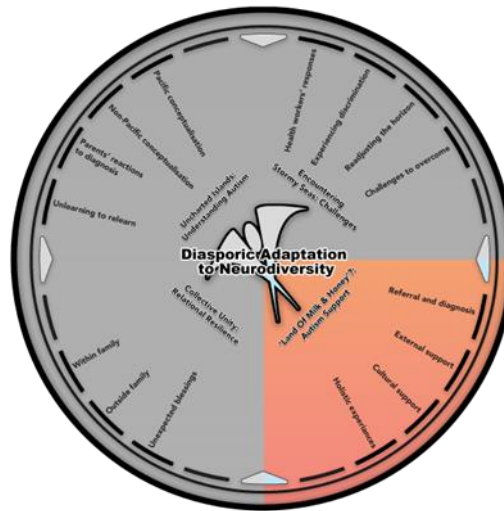
This story is reflective of how neurodiverse children can be incorrectly perceived and treated differently, due to a lack of understanding of their idiosyncratic behaviour. However, this story also demonstrates the power of information, awareness, and relationship in changing mindsets and restoring intergenerational familial bonds.

Pacific parents also discussed a number of resilience factors that enabled them to carry on through difficult phases of parenting a neurodiverse child. These included: taking time out/a break, drawing on their personal faith, a sense of self-efficacy/confidence/faith in oneself, undertaking education/personal development in relation to autism, viewing spousal partner as a model/source of strength, a feeling of having people on their side in public situations, experience in coming through very difficult situations and hard times, acts of regular self-care, being able to safely express emotion, and a motivation to raise well-rounded children. These are all factors which are regularly mentioned in the literature on parenting autistic children as being protective of adverse outcomes for parents (Crane et al., 2018; Higgins et al., 2022; Pearson et al., 2022).

Research Question 2: What Available Supports are Pacific Parents Raising Autistic Children Accessing or not Accessing, and What Supports do They Need That Aren't There?

Talanoa with Pacific parents in this study covered the supports that families were currently receiving both within and outside the family, and considered what support they might prefer but not currently available. The theme of '*Land of Milk and Honey*'? *Autism Support* was distilled from these talanoa.

Theme 4: ‘Land of Milk and Honey’? Autism Support



The phrase “land of milk and honey” is a biblical reference used to describe a land that is productive and affluent, overflowing with resources and scarce in enemies, leading to thriving inhabitants (Exodus 3:8). This phrase has been used many times to describe Aotearoa’s situation when migrants from the Pacific seek new opportunities for growth, success, and resources to support families back in the islands (Mila, 2017). However, the land of milk and honey more often evaporated like a mirage due to the realities of the socio-political-economic-spiritual climate which Pacific peoples entered into (Mila, 2017; Pulotu-Endemann & Faleafa, 2017). Consequently, Pacific peoples remain significantly disadvantaged in almost all socio-economic indicators compared with other groups in Aotearoa (Anae, 2010; Ioane & Tudor, 2017; Pulotu-Endemann & Faleafa, 2017). This analogy parallels with the autism support journey in Aotearoa, where unfortunately, significant disparity exists between what is technically ‘available’ and what is, in reality, accessible, for Pacific families (MoH, 2019). A stark reminder of the inequalities that exist include the fact that while 19% of Pacific peoples in Aotearoa have a disability (with over half of these having more than one disability), only 4.6% of eligible Pacific peoples are accessing Disability Support Funding (MoH, 2019; Stats NZ, 2014). Parents in this study discussed the difficulties in getting autism and support information from health professionals, delays in diagnosis, a lack of awareness of funding streams and how to access these, misinformation and gatekeeping by funding agencies, lengthy and invasive assessment processes for supports, and a lack of trusted carers available to care for their children.

Referral and Diagnosis. There was a wide variation in the age at which Pacific parents first noticed signs that something might be delayed or developing differently with their child. Pacific parents reported the first signs they noticed which spurred them to seek further advice and referral for developmental assessment through their GP/paediatrician:

Vasa: At eight or nine months, he wasn't responding to his name and there was no eye contact or anything like that. ...My older sister has two on the spectrum ...so when I had [our son], I sort of saw similarities. So I kind of picked it up fast and I got him diagnosed at two. Fifteen months later, [our daughter] came along and she was different but then I started seeing signs just a little bit later than I had with [our son]. But then I got her diagnosed at two as well.

Ofania: At his, probably his 18 month mark, you can tell, well I could, I could tell that there was something not quite right with [my son], you know, he wasn't hitting his milestones, like um, saying Mum or Dad, or you know, just saying anything really, and he'll just sit there and just line up his pegs and his cars, and he'd just line everything up and I was just sitting there going 'OK, this is new, I've never seen this'.

Lanuola: He was a little baby but he was strong and, you know, we had no concerns. He was sort of reaching milestones, but then around two, two and a half, the sort of language and some behaviour stuff had sort of started coming out there, he sort of regressed quite a lot, almost, not quite vacant but, you know, that sort of little spark had sort of gone. And so we got, he got diagnosed at around two and a half, or three... When [our daughter] was about one, just over one, we started noticing some things with her, she started having pica...because of Covid and things like that she wasn't seen by the paediatrician until she was almost three, and so she's only just been diagnosed now.

However, like many first-time parents, some Pacific parents in the study did not notice any early developmentally significant signs due to no guidance and little basis for comparison.

Salote: We just thought that he's just a one-year-old lining up cars, lining up cans, lining up everything and I never stopped to think that lining up meant anything else other than just playing.

Heirava: I just thought he's normal and that's how he is, cos he's my first baby, so I, it's hard for me to see what's the difference, you know? But now I can tell cos I've got my other children.

Within a system which already maintains long waiting-lists for assessment, and where ethnic disparities in both referral and delayed assessment exist, significant delays in diagnosis are likely for parents who have no concerns about their child's

development. Rather than simply eliciting parental concerns about their child's development, it may be more helpful for parents to be given an indication of expected milestones for chronological age and elicit the child's progression against these at routine WCTO/Plunket visits. Using a standardised benchmark such as the CDC's paediatric developmental milestones (Zubler et al., 2022), it is likely that any children significantly below the norm would be flagged for further monitoring and/or assessment early, rather than waiting until significant language and/or social behavioural impairment is recognised.

Many Pacific families were unsatisfied with the diagnosis process they experienced. Families perceived little empathy towards them in receiving their child's diagnosis, they felt rushed, that their concerns were not heard, that the clinic conditions were not right for a valid assessment of their child (including strengths as well as perceived weaknesses), and families were disappointed at the lack of information given to them. Pacific parents in this study shared their experiences:

Ofania: And so we just went in and they were going 'Oh yep', after probably 20 minutes, half an hour of observing him 'Oh yeah, so he's autistic'. Yeah, and that's what they said. We're like 'Oh, K, what does that mean, is it curable?' You know, we know nothing. We've never been exposed or, nothing really. So when we did look it up, it's just a massive, massive, it was just heaps of things to read.

Katalina: I was pissed because he said something like 'He's never gonna, you know, he's never gonna be a Dr or a lawyer, he's never gonna go to College or go to Uni. So just go home and have a drink of wine, have a glass of wine', and, you know? Just ugh, that kind of attitude. ...Like, who does that? Are you crazy? Yeah, I think it most definitely could have been a bit more tactful. The way they speak to families, it's just nuts.

Akanesi: I think the way it was presented wasn't really, I dunno, didn't feel like it was, there was empathy towards it.

Katalina and Mateo were concerned about the conditions during the assessment and the delivery of the diagnosis.

Katalina stated:

In my head I was thinking, how can you, like, give this diagnosis in this short time when all my son done was cry, like, you know? I don't know how they are able to diagnose a child in that timeframe, in those conditions, like how is that possible? That's someone's, that's, like that kid could've been having a bad day, like, someone's neurotypical, normal child could have been just having a shit day as well, you know, had a bad sleep the night before and you've just given him this diagnosis when really, I dunno, I dunno, I'm not a Dr. But I don't get it, I just don't get it.

Mateo: I don't know if it was just him being [non-Pacific], just not really fully understanding how to deliver it to an Island family like that. Yeah, it was just pretty blunt.

Katalina: It was horrible, it was a horrible experience. It was, I don't know another word.

Katalina and Mateo's experience concurs with UK parents who were unsatisfied with the clinical conditions of their child's assessment, including the unfamiliar setting and clinical manner of the professionals disallowing assessment of the child as a whole person including their strengths (Boshoff et al., 2019; Carlsson et al., 2016).

Many Pacific parents spoke of not receiving adequate information at diagnosis about autism itself, the current knowledge on autism etiology, and next steps for support:

Katalina: They send you off with nothing, like you literally get nothing, you gotta bloody, your head's just above water, you know, you're only just keeping your head above water as it is, and then you've gotta kind of swim around and find your own way.

Akanesi: You know, when they just tell us right there and then, you just, you know, you pretty much have to do everything on your own. It's weird, and you wonder how many people are going through it now.

Higano: You shouldn't have to go looking. If you're in the system, they should come to you.

Vasa: Right in the beginning when they were much younger, it just was really, really difficult, and I didn't know where to go for help. I'll admit that even today I still don't know where.

Conversely, overwhelm was the flipside of receiving a wad of paper resources with no context or further explanation:

Akanesi: I remember [the pediatrician] giving us pamphlets, websites, pretty much told us to go away and read about this, look into this, pretty much do your own research. Go to groups, look online, Facebook.

Higano: That piece of paper with all the lists sat on the fridge for ages.

Akanesi: For ages.

Higano: It wasn't helpful, to go and push yourself to do something.

Akanesi: Yeah, you're right, it wasn't helpful because a lot of them don't really cater for our needs.

Heirava: it was too much. For me I want someone to just talk, for me I don't, leaving the papers.

The doctor tried to explain what autistic is, but the first time I didn't understand what it is, and why, and why it happened, but now I understand.

Finally, despite their own, difficult experiences, some Pacific parents were mindful of how the long, arduous process to get past GPs, gain a referral, interact with specialists, and so on would be for non-confident parents or those with English as a second language:

Salote: With our journey it's made me think about how hard and how sad it is, it must be, for families who are pretty much, you know, bumped off at the very initial stages of this process. You know, like, I thought about, oh my gosh if this is how long it took me, and all these phone calls, and having to speak English, I wonder what it must be like for those poor families, Pasifika, Māori or whatever, that can't speak fluently and confidently about what's happening.

Drawn together, elements which make an assessment easier on parents include the following: clinician creates genuine rapport with family, a family-centred, strengths-based assessment of the child as a whole person, culture and faith are assessed, evidence-based child developmental and autism assessment tools are used, empathic delivery of any diagnosis, sufficient but not unwieldy information on autism and next steps for support is given (ideally local and ethnic-specific support), information on disability support funding is given, support people and where needed interpreters are encouraged and accommodated, and the clinic environment is considered with neurodiverse children in mind (Boshoff et al., 2019; Broadstock, 2018; Crane et al., 2018; Le Va, 2014; O'Keefe et al., 2022; Pearson et al., 2022).

External Support. An autism diagnosis was perceived as the gateway to external supports and funding for autistic children in Aotearoa. Following receiving a diagnosis for their child, Pacific parents were able to access a myriad of supports. Salote stated: “finally when we got the referral, saw the paediatrician, got the diagnosis, then we were able to go from there to find supports like speech language therapists”. Heirava agreed: “if you do it early, you will get the help, if you leave it for long, the more you get onto it the more you will get help and relax”, and Higano felt similarly:

Some people look at it as a label but it's a diagnosis, and it's a diagnosis to help you. You know, it's quite confronting, but the sooner you know about it, maybe this is me, but you gotta go and do something about it.

However, navigating the existing support system was significantly difficult due to its fragmentation and perceived gate-keeping by funding distributors such as Needs Assessment and Service Coordinators, which often led to disempowerment and struggle for Pacific families.

Pania: I coincidentally met a parent who said her child does one-on-one swimming lessons and I really love swimming. And I said ‘Wow, is that expensive?’ She said ‘No, I use my Taikura days’ and I was like what are “Taikura days”? ‘Oh, you know, the funding you get, Carer Support’ and I was like ‘No, what is that?’ Why don’t I know this, why isn’t there a thing saying you’re entitled to all of this? Like how do we, are we supposed to get this at diagnosis, or?

What Pania discussed was unfortunately very clear within this study also, as almost all families were unaware of some or all major funding streams available to their child through Disability Support Services and the Ministry of Social Development (Individualised Funding, Carer Support, Child Disability Allowance/Disability Allowance, Community Services Card). Most families within this study were receiving Carer Support, and some children were receiving Ongoing Resourcing Scheme funding for learning support at school, but most were not. No families were receiving Individualised Funding (IF) at the time of talanoa. Some families who knew about Individualised Funding had been given misinformation that their child was ineligible due to age and/or diagnosis, and others had found the application/assessment process insurmountable amongst the daily realities of caring for their autistic children. Pacific parents shared their experiences of support funding:

Salote: I find that a lot of these agencies and organisations when they do assessments, are very stingy in the sense that they think I’m asking for the money to be given to me?

Lanuola: I'm like grateful for Carer Support but I didn't know that we could get [both Carer Support and IF]. Because I know my friend, she's got IF and she's able to have someone come in, you know, a lot, and I'd love to be able to do that.

Vasa: OK I've got no idea that [IF] even existed and I'm so annoyed. I've asked Taikura, is there anything else or anywhere else I can go to? The answer was no, there's not much else that the kids can, that they can offer the kids, or anyone else can offer the kids.

Katalina: I had heard about it, I just didn't understand it, and I thought it was one or the other [Carer Support or IF]. ...and what I had heard about it, I thought it was too much hassle, so I didn't go that way, kind of thing, you know?

Pania: For a lot of families it hasn't changed, they're still getting the diagnosis not knowing where to go next, or they're getting more help from family than actual resources that are supposed to be set up to help them, or keeping it in-house, because they don't know where else to go.

The gatekeeping and assessment hoops that parents needed to go through meant that many Pacific parents were not accessing what they were eligible for.

In addition to receiving some disability support funding, Pacific parents in this study had engaged with a range of therapies, interventions, and support people or organisations, including the following in Table 2 below:

Table 2

Table of Therapies, Interventions, and Supports Accessed by Pacific Parents of Autistic Children in this Study

Acorn Autism (private, ABA-based provider)
ASD Plus Programme
Chiropractor (private)
Early Intervention Support Teacher
Educational Psychologist
Explore Behavioural Services

Hanen 'More than Words' Programme

Integrative Pediatrician (private)

Makaton Sign Language

Music Therapy (private)

Occupational Therapy

Picture Exchange Communication System (PECS)

Rapid Prompting Method (private)

Speech and Language Therapist (private, individual therapy with child)

Speech and Language Therapist (publicly funded, SLT works with parents)

Stepping Stones 'Triple P' Parenting Course

Note: Interventions were publicly funded unless noted otherwise.

This is considered to be a short list, and is considerably shorter than the 21 early interventions that are available and which parents of autistic children in Aotearoa would like for their children (Kasilingam et al., 2021). In addition, six of the above interventions were only available privately, creating a divide in who can access appropriate intervention in Aotearoa, and suggesting those with extra resources may achieve better child outcomes through increased intervention (Wallace-Watkin et al., 2021).

It was often difficult for Pacific families to think of what currently unavailable supports they would like to have, because they were not aware of what was feasible. Consequently, the most common supports Pacific parents desired were trusted carers for their children, the ability to pay family for the care they already provided, and help with household chores and maintenance (including cooking for some, while others found cooking therapeutic). Undoubtedly there were other practical and non-essential supports that would have supported Pacific parents and improved child outcomes, yet even when asked to imagine no financial or other barriers to the supports, Pacific parents chose the above three forms of assistance. This is likely reflective of how these simple essentials would be life-changing for Pacific families raising autistic children in Aotearoa. Lanuola explained what would make a difference in their family: "I guess having more access to trusted people to do that sort of [caring] role. Like, it's more someone that could be a buddy to them and take them out and do stuff and give us a break". Katalina also shared her miracle supports: "I mean, other than Individualised Funding, that

would make a huge difference for us for our son, pressure off our shoulders... I was always thinking cleaner? But now I'm like, no, chef, for sure". It is concerning that disability supports which fit the assistance these parents described are currently provided by Te Whatu Ora, Whaikaha, and Disability Support Services, but parents were not furnished with this information or how to navigate the relevant assessment processes. Clinicians therefore have an opportunity to assist parents to navigate the system, and where relevant and appropriate, to assist families to find an advocate or to take on an advocacy role for the family.

Cultural Support. Discussions with Pacific parents also touched on the felt importance of cultural support to parents, and its value in their journey through the health and disability systems with their autistic child/ren. Cultural support was defined during talanoa as either Pacific-run health services and organisations, and/or having health professionals who understood Pacific peoples and worked with families according to Pacific values, whether or not they were of Pacific descent. There was variation in parental views on the importance of cultural support, concurrent with the autism literature (Boshoff et al., 2019; Lilley et al., 2020; Tupou et al., 2021). While some parents felt that appropriate cultural support would have made a world of difference to their child's diagnostic and early intervention experience, others felt that cultural needs were secondary to the need to be diagnosed and receive support. Some parents would have preferred culturally appropriate care, like Heirava: "I don't mind, but yeah, I'd prefer a Pacific to see some more understanding, our, you know, as a Pasifika". Ofania felt similarly: "mmm, culturally appropriate? It'll be lovely, it is, it would be lovely to have a bit more than what there is now cos the only PI thing is the PASG".

Some parents thought that autism was a great leveller, and that culturally appropriate care would have been nice, but might become more important as the children grow:

Akanesi: Culture is not really relevant? At this stage.

Higano: Yeah, at this stage.

Akanesi: It goes out the door because the kids are pretty much on the same level because we understand [what it is like to have an autistic child], so we're in the same [boat]. I dunno, I could have a millionaire walk in here with a kid on the autism spectrum and then all of a sudden we're the same. So for me, it's not so much the culture.

Higano: Not yet. I think it will be further down the track. I see that, but yeah, you know, I mean it would've been, any time you have a Pacific Island person as a Dr, yeah, you know, three cheers!

Akanesi: Yeah.

Higano: That's awesome. That would've been pretty cool, the ways in which it could've [been] approached and...but you know, it wasn't the sort of the thing that we looked at, you know, 'Oh, we'd like to have a Pacific Island Dr'.

Lanuola agreed: "we're quite European in our ways, even though we love our culture, we want to keep that in our family, but it wasn't a huge [thing] for us, to have that for the diagnosis". Pania experienced culturally appropriate care in Aotearoa was in short supply and high demand, "I was signed up to have a Māori person and they came over once and then I never even heard from them again, so I don't know what that kind of thing was, but, you know, there was nothing else".

Other parents perceived cultural sensitivity made all the difference to their receipt of an autism diagnosis for their child:

Salote: It was very important for me. Like I said, with the links to, well, because my family is quite close so it's like family and culture, yeah. So it was very important to me because I guess the approach, and I think if you're sort of culturally sensitive and you know how to get a point across because of the way people are raised culturally as well. The way we received that information from that paediatrician that talked to us about [our son], you know, made a whole lot, made a huge difference in helping us to come to terms with it and then think positively about where to go to next. Rather than accept it, 'Oh my gosh, it's the end of the world', and then just sort of spiral downward.

Finally, some parents eschewed Pacific health providers for fear of judgment in not being the stereotypical 'good' Pacific Islander:

Akanesi: I'd feel more comfortable if it was just, if they're not [Pacific] cos you don't get that judgement.

Higano: ...drawn into the things of how [people] should be as a Pacific Islander.

Akanesi: Yeah.

Higano: There's a perception that you must be like this, if you had elders, you must be like this. Whereas your average or typical clinic and everything, [they're] like, 'OK, stick to the facts', you know, this is what they're here for.

From talanoa discussions, it appeared that parents were more likely to devalue or avoid Pacific health providers and culturally appropriate care if they did not feel strong in their Pacific language or cultural knowledge, or had concerns about confidentiality, or both. For parents in this study, these feelings arose from perceived loss of proficiency in their Pacific culture and language over time, or "not being brought up" strongly in their Pacific language and/or culture, and were likely reflective of internalised shame. There was also a belief that it was unlikely that culturally appropriate care was available, so parents navigating the health system expected and some even valued routine, culture-blind care due to its predictability.

This section demonstrates the range of nuanced beliefs and attitudes related to culturally appropriate care in just one small sample of Pacific parents in Aotearoa. As discussed earlier, it is important to remember that Pacific peoples are a vastly heterogeneous group subsuming significant diversity, including diverse opinions. Therefore, it is imperative to include within assessment the cultural background and experiences of Pacific families, as well as canvassing parental preferences in relation to culturally appropriate care, and the importance of culture and language to them in raising their children. This is to avoid a 'one-size-fits-all' approach, which is a misnomer that rarely fits anyone in reality (Kapeli et al., 2020).

Pasifika Autism Support Group. The Pasifika Autism Support Group (PASG)³⁰, although born out of a desire to journey with others experiencing the same, is typical of the innovation of Pacific peoples when little external resources are forthcoming. PASG was founded by Pacific parents supporting their autistic son and is meeting a need in the community that is not met elsewhere. PASG is now regularly being sought out for advice on reaching Pacific families, and for public comment (Trezona, 2018). PASG currently has 60 families on the active member database in Auckland and a further 20 families in Wellington, with a third chapter set to be established in Christchurch in 2023. The Facebook page currently has over 2,000 members. The Founders' goal is to make PASG available to Pacific families raising autistic children across Aotearoa. Some of the reasons that parents find the network so helpful include:

³⁰ This Tagata Pasifika clip beautifully captures the PASG ethos, and the journey of Pacific parents raising autistic children in Aotearoa. View here: https://www.youtube.com/watch?v=bp9SQow7zhc&ab_channel=TagataPasifika

Ofania: I attended some of those groups that they have for the, that the Autism NZ was doing and you know just trying to find all the information and stuff like that. But yeah, that was, there was just nothing, especially for PIs. Cos I'm into the PI thing and just trying to, yeah, there was just nothing. ...When I heard about the PASG I was like 'OMG we're not alone!' And that's why from then on I said 'OK, if I'm learning and I'm finding it hard, I'm gonna bring my family in', because we can all learn together.

Salote: I mean speaking of supports and reaching out and comfortable people, joining PASG has been really great for us, ay. We're so happy that you know that we joined and wish we'd joined earlier but, you know, still, it's been so good to just, to congregate and to meet, and to connect with other Pasifika parents.

Furthermore, PASG is a place where parents can feel comfortable that their child/ren's behaviour is not going to cause offense, as Mareko explained: "at PASG it's different, kids are encouraged to be themselves and so whatever the noise level is, is what it is". Pania agreed: "I think that's one thing that PASG does well because it's casual like that. And you can opt in or not". Lanuola agreed that this is a key drawcard of PASG: "I guess we were drawn to the PASG group, cos you know, it's really familiar and kind, approachable". This concurs with prior research where parents enjoyed support groups they could attend without judgment (Lutz et al., 2012). PASG was also a rare place where fathers felt comfortable to go, even if they did not engage in other groups. Salote opined:

I think it was also really good for us as a family, and for Mikaele, because while I can sort of network and reach out to lots of other mums and parents and stuff but he wasn't one to do the same and I think since we connected with PASG it's sort of given him the opportunity to connect with other Dads. It doesn't seem like the Dads really reach out as much as the mums kind of thing with that whole networking with other parents of autistic children. Yeah, I was really happy to see that he liked it and that he was really stoked to talk to other Dads. I was like yay!

Mikaele himself stated that he enjoyed PASG for the: "parents coming together, just supporting each other, sharing stories". Similarly, Mareko found that: "it's just great to be there and just give support to other families and really just talking about our stories and network and try and help each other, it's really good being part of PASG".

However, there was a feeling that there were many more families that could be benefiting from PASG, as Lagi commented: “sometimes the island people are shy to take their kids to groups like that. One lady, I say ‘Don’t get shy, just come, bring your kids, there’s nothing wrong’”. Ofania also encouraged others to attend to benefit from the support network and shared information: “I hear people saying ‘Aw my cousin’s kid, and this and this’, and I’m like ‘OK then, then you should come to these groups!’ ‘You should join in because honestly it’s really good, informative’”. As discussed, support groups such as PASG are important places where parents can find social support, information, relational networks, and where neurodiverse children can be themselves. Parent support groups post-autism diagnosis have been found to be associated with higher self-efficacy in coping and increased advocacy skills for regular attendees (Banach et al., 2010). There is good evidence that support groups can be helpful for parents with follow-on benefits for autistic children (Crane et al., 2018; Lutz et al., 2012; Pearson et al., 2022). However, barriers to attending support groups included low uptake by ethnic minorities due to a lack of awareness of groups, felt stigma for needing such a group, feeling unwelcome, and groups not meeting the needs of families (Crane et al., 2018; Pearson et al., 2022). Therefore clinicians should offer information to parents on support groups relevant and accessible to them, and benefits of attendance to assist with their decision-making.

Holistic Experiences. To demonstrate the breadth of experiences which Pacific parents in this study discussed during talanoa, example quotations are provided in Table 3 below which touch on a range of topics and the parent participants’ perceptions of them in relation to raising autistic children in Aotearoa.

Table 3

Holistic Experiences: Family and Personal Life Domains where Pacific Parents Experienced Adaptation Following their Child/ren’s Autism Diagnosis

Life Domain	Pacific Parent Quote
Advocacy	Katalina “not being mā or, you know, shame to let people know, like, he’s human. If you’re gonna speak, like, address <i>him</i> , you can address him, ask him”

	<p>Pania “we have been empowered to talk to professionals or people we would usually just, whatever, but like no, we’ve armed ourselves with ‘No we are worthy’. ‘OK that’s not appropriate’, and also just advocating for them”</p>
<p>Autism Awareness</p>	<p>Mareko “I grew up in the ‘80s and even then the knowledge was really, really you know, the awareness was low. But now it’s way better, but just in terms of we didn’t know at all, our parents didn’t know, and, you know, if we talked to someone in the ‘80s about that like a clinician or someone, a Dr, probably, and we’d believe them, they’d probably just tell us they just need to go to a psychiatric ward or something like that and unfortunately that’s what’s happened to people in the past”</p> <p>Salote “she’s working really hard in Samoa to try and get more initiatives and awareness around autism and I was like ‘Oh man that is so ballsy and brave of you for doing that man’, because, I mean, as you know and as we know, it’s still very much a frowned-upon topic you know these needs, high needs conditions”</p>
<p>Becoming an Autism Expert</p>	<p>Heirava “for me, when I look at them, it’s finding hard, cos their children can’t sit still, they on the wall. And yeah I think, you can tell, but I don’t know. I can tell kids that have got autistic cos I’ve got one. I can see the signs”</p> <p>Mateo “you don’t wanna sort of offend cos you know how not all people like to hear that, especially, you know, islanders”</p> <p>Salote “I see signs but she’s in what I believe, and this is my judgement, but in a state of denial”</p>
<p>Caregivers</p>	<p>Salote “you couldn’t just readily give them to people even that were so willing to look after him because of that communication barrier as well you know and if I did, I’d have these fears of like ‘Oh what if they’re asking him and he doesn’t understand and he doesn’t respond and then they panic, and I panic’. At the end of the day, it’s just, like, just don’t worry about it we just won’t get anybody”</p>

	Vasa: "When I think of Pacific care, I just would love them to be surrounded by the culture through language and dance"
Communication	Salote "there were times when, you know, some family members would be like 'Oh just leave him to answer, you know, just let him answer' and I'm like 'Well, he can't! That's why I'm answering for him'"
Eating	Salote "he's very picky with particular things, and it's something about certain smells, that sort of thing. But it's like, the moment the poor kid doesn't want to drink or eat something it's like, 'Oh, he's so not [Pacific identity]!"
Emotions	Higano "at the end of the day, you're gonna feel, you know, how you react to things is actually what you can control. You know, there's some worse things in the world" Pania "we got that diagnosis and then they said, you know, 'It's a lifetime thing' and I was, like, 'Hold up, what? What? And how did this...?' You know, it was like in the movies *wailing crying face*. And then, yeah, I walked out of there, two kids, and a piece of paper about something"
Exposing the Child to Experiences	Mikaele "I think at the time with those fears it was like I was, it was stopping me from kind of giving him the chance to put him in a situation and taking away the chance for me to intervene and try and find out along the way. It was stopping all of that by hiding along the way. So the more exposure out there for him, and for me to be able to like 'How as a parent am I gonna deal with this situation?', it actually was just better to just chuck them in the deep end, deal with it in public, deal with the judgements, deal with all the shit that's happening right there, for both of us to learn. And I found that we were just so good at just managing that, going out in public, and I only became more brave"
Faith	Akanesi "all I can just put [my strength/resilience] towards is just my faith, and that's it. No magic words, nothing else, it's just exactly it"
Fear	Salote "as soon as I walked out I just, like, burst into tears because I think it had only just hit me then, that it had just confirmed all of my fears and it was a very fearful time too, because, you know, it was so new, I didn't, I had never heard of the condition. I didn't know anybody who had any

	<p>children, it was not something that was common in [Pacific] culture or anything like that, so a lot of it was very, very new and it was a scary time”</p> <p>Mikaele “I didn’t want to accept it cos I had a lot of fears and worries about how my son would struggle, worries about how people would judge him, worries about bullying, all that stuff. Worries about being behind in school and behind in a lot of things. So because of that fear, I was just, just in denial, I’m not gonna accept this”</p>
Financial	Lanuola “financial stability - that’s become a big thing for us so that we can get them in a good place when we’re gone. That’s a big one”
Grateful	Higano “cos you get to learn about a whole new world, you get to be invited into that world, get to be a part of it, and immerse yourself in it and you actually learn a whole lot more about people”
Guilt	<p>Salote “the hardest thing for me was because we didn’t know anything about autism at the time and I still carry the guilt of not noticing earlier, and not intervening earlier with regards to [our son]. And as I started to notice more about the way he was and particularly around his language and I had finished my teaching, there was a time where I felt so shit because here I was going to school and teaching and nurturing everyone else’s child and I felt that I hadn’t paid enough attention to my own child”</p> <p>Heirava “cos my family didn’t have an autistic, we didn’t have anyone in my family who’s autistic and yeah that’s why, I feel like, I don’t do the right thing”</p>
Judgement from Family	Salote “the family pressure is what kills me all the time, but I’ve really had to learn to rise above it and just protect my child before I try to please everybody else. You’re just kind of sitting there, you know, feeling like a useless mother because of these things that your child doesn’t meet according to what everyone’s expectations are, you know, sort of thing. So yeah, a lot of learning on how to deal with that, and for me as well, it was only when I got the support of other parents and friends with autistic children that helped me to learn and have strategies on dealing with pressure, family pressure”

	<p>Lanuola “Family relationships – yeah. It’s really sort of shown us who the really key people are that have that time and energy for us now”</p>
Isolation	<p>Heirava “Like, going out to my friends’, now I have to, like, limit going there and go without them. Cos I know if I go there with [my son] they’re not, like, comfortable with him, like, playing around their house and, you know, I don’t want him to do that”</p> <p>Mikaele “I remember being in that situation where it’s, like, the shame of ‘What if my boy plays up here, and there, and there’?”</p> <p>Salote “it’s really the fear of other people’s judgements”</p>
Lockdown	<p>Lanuola “just in the last with Covid and stuff, his coping has been a bit harder. As you can see, sometimes he’ll have these little outbursts which, you know, I find a bit concerning. Because he’s not been able to cope very well, and they can be a little bit destructive which, you know, they didn’t used to”</p> <p>Vasa “the first lockdown really slowed everything down. That gave us time to be with the kids”</p>
Managing the Family	<p>Lanuola “For me, I just want them just to have even short time with them. And they can do whatever they like with them, as long as there’s still some connections”</p> <p>Ofania “it’s just, trying to, getting your head around that there’s somebody different, there’s someone different in amongst your family group that’s, that you basically have to teach everyone around you just to be aware. That, you know, this is him, can we, you know, he’s as normal as you can be, the only thing difference is that he just can’t talk. Talk to him normally, you know”</p>
Mental Distress	<p>Vasa “back when they were younger, on the go, all the time, meltdowns constantly and just, I don’t know, I’d break down. You know, I’d break down, a lot of break downs for me as well”</p>

	Katalina “when I did leave [work], that was kind of necessary, I was so stressed to the point where I was, like, physically ill”
Moving	Akanesi “we were thinking of going to Australia, just for support for the kids, especially my kids. Cos we’ve got, not a lot, we don’t have a big family here, all my family’s there”
Parenting Strategies	<p>Salote: “[apologies], that’s something that we didn’t get growing up, our parents made no mistakes you know, what you’re told is what you do and they can do no wrong”</p> <p>Vasa “we still, even today, don’t know what we’re doing half the time, d’you know, we’re so, sometimes there are days, there are good days and bad days. And all we know is just to take it one day at a time, and we’ve been doing that for 13 years now”</p> <p>Lanuola “I guess learning that having that calmness about me will come out in them more”</p>
Parenting as a Team	<p>Mikaele “we will work, I guess, as best as we can from here to bring out the best in our boy, and I just really started, you know, I guess coming to terms with it but also just being on the same page with [my partner] as well”</p> <p>Lanuola “we’re a good team and we know that”</p> <p>Higano “that’s me appreciating that I need to be there all the time, or as much as possible, a lot more than I was, you know”</p>
Physical Health	Katalina “his body needs it, his mind needs it, you know, we all know how much better we feel when we’ve done something physical”
Resilience	<p>Higano “I’d say my job [as a teacher], my wife, the education that I do for myself to get better at it and the opportunity to practise it, that’s what helps build my resilience”</p> <p>Ofania “my sisters will ring up and say ‘Oh c’mon sister we’re coming to pick you up!’ We’ll go and have a suli, we’ll go and have a lunch by ourselves, we won’t tell the kids.</p>

	<p>And that I love to do, and it just puts your life into perspective, that yes, it's good that you're doing all this for your children and you're doing all this for them to learn, but you just need to have a bit of time, aaahhhh, or else you'll just go crazy!"</p>
Routine	<p>Salote "for him it was it was giving him room to understand situations, because what we learned very early on was that he thrives on routines. When he was little a routine was what worked best for him and that was his safe place, was learning what the routine is. And so he still has a lot of those traits now where he needs the routine"</p>
Safety	<p>Akanesi "Unfortunately we're not there all the time you know, we don't really see what goes round in the back, school and stuff"</p> <p>Vasa "seriously, the biggest thing that I just wish and hope for is just for nice people, like, I just don't want to be scared of my kids not being safe. I just wanna go out and do normal things and have them just be happy and safe. That's my biggest wish"</p>
Sharing Diagnosis with non-Family	<p>Salote "I always want to be in a safe space to be able to share that information safely and confidently because, like, it's like I said, you know, you're always gonna have people like 'Oh, so why weren't you preaching about this before?' Or, when you don't preach about it, it's like 'Oh, why are you hiding it, are you embarrassed?' You know, it's like you can't really win. So now it's just, like, I'm happy where we are where we can, like you said, share when there's a need for it, when you can see that people are willing to listen and understand"</p>
Siblings	<p>Salote "even now, I would say [our son's sibling]'s the person that he's most confident and feels the most safe [around]"</p> <p>Mikaele "without being judged, yeah, he feels so, like, sort of accepted by her"</p> <p>Salote "and he can just talk, and talk, and talk and I can see how, if I put myself in his shoes, just that safety net around them when it's just them two, like, 'I can just say whatever I want, even if it doesn't make sense, she'll always accept me for the way I am'. There's no rules around language or around what's said, you know, right or wrong"</p>

	<p>Mareko: “they’ve put up with a lot. You know, you’ve gotta let them have their respite or let them be away from him, so when they want to do that you just let them do it because, yeah, they put up with a lot”</p>
<p>Social Relationships</p>	<p>Akanesi “one of the biggest changes for me, since having a child with autism is because I’m quite sociable. I enjoy having friends over and vice versa and you know, you always dreamed of having our kids and their kids, and so for me, I can’t really do that all the time with my kids, that’s something different for me”</p> <p>Vasa “friends, friends? I don’t have any friends!”</p>
<p>Sports</p>	<p>Ofania “we’ve always done a lot of sports in our family. I can’t do that because of, we’ve got [my son], and I can’t go to sports because then I’ll have to take my baby with me”</p> <p>Pania “I was like, when is it not quitting but just deciding ‘Aw this just doesn’t work for him?’”</p>
<p>Spousal Relationship</p>	<p>Lanuola “I think we try to have quality time and try and make time for little holidays and getaways to actually experience fun. And that works on our marriage and helps to keep us strong”</p>
<p>Stay at Home Parenting</p>	<p>Akanesi “I tried working with [oldest autistic son], the first one. It got really hard and then I decided to, no, I’m just gonna be at home now with the kids. But we survive, you know, and I haven’t looked back since. I mean I was gonna go to work with the kids but not when you’ve got two kids on the spectrum, it’s too hard”</p>
<p>Technology</p>	<p>Mareko “That’s what I don’t like about technology now, is that everyone is accessible, can access it. And then there’s no filter on it until laws come out, and again, it’s the parents need to watch that. But kids can hack into stuff real easy. You know, the quick turnaround of sharing a post with, like, a link can get passed behind the parents’ back on something like a cell phone, or on the Messenger on Facebook, or something, where the parents can’t see that”</p> <p>Pania “..in the same vein, technology is what is making autism awareness spread faster than it would have in the ‘80s. Yeah, access information, support groups. You know, in the middle of the night, ‘Ooh I’m having trouble with whatever’, there’s always someone online“</p>

Telling the Family	Mareko “yeah my family were quite open about it. My Dad’s like ‘Oh OK’. Once they know they know and so they’re like, ‘Oh well he’s still the same kid, we still love him’, so yeah”
Understanding the Child	<p>Salote “it’s constantly getting into his mind and seeing how he thinks so that we can get whatever message across to him, effectively, you know”</p> <p>Vasa “the important thing for us is just learning about the kids, cos they’ve grown so much now. Just learning about them individually and what their qualities, what their likes, what their dislikes are and what their, not so much, not too many triggers now, but there are some new triggers that come up”</p>
Work	<p>Salote “when I saw the word ‘work’, it reminded me of what I thought about the other day which is I guess tied into faith and spiritual too. I never really planned to be a teacher, a primary school teacher, and when I look back, the timing of when I studied, became a teacher, [our son]’s diagnosis and all these things that happened when they happened and even more so now, being a teacher now and I feel like [our son] has been like the, probably the best student to have shaped my teaching practice”</p> <p>Lanuola “so yeah, work, I’ve had to change my work. So I only work part-time now on Friday, Saturday night shift so I can be available for the kids during the week”</p> <p>Vasa “in the first eight years with these two, it was really hard because Malama was going through uni, I was a stay-at-home mum. Once he graduated, he went into the workforce then I went to uni and so we did this whole switch thing”</p>
Worry	<p>Akanesi “How are they gonna cope in reality when we’re away, when we’re gone, you know, it’s something that worries me all the time. Constantly”</p> <p>Higano “If they were left to their own devices and themselves ay, they would be fine. It’s the way like you said, it’s the way others treat them which is the biggest worry”</p>

These quotations aptly demonstrate the wide range of emotions that parents feel across the daily realities of adapting their and their family's lives to raising neurodiverse children. The old adage 'children don't come with a manual' has never been truer than for a neurodiverse child. However, following a short period of adjustment of expectations and parents' idealistic views of parenting, Pacific parents generally adapted successfully and began to appreciate and even value the challenge of unlearning to relearn.

Research Question 3: How is Pacific Language and Culture Maintained within Pacific Families Raising Autistic Children in Aotearoa?

Parents' decisions regarding their children learning to speak English only, or both English and their Pacific language/s, are influenced by the parents' experiences of language learning in childhood (MoH/MoE, 2016; Paterson et al., 2018; Pulotu-Endemann & Faleafa, 2017; Te Pou, 2010). In Aotearoa, the Education Ordinance policy from 1847 until the early 1970s prohibited speaking languages other than English, resulting in harsh physical punishment for offenders (Higgins & Keane, 2015). Through instilling fear, and the associated devaluation of Indigenous languages, the Ordinance achieved its intended purpose of privileging English within the school environment, and the loss of Indigenous te reo Māori speakers (Smith, 2021). Although the Education Ordinance mostly affected Māori, Pacific peoples were also affected, as Katalina explained: "my mum went to school when if you spoke in your native tongue you were strapped". Similarly with Māori parents who directly experienced punishment and shame for speaking their Indigenous language, many Pacific parents of this era also chose not to share their heritage language with their children to prevent the trauma and shame that they experienced as children (Smith, 2021). The children of the parents who experienced these policies until the early-1970s are now the parents within the current study, and so the effects of language loss are evident in the current generation who are attempting to learn their heritage languages as second-language learners and championing language bilingualism for their children. As Katalina lamented:

It would be nice to know the language too, and be able to instil that in the children. I just hope that one day that that's something that they do pursue. Two courses later I still don't know anything! Hardly anything anyway.

Furthermore, the first generations of Pacific migrants often eschewed parts of their Pacific culture/s which they perceived incongruous with or superfluous to succeeding in their new communities, including their Pacific languages,

leading to inevitable language loss (Enari & Taula, 2022). Lanuola stated: “my mum... wanted us to learn English and sort of fit in, in New Zealand”. Other parents spoke about this phenomenon within their own families:

Mareko: I don't speak fluent, my sisters do... And my Dad he always spoke to us in English. My mum too. That's the whole same issue. You get taught not to, that's the way you get work is to make sure you learn the way of Western society so you can get work and stuff. Unfortunately.

Higano: [Speaking English] that's [what] a lot of the older generation see as being successful. That's why, you know, there are readings and there are quotes that “Oh, we're going to NZ to be successful” so we're gonna dump all the... cos the language is dead, dying, you know it's... Cos they're chucking all these things aside because that's the goal, that's how we need to fit in.

Vasa: I'm only just coming to understand the culture now, in my old age and I'm like ‘Oh my gosh, I've just missed out on so much’, and I hate that I don't know the language so I would love the kids to know the language.

Katalina: I wish, I really, really wish that I could give that to my kids that they would be raised bilingual and knowing their, more about their culture, and they still can ...like how cool would that be... but again, we were raised Palagi styles [to speak only English].

Akanesi: I think they wanted us to speak English so we can, because we were fresh, we came straight from [Pacific island] so they wanted us to learn the language, but then, we lost it. When you get older you start to realise, wow, how important your language is. I don't speak [Pacific language] at home, I should, but I'm actually broken—even though I'm full [Pacific culture]—which I'm still embarrassed of... I can say little bits, and I can understand it, but I can't, yeah.

Consequently, in families where only one parent was fluent in a Pacific language, and in couples of different cultural backgrounds, the main language at home tended to default to English even if initially a bilingual strategy was used. Salote reported:

Language was very important to me and then when he started at the [language nest] I thought it would be really beneficial and possibly easier for him to be bilingual... so we were speaking both at home and mainly [Pacific language] at [the language nest]. But I think the struggle for us at home

is that Mikaele doesn't speak fluently and so I found myself speaking English more than [Pacific language] so that everybody understood whereas thinking back to it now that probably would've been the ultimate opportunity for him to learn to speak fluently as well. But yeah, we, I think speaking English completely just sort of happened? So while we were speaking both and as [our son] sort of grew up and went to Primary, English was just the more preferred language for him.

Vasa said: "I would love the kids to know the language, and I get Malama to, 'Can you just speak and teach them?' And he does a bit but he's like he doesn't want to, like 'Oh, they'll be fine'". Regarding teaching his children his heritage language, Mateo added: "it's never been a biggie for me".

By contrast, families who evidenced close-knit multi-generational family structures, particularly those with strong matriarchal leaders who regularly spoke their heritage language, were more resilient to language loss. Notably within these families, grandmothers of study participants had been heavily involved in teaching these parents their heritage language, and the mothers of study participants were now teaching the children in this study, along with the children's mothers. Ofania commented:

Our Nana, she's the one who raised us. She didn't understand English so we had no choice but to learn the language, you know, if we wanna get fed! If we wanna eat we have to learn how to speak, you know, and that was my cousins, first cousins, and there was a lot of us, and she was the one who looked after us while our parents went to work.

In addition to parents' own experiences of language learning, the international literature on autism and heritage language learning reports that health professionals regularly advise parents of autistic children to focus resources and effort solely on the attainment of English (Hastedt et al., 2022; Howard et al., 2021). Practitioners continue to provide this advice to parents despite scant evidence that monolingualism conveys any language benefit to these children, and despite increasing evidence that children with language delays and/or autism can be successfully bilingual (Drysdale et al., 2015; Hastedt et al., 2022; Howard et al., 2021; Lim et al., 2019; Zhou et al., 2019). Parents in the current study also spoke about receiving encouragement from health practitioners and professionals to prioritise English, and that learning more than one language would hinder their autistic child/ren's development. Heirava: "for me he can't understand, I think his brain can't process the two languages".

In Pacific cultures, questioning or going against the advice of professionals could be received as a challenge or offensive and so is best avoided (Ioane & Tudor, 2017). Only two families in the study felt strong enough to question within themselves the advice of professionals, informed by their experiences as a teacher and a bilingual speaker. When asked if worried about mixing languages, Akanesi replied: “not really. I think it was more because we know how good it is for our kids”. Ofania exclaimed: “just like us! We hear a language that may sound like Samoan but, oh no, that’s Tokelauan, you know, things like that. ...So I was going if we can think like that, I’m sure he’s the same!” Higano agreed:

There was that thing with possibility of confusion, we’ve come across some people who we’ve worked with who were teaching us stuff and trying to tell us that you have to be careful you don’t confuse them. But we know that it works the other side of the brain. The research shows that there’s more of a boost, there’s more opportunity for them to sort of, to get all those cogs working and stuff and it did seem a little bit strange to me. I didn’t say anything at the time but it didn’t sit right, I don’t really think you’re gonna confuse them.

No matter the parents’ beliefs about the ability of their children to learn both English and Pacific language, all would like their children to do so. Lanuola stated: “when [our son] can, we’ll definitely do that [teach him his heritage language] and it’ll help us too, because we need to brush up on that, a lot”. Heirava concurred: “that’s my aim for my children to speak my language. All my kids speak English, they don’t speak my language but they understand my language”.

Pacific parents appeared to use simple strategies in teaching children their heritage language. Like Ofania, parents used short phrases, repetition, observation, and naturalistic bilingual speaking at home: “certain words that I think he knows and because it’s repetitive. And I’m always continuing that, mai hui, mai lima, it’s not the whole sentence but it’s just the important words—the shortened, short version”. When asked if Heirava used visuals or any other language strategies, she replied:

No, just speak to him. I just talk to them like normal ...especially I talk to him and then I watch out, yeah to teach him, he’s quite good. I know some of the sick children if you tell them what to do, they don’t, but him, it’s easy for me to, you know, not taking his hand and go to the bathroom and go brush your teeth and standing there watching him, no, I just tell him what to do and he goes and he’s very easy.

It is not surprising that a key language learning strategy for Pacific peoples is naturalistic speaking given Pacific languages are historically oral cultures (Addis, 2012). In addition, Heirava's community were working together to create an option for their children to learn their i-Kiribati language—the first i-Kiribati language nest in Aotearoa. She commented: “once that manaeba [traditional meeting house] starts, that's one of our plans to get the childcare, i-Kiribati childcare and, you know, and we teach the i-Kiribati language to them as well”.

Although parents often are not cognisant of using language strategies, they most likely are. For example, in a study of infants considered either at higher likelihood or not for autism, most parents were found to use a range of natural language strategies with their infants (Choi et al., 2022). The authors outlined some of the strategies used, including: coordinated vocalisations, heightened responsiveness to infant vocalisations, scaffolding play, and nonverbal gesturing including both declarative gestures (for joint-attention and interest, e.g. pointing) and imperative gestures (to elicit infant action, e.g. beckoning). The study found that increased use of declarative gestures at 12 months was associated with higher vocabularies in toddlers at three years, regardless of whether the child later received an autism diagnosis (Choi et al., 2022). This finding suggests that parents, including Pacific parents, have instinctual and/or learned knowledge around how to elicit language from infants, and that parents regularly use these strategies to increase their children's language development. Interestingly, although nonverbal communication is often impaired in autistic children, for example pointing behaviour (APA, 2022), autistic children still benefit from the use of declarative gestures to share interest and attention. This is a good reminder to discuss with parents the potential positive impact of their continued interaction and engagement with their child, even if language impairment or delay has been recognised, and not to stop communicating with the child once diagnosed.

Regarding the maintenance of culture within Pacific families raising autistic children in Aotearoa, parents engaged in a range of activities to keep culture alive within their families. These included: bilingual speaking at home, making traditional garlands for cultural events, involvement in Pacific women's groups, children engaging in cultural events through church or language nests, dressing traditionally for cultural/family events, placing children in a bilingual unit at school, baptising children, returning to the islands regularly, participating in cultural sports days, participating in hair-cutting ceremonies, teaching children cultural protocols, and living and teaching children Pacific values.

Some families, for a variety of reasons, described themselves as not being fully immersed in their culture or not fully immersing their children. However, these parents felt that 'culture' included a contemporary execution of traditional

Pacific values, which parents felt they regularly included within their family living. This sentiment is reflected in the Samoan *alaga'upu*, 'e sui faiga, ae tūmau fa'avae' meaning our practices change but the [values/]foundations remain (Fuata'i, 2007). For example, Katalina opined: "[the values] never leave you, your blood, at all", and Mareko agreed: "yeah, the values and the commandments are there". Pania thought of culture as being resident within family members: "with *whānau/āiga*, *that is* culture/language—like it's kind of all in one" (emphasis added). Some families were confident that when it came to teaching their children their Pacific culture "they could learn here at home" (Vasa). Finally, there was a feeling that while culture will always be there because it lives in people such as the parents and the parents live the culture, Pacific language was more at-risk. Akanesi stated:

I think it's important to know your cultural protocols, you know, when you go to your families. I try and teach my boys that when I can. ...But when you get older you start to realise, wow, how important your language is, not so much culture, for me, culture is, will always be there.

A number of practice implications are brought together from the above findings of this research. These are provided in the following, final chapter.

Chapter 7: Practice Implications and Conclusion

Practice Implications

The first practice implication concerns the element of trust within relationships with Pacific peoples. The Pacific methodology utilised in this study created a safe space where trust could be established and sustained with Pacific parents who previously have not been engaged in autism research. Adherence to Pacific protocols and the nurturing of relationships was considered key to this process. Evidence for trust being successfully established were comments from parent participants about the data “being [the researcher’s]” or “gifted”, and “trust[ing the researcher]” regarding treatment of the talanoa data. These comments were made throughout the research process when the researcher would check transcripts with the participants, and when permission was sought to base Mika’s personage and traits on a child from a participating family. The willingness of parents to gift their stories to the researcher was considered due to the positive relationships formed between parents and the researcher, and the desire to share experiences for the greater good. This quality of Pacific parents and outward focus is underpinned by Pacific peoples’ collective worldview where *tausi tagata*, taking care of the ‘we’, is prioritised (Ioane & Tudor, 2017). The implication for clinicians here is to take time to respect Pacific relational ethics and processes of *teu le vā*, to produce better outcomes for Pacific communities.

Table 4, below, presents a summary of the findings regarding Pacific parents’ adverse experiences throughout their adaptation to parenting autistic children and how clinicians might proactively mitigate these experiences.

Table 4

Summary of Clinical Practice Implications from Study Findings

Identified Need for Pacific Parents	Potential Solutions
of Autistic Children in Aotearoa	
Pacific term for autism	Clinicians could use the Pacific term <i>Tagata a Sa'ilimalo</i> to refer to people with a disability and their families until a specific term for autism is developed. Pacific clinicians together with Pacific linguists could develop a suitable term that describes Pacific autistic people from a Pacific worldview

Equitable access to the Aotearoa health system	Clinicians may examine accessibility of appointment times, distance, parking, clinic location, childcare, work commitments, and pre-emptively offer families solutions where such barriers exist
Health professionals' understanding of Pacific parents	Be cognisant of Pacific parents demonstrating respect through allowing the clinician to lead the discussion. Spend time gathering Pacific parents' thoughts and feelings on discussions. Genuinely check parental understanding, rather than a yes/no check for questions
Earlier autism screening	Clinicians can elicit children's developmental progression against a dimensional standardised benchmark such as the CDC's paediatric developmental milestones to contextualise parental concerns/flag for further assessment
Appropriate clinic environment	Provide an assessment clinic environment which considers neurodiverse children and Pacific families' needs
Warm, genuine, empathic clinician manner	Consider own biases. Consider and adapt communication styles (including non-verbal language) particularly at times of significant news and change required for parents
Health professionals' cultural humility	Undertake professional development focused on diversity, and cultural competence with Pacific peoples. Undertake cultural supervision and consultation <i>before</i> meeting with Pacific families to ensure correct pronunciation of names, and use of appropriate Pacific relational protocols. Ensure a family-centred, strengths-based assessment of the child as a whole person within a family system, ensure support people and interpreters are encouraged and accommodated, and that culture and faith are assessed
An equitable Aotearoa health system	Seek to uncover where systemic issues have caused a lack of best-practice through client history, and act to redress or ameliorate these

Parental adjustment to diagnosis	Give hope at diagnosis, avoid limiting statements about the child's capacities which are as yet unknown. Explore factors which impact parental acceptance of diagnosis and seek to ameliorate these
Parental understanding of autism	Give a considered amount of clear, highly visual, and practical information that will help parents understand their child's autism, and things they might expect. Include support group and further sources of information <i>relevant to them</i>
Addressing parental grief	Explore and validate grief. When appropriate, assist parents to undertake steps toward helpful action, such as advocacy. Referrals for further emotional support for parents may be appropriate
Wider community awareness and acceptance of autism	Raise public health awareness and contribute to community education on autism, through direct consultation and/or creating information-sharing tools families can use based on existing relationships. Understand that real-life situations such as teaching neurodiverse students and being part of church/other communities with neurodiverse people offer the best chances to change negative mindsets
Pacific family and community acceptance of an autism diagnosis	Clinicians can assist in the destigmatisation of conditions through educating and advocating for awareness and acceptance within their communities of practice. Assisting families with capacity to advocate for their children and to teach others about autism is also important. Resources could be developed to share with Pacific families and communities. Additionally, clinicians should allow families who have been adversely treated to have their experiences heard and validated
Language and culture maintenance	Assess parental preferences and values relating to culture and language. Familiarise with the literature on language learning in autistic children and offer parents evidence-based information, while allowing space for parental preferences and values

Parents' awareness of services and supports which they are eligible for	Clinicians should familiarise themselves with the supports available for identified <i>tagata sa'ilimalo</i> and share with parents or assist parents to navigate the system. Clinicians can assist parents in finding a health and disability advocate where needed, and/or where relevant and appropriate, advocate to ensure parents receive needed supports
Public health professionals' understanding of autism	Seek out and provide staff with/undertake neurodiversity-related professional development opportunities as a priority
Inclusive education environments	In all cases, a thorough investigation of what support schools provide, available funding, and each child's specific learning needs, is warranted. Consider the most inclusive and supportive environment for a Pacific autistic child may be a bilingual unit based on te Āo Māori or Pacific family values
Supporting children to reach their full educational potential from Early Childhood, through Primary, Secondary, and beyond	Support parents to identify aspirational goals, facilitate increased effective communication between the family and education providers through direct consultation or provision of advice, and facilitate agreement on shared goals for the child and how these will be implemented
Parental social support	Clinicians can provide information to parents on the benefits of support group attendance and information on relevant support groups within their local community
Parental practical support	Understand that Pacific parents who lack available or suitable support are at risk of burnout and relationship problems. Assist parents to lean on eligible supports and create wider reliable networks
Parental acceptance of assistance	Explore with parents the reasons for non-acceptance of help. Graded tasks may be useful to allow parents to slowly accept needed assistance
Avoiding parental burnout	Take time to address self-care and respite needs within the parental unit, working with parents to find strategies which are acceptable to the family while providing adequate rest and recuperation

Future Research

All avenues of research with Pacific autistic people remain wide open and only some suggestions are included here. For example, quality epidemiological studies are needed to numerate Pacific autistic people in Aotearoa. This information can then be used to forecast levels of support and funding required over time. Research by autistic people about their experiences deserves prioritisation. Further, research is desperately needed to ascertain how best to disseminate knowledge of funding and autism services within Pacific communities. The flexible types of support and funding that would allow more Pacific families of autistic children to utilise disability supports such as respite are also needed. Furthermore, current demographic information on families of autistic children and their access to support services is required to ascertain gaps and design communication strategies. Moreover, research on conceptualisations of Pacific child development would assist in developing autism destigmatisation education for Pacific communities. More research on frameworks for working with Pacific families raising autistic children in both health and education systems would also assist families in accessing relevant supports. Lastly, research on the implementation of early interventions for autistic children in Pacific languages would assist children to experience the associated benefits while maintaining bilingualism.

Conclusion

This exploratory descriptive study represents the first research to the author's knowledge which focuses on the experiences of Pacific parents raising autistic children in Aotearoa and internationally. While this study provides new insights and a valuable contribution to the fields of autism, Pacific health, and clinical psychology, these results are not generalisable to all Pacific peoples or all autism communities. The research questions answered in this study included: 1) What are the holistic lived experiences of Pacific parents raising autistic children, in Aotearoa?; 2) What available supports are Pacific parents raising an autistic child accessing or not accessing, and what supports do they need that are not there?; and, 3) How is language and culture maintained within Pacific families of autistic children in Aotearoa?

Overall, the findings of this study are consistent with international research on parents' experiences of raising autistic children. However, this study has also identified new knowledge and insights which were not previously captured in research. The new knowledge relates to the holistic experiences of Pacific parents raising autistic children within Aotearoa, and particularly relates to the support needs, and language and culture maintenance for Pacific families with autistic children. An overarching theme for how Pacific parents perceived raising autistic children was identified as

Diasporic Adaptation to Neurodiversity. This was because Pacific parents in Aotearoa were themselves either diasporic settlers to Aotearoa, or the children of migrants from the Pacific region, and while adapting to their new homeland they were also adapting to raising neurodiverse children. Beneath the overarching theme were identified four major themes which gave further voice to the adaptation journey of Pacific parents of autistic children within Aotearoa. These included: 1) Uncharted Islands: Understanding Autism; 2) Encountering Stormy Seas: Challenges; 3) Collective Unity: Relational Resilience; and, 4) 'Land of Milk and Honey'? Autism Support. These themes discussed in further detail the understanding of Pacific parents of autism itself—before diagnosis, and as it developed over time, parents' reactions to diagnosis, the unlearning required of parents (Theme 1); experiences with health professionals, judgement and discrimination, readjusting family hopes and dreams (Theme 2); resilience from within parents' relational networks (internal and external to the family), language and culture maintenance, the blessings of raising a neurodiverse child (Theme 3); and, parents' experiences of referral and diagnosis of their child/ren, autism supports families were/were not accessing, parents' attitudes toward cultural support, and a range of holistic experiences of raising an autistic child (Theme 4).

It was found that Pacific parents, while not particularly subscribing to traditional Pacific beliefs and attitudes towards neurodiversity and disability, were still influenced by these through others' negative perceptions, behaviour, and overt judgment of their child and themselves. This often included Pacific communities. The stigma of difference within Pacific communities which resulted from presumed etiologies of parental misdemeanour was one major barrier which continued to negatively influence perception of autistic children and their parents and led parents to isolate themselves and their children. Further difficulties for Pacific parents in adjusting to parenting neurodiverse children included: health professionals' lack of knowledge of autism, systemic racism present within the Aotearoa health system leading to longer delays to diagnosis and worse support experiences, the grief involved in readjusting hopes and dreams for autistic children, health professionals' devaluing of Pacific languages and lack of cultural understanding, and gate-keeping and a lack of support information given to parents eligible for support. However, a number of positive benefits also came with parenting an autistic child, which included: gaining diagnosis which opened access to support, drawing on parents' established relational networks for social support and practical help, meeting other Pacific parents of autistic children, creating and enjoying wonderful experiences with their children, maintaining Pacific language and culture within the family, becoming a team, educating others, advocating for their children, witnessing generational change, and achieving relational resilience.

The value of the findings in this study are, firstly, for the parent participants to see themselves and become aware that there are many other Pacific parents like them, experiencing very similar experiences throughout Aotearoa in raising their autistic children. It is the author's hope that Pacific parents may draw strength from seeing their own and others' stories captured in research, and that they might find others' strategies helpful in their journey. Secondly, capturing these parents' experiences, both positive and negative, is illuminating and instructive for clinical psychologists, clinicians, and health professionals who work with Pacific families. This study contributed conceptual information on the wider Pacific worldview which confers understanding of Pacific peoples within health systems in general (adding to cultural competency of health professionals who utilise this information). Additionally, highly specific information on the Pacific autism diagnosis and support experience within Aotearoa was elucidated which can guide clinicians on what their Pacific clients may be experiencing and how to intervene. Thirdly, this study contributed knowledge to the wider field of autism about how autism is experienced by parents of autistic children in Aotearoa from Pacific cultures, and how autism affects Pacific language and culture maintenance within these families.

In navigating the journey of raising Pacific autistic children in Aotearoa, how will we know when we have reached our destination? The voices of Pacific parents tell us it will be when Mika (front cover) is valued and appreciated as an important member of his Aotearoa Pacific community. It will be where Mika is able to participate fully and realise his full potential within Aotearoa's education system. It will be where Mika is supported to live a full life and enjoy access to the community, activities, work, and leisure according to his potential and preferences. It will be where Mika is supported to live out a strong Aotearoa Pacific identity, in his way. It will be when Mika achieves self-determination according to his God-given potential, and when he achieves *soifua maloloina* total health and wellbeing. Only then, will we have reached where we need to be, only then will we have arrived.

References

- Adds, P. (2012). E kore au e ngaro. In Mallon, S., Māhina-Tuai, K. U., & Salesa, D. I. (Eds.), *Tangata o le moana: New Zealand and the people of the Pacific* (pp. 17–36). Te Papa Press.
- Airini, A., Anae, M., Mila-Schaaf, K., Coxon, E., Mara, D., & Sanga, K. (2010). *Teu le Va - Relationships across research and policy in Pasifika education: A collective approach to knowledge generation and policy development for action towards Pasifika education success*. Ministry of Education.
- Alefaio-Tugia, S. T. (2015). *Galuola: a NIU way for informing psychology from the cultural context of Fa'aSamoa*. (Unpublished doctoral thesis). Monash University, Melbourne, Australia.
<https://doi.org/10.4225/03/58abad465cdc1>
- Alefaio, S. (2018). Samoan indigenous psychology. In Li, W. W., Hodgetts, D., & Foo, K. H. (Eds.), *Asia-Pacific Perspectives on Intercultural Psychology* (pp. 218–231). Routledge.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.).
<https://doi.org/10.1176/appi.books.9780890425596>
- American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.).
<https://doi.org/10.1176/appi.books.9780890425787>
- Anae, M. (2005). Samoans – Life in New Zealand. Te Ara - the Encyclopedia of New Zealand,
<http://www.TeAra.govt.nz/en/samoans/page-2>
- Anae, M. (2010). Research for better Pacific schooling in New Zealand: Teu le va – a Samoan perspective, *MAI Review*, 1, 1–24. <http://www.review.mai.ac.nz/mrindex/MR/article/download/298/298-2299-1-PB.pdf>
- Anae, M. (2016). Teu Le Va: Samoan relational ethics. *Knowledge Cultures*, 4(3), 117–130.
<https://link.gale.com/apps/doc/A458164605/AONE?u=vuw&sid=AONE&xid=787194af>
- Anae, M. (2020). *The platform: the radical legacy of the Polynesian Panthers*. Bridget Williams Books.
- Anderson, A., Birkin, C., Seymour, F., & Moore, D. (2006). *EarlyBird Evaluation*. Ministry of Education.
https://www.educationcounts.govt.nz/_data/assets/pdf_file/0010/7021/EarlyBird-full-report.pdf

- Anderson, A., & Carr, M. (2021). Applied Behaviour Analysis for Autism: Evidence, issues, and implementation barriers. *Current Developmental Disorders Reports*, 8, 191–200. <https://doi-org.ezproxy.massey.ac.nz/10.1007/s40474-021-00237-x>
- Aporosa, S. A., Atkins, M., & Leov, J. N. (2021). Decolonising quantitative methods within a Pacific research space to explore cognitive effects following kava use. *Pacific Dynamics: Journal of Interdisciplinary Research*, 5(1), 74–92. <http://dx.doi.org/10.26021/10642>
- Armstrong, T. (2015). The myth of the normal brain: Embracing neurodiversity. *AMA Journal of Ethics*, 17(4), 348–352. <https://doi.org/10.1001/journalofethics.2015.17.4.msoc1-1504>.
- Assailly, J-P. (2022). What's new in cognition? In *Child Psychology: Developments in knowledge and theoretical models* (Vol 3, pp. 71–90). <https://doi.org/10.1002/9781119902140.ch4>
- Ataera-Minster, J., & Trowland, H. (2018, June). *Te Kaveinga—Mental health and wellbeing of Pacific peoples. Results from the New Zealand Mental Health Monitor & Health and Lifestyles Survey*. Health Promotion Agency. <https://www.hpa.org.nz/sites/default/files/FinalReport-TeKaveinga-Mental%20health%20and%20wellbeing%20of%20Pacific%20peoples-Jun2018.pdf>
- Bailey, B., & Arciuli, J. (2020). Indigenous Australians with Autism: A scoping review. *Autism: The International Journal of Research and Practice*, 24(5), 1031–1046. <https://doi.org/10.1177/1362361319894829>
- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z. ... Dowling, N. F. (2018). Prevalence of Autism Spectrum Disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveillance Summary*, 67(6), 1–23. <https://www.cdc.gov/ncbddd/autism/addm-community-report/index.html>
- Banach, M., Iudice, J., Conway, L. & Couse, L. J. (2010). Family support and empowerment: Post Autism diagnosis support group for parents. *Social Work with Groups*, 33(1), 69–83. <https://doi.org/10.1080/01609510903437383>
- Banerjee, I., Lambert, J. M., Copeland, B. A., Paranczak, J. L., Bailey, K. M., & Standish, C. M. (2022). Extending functional communication training to multiple language contexts in bilingual learners with challenging behavior. *Journal of Applied Behavior Analysis*, 55(1), 80–100. <https://doi.org/10.1002/jaba.883>

- Barber, A., Yerby, L., Tomeny, T., Baker, L. & Morales-Aleman, M. (2022). Brief Report: Exploring rural and urban caregiver descriptions of Autism symptoms and aetiology. *International Journal of Disability, Development and Education*, 69(4), 1430–1441. <https://doi.org/10.1080/1034912X.2020.1767763>
- Barokova, M., & Tager-Flusberg, H. (2018). Commentary: Measuring language change through natural language samples. *Journal of Autism and Developmental Disorders*, 50(7), 2287–2306. <https://doi.org/10.1007/s10803-018-3628-4>
- Bazeley, P. (2021). *Qualitative data analysis: practical strategies* (5th edition.). SAGE Publications Ltd.
- Bathgate, M., & Pulotu-Endemann, F. K. (1997). Pacific people in New Zealand. In P. M. Ellis & S. C. D. Collings (Eds.), *Mental health in New Zealand from a public health perspective*. Ministry of Health.
- Becerra, T. A., von Ehrenstein, O. S., Heck, J. E., Olsen, J., Arah, O. A., Jeste, S. S., Rodriguez, M., & Ritz, B. (2014). Autism spectrum disorders and race, ethnicity, and nativity: a population-based study. *Pediatrics*, 134(1), 63–71. www.pediatrics.org/cgi/doi/10.1542/peds.2013-3928
- Beehive.govt.nz (2021, August 1). Government offers formal apology for Dawn Raids. <https://www.beehive.govt.nz/release/government-offers-formal-apology-dawn-raids>
- Begeer, S., Bouk, S. E., Boussaid, W., Terwogt, M. M., & Koot, H. M. (2009). Underdiagnosis and referral bias of autism in ethnic minorities. *Journal of Autism and Developmental Disorders*, 39(1), 142–148. <https://doi.org/10.1007/s10803-008-0611-5>
- Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012). Resilience in family members of persons with Autism Spectrum Disorder: A review of the literature. *Issues in Mental Health Nursing*, 33(10), 650–656. <https://doi.org/10.3109/01612840.2012.671441>
- Bennett, S., Flett, R., & Babbage, D. (2014). Culturally adapted cognitive behaviour therapy for Māori with major depression. *The Cognitive Behaviour Therapist*, 7, E20. <https://doi.org/10.1017/S1754470X14000233>
- Bennett, S. T., Flett, R. A., & Babbage, D. R. (2016). Considerations for culturally responsive Cognitive-Behavioural Therapy for Māori with Depression. *Journal of Pacific Rim Psychology*, 10. <https://doi.org/10.1017/prp.2016.5>

- Bernier, A. S., & McCrimmon, A. W. (2021). Attitudes and perceptions of Muslim parents toward their children with Autism: a systematic review. *Review Journal of Autism and Developmental Disorders*, 1–14. <https://doi.org/10.1007/s40489-021-00256-9>
- Bernier, R., Mao, A., & Yen, J. (2010). Psychopathology, families, and culture: Autism. *Child and Adolescent Psychiatric Clinics of North America*, 19(4), 855–867. <https://doi.org/10.1016/j.chc.2010.07.005>
- Bevan-Brown, J. (2004). *Māori perspectives of autism spectrum disorder: Report to the Ministry of Education*. Ministry of Education.
- Bevan-Brown, J. (2013). Including people with disabilities: an indigenous perspective. *International Journal of Inclusive Education*, 17(6), 571–583. <https://doi.org/10.1080/13603116.2012.694483>
- Bevan-Brown, J. & Moldovanu, A. (2016). The role of culture in the perception, assessment, diagnosis, treatment and education of children and young people with autism spectrum disorder. In Bevan-Brown, J. & Dharan, V. (Eds.), *Autism spectrum disorder in Aotearoa New Zealand: Promising practices and interesting issues* (pp. 155–168). NZCER Press.
- Bilaver, L. A., Sobotka, S. A., & Mandell, D. S. (2021). Understanding racial and ethnic disparities in Autism-related service use among Medicaid-enrolled children. *Journal of Autism and Developmental Disorders*, 51, 3341–3355. <https://doi.org/10.1007/s10803-020-04797-6>
- Birkin, C., Anderson, A., Seymour, F. & Moore, D. (2008). A parent-focused early intervention program for autism: Who gets access? *Journal of Intellectual & Developmental Disability*, 33(2), 108–116.
- Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2019). A meta-synthesis of how parents of children with autism describe their experience of advocating for their children during the process of diagnosis. *Health & Social Care in the Community*, 27(4), e143–e157. <https://doi.org/10.1111/hsc.12691>
- Botha, L., Griffiths, D., & Prozesky, M. (2021). Epistemological decolonization through a relational knowledge-making model. *Africa Today*, 67(4), 50–72. <https://doi.org/10.2979/africatoday.67.4.04>

- Bowden, N., Thabrew, H., Kokaua, J., Audas, R., Milne, B., Smiler, K., Stace, H., Taylor, B., & Gibb, S. (2020). Autism spectrum disorder/Takiwātanga: An Integrated Data Infrastructure-based approach to autism spectrum disorder research in New Zealand. *Autism*, 24(8), 2213–2227. <https://doi.org/10.1177/1362361320939329>
- Braun, V., & Clarke, V. (2022). *Thematic analysis: a practical guide*. SAGE Publications Ltd.
- Breen, C., Gillespie, A., Joseph, R., & Toki, V. (2021, October 6). Putting Aotearoa on the map: New Zealand has changed its name before, why not again? *The Conversation*. <https://theconversation.com/putting-aotearoa-on-the-map-new-zealand-has-changed-its-name-before-why-not-again-168651>
- Brett, D., Warnell, F., McConachie, H., & Parr, J. (2016). Factors affecting age at ASD diagnosis in UK: No evidence that diagnosis age has decreased between 2004 and 2014. *Journal of Autism & Developmental Disorders*, 46(6), 1974–1984. <https://doi.org/10.1007/s10803-016-2716-6>
- Broadstock, M. (2011). *New Zealand Autism Spectrum Disorder Guideline supplementary paper on applied behaviour analysis*. New Zealand Guidelines Group. <https://www.health.govt.nz/publication/new-zealand-autism-spectrum-disorder-guideline-supplementary-paper-applied-behaviour-analysis>
- Broadstock, M. (2014). *New Zealand Autism Spectrum Disorder Guideline supplementary paper on implications of DSM-5 for the diagnosis of ASD*. INSIGHT Research. www.health.govt.nz/publication/new-zealand-autism-spectrumdisorder-guideline-supplementary-paper-dsm5
- Broadstock, M. (2018). *New Zealand Autism Spectrum Disorder Guideline supplementary paper on the impact of ethnicity on recognition, diagnosis, education, treatment and support for people on the autism spectrum*. INSIGHT Research. <https://www.health.govt.nz/publication/new-zealand-autism-spectrum-disorder-guideline-supplementary-paper-impact-ethnicity-recognition>
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press.
- Brown, H. M., Stahmer, A. C., Dwyer, P., & Rivera, S. (2021). Changing the story: How diagnosticians can support a neurodiversity perspective from the start. *Autism: The International Journal of Research & Practice*, 25(5), 1171–1174. <https://doi.org/10.1177/13623613211001012>

- Cammock, R., Conn, C., & Nayar, S. (2021). Strengthening Pacific voices through Talanoa participatory action research. *AlterNative*, 17(1), 120–129. <https://doi.org/10.1177/1177180121996321>
- Carlsson, E., Miniscalco, C., Kadescjo, B., & Laakso, K. (2016). Negotiating knowledge: Parents' experience of the neuropsychiatric diagnostic process for children with autism. *International Journal of Language and Communication Disorders*, 51, 328–338. <https://doi.org/10.1111/1460-6984.12210>
- Carr, A. (2016a). Autism Spectrum Disorders. In Carr, A. (Ed.), *The handbook of child and adolescent clinical psychology a contextual approach* (3rd ed., pp. 284-313). Routledge. <https://doi-org.helicon.vuw.ac.nz/10.4324/9781315744230>
- Carr, A. (2016b). Classification, epidemiology and treatment effectiveness. In Carr, A. (Ed.), *The handbook of child and adolescent clinical psychology a contextual approach* (3rd ed., pp. 66–96). Routledge. <https://doi-org.helicon.vuw.ac.nz/10.4324/9781315744230>
- Carr, A. (2016c). Normal development. In Carr, A. (Ed.), *The handbook of child and adolescent clinical psychology a contextual approach* (3rd ed., pp. 3–35). Routledge. <https://doi-org.helicon.vuw.ac.nz/10.4324/9781315744230>
- Centers for Disease Control and Prevention (CDC). (2019). *Autism Data Visualization Tool*. <https://www.cdc.gov/ncbddd/autism/data/index.html>
- Choi, B., Castelbaum, L., McKechnie, R., Rowe, M. L., Nelson, C. A., & Tager-Flusberg, H. (2022). Brief Report: Parents' declarative use of deictic gestures predict vocabulary development in infants at high and low risk for Autism Spectrum Disorder. *Journal of Autism & Developmental Disorders*, 52(2), 914–922. <https://doi.org/10.1007/s10803-021-04989-8>
- Chiu, C., Kwan, L. Y.-Y., & Liou, S. (2014). Professional and disciplinary cultures. In A. B. Cohen (Ed.), *Culture reexamined: Broadening our understanding of social and evolutionary influences* (pp. 11–30). American Psychological Association. <https://doi.org/10.1037/14274-001>
- Christensen, D. L., Baio, J., Van Naarden Braun, K., Bilder, D., Charles, J., Constantino, J. N., Daniels, J., Durkin, M. S., Fitzgerald, R. T., Kurzius-Spencer, M., Lee, L.-C., Pettygrove, S., Robinson, C., Schulz, E., Wells, C., Wingate,

- M. S., Zahorodny, W., & Yeargin-Allsopp, M. (2016). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. *Morbidity and Mortality Weekly Report: Surveillance Summaries*, 65(3), 1–23. <https://www.jstor.org/stable/10.2307/24805790>
- Clifford, T. & Minnes, P. (2013). Logging On: Evaluating an online support group for parents of children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 1–14. <https://doi.org/10.1007/s10803-012-1714-6>
- Corcoran, J., Berry, A., & Hill, S. (2015). The lived experience of US parents of children with Autism Spectrum Disorders: A systemic review and meta-synthesis. *Journal of Intellectual Disabilities*, 19(4), 356–366. <https://doi.org/10.1177/1744629515577876>
- Coutts, B., & Fitness, N. (2018). *Pacific history* (1st edition). Nelson, A Cengage Company.
- Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism diagnosis in the United Kingdom: Perspectives of Autistic adults, parents and professionals. *Journal of Autism & Developmental Disorders*, 48(11), 3761–3772. <https://doi.org/10.1007/s10803-018-3639-1>
- Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of Autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism: The International Journal of Research and Practice*, 20(2), 153–162. <https://doi.org/10.1177/1362361315573636>
- Crowe, A. (2018). *Pathway of the Birds: The voyaging achievements of Māori and their Polynesian ancestors*. David Bateman Ltd.
- Culbertson, P., Agee, M. N., & Makasiale, C. Ò. (2007). Introduction. In Makasiale, C. Ò., Agee, M. N., & Culbertson, P. (Eds.), *Penina uliuli: contemporary challenges in mental health for Pacific peoples*. University of Hawaii Press.
- Dai, Y. G., & Carter, A. S. (2022). Characterizing accommodations by parents of young children with Autism: A mixed methods analysis. *Journal of Autism and Developmental Disorders*, 1–14. <https://doi.org/10.1007/s10803-022-05652-6>

- de la Paz, O. (2019). *The Boy in the Labyrinth: Poems*. The University Of Akron Press.
<https://eds.s.ebscohost.com/eds/ebookviewer/ebook/bmxlYmtfXzlyMjMyNjhX0FO0?sid=863decd6-93c3-40f2-9bb9-4a383d38370b@redis&vid=1&format=EB&rid=9>
- de Valenzuela, J. S., Bird, E. K.-R., Parkington, K., Mirenda, P., Cain, K., MacLeod, A. A. N., & Segers, E. (2016). Access to opportunities for bilingualism for individuals with developmental disabilities: Key informant interviews. *Journal of Communication Disorders*, 63, 32–46. <https://doi.org/10.1016/j.jcomdis.2016.05.005>
- Devere, H., & Lialiga, M. F. (2013). Covenant or contract: The Treaty of Friendship between New Zealand and Samoa 1962. *Journal of Pacific Studies*, 32(2), 116–132.
- Dix, K. (2019, October). Bill Urale & The Overstayer Clothing Company. New Zealand Fashion Museum.
<https://www.nzfashionmuseum.org.nz/bill-urale-the-overstayer-clothing-company/>
- Doyle, C. M., Lasch, C., Vollman, E. P., Desjardins, C. D., Helwig, N. E., Jacob, S., Wolff, J. J. and Elison, J. T. (2021). Phenoscreening: a developmental approach to research domain criteria-motivated sampling. *Journal of Child Psychology and Psychiatry*, 62, 884–894. <https://doi-org.ezproxy.massey.ac.nz/10.1111/jcpp.13341>
- Drysdale, H., & van der Meer, L. (2020). Rates of autism spectrum disorder diagnoses for children and adolescents in the Hutt Valley Region of New Zealand between 2012 and 2016. *Research in Autism Spectrum Disorders*, 73. <https://doi.org/10.1016/j.rasd.2020.101547>
- Drysdale, H., van der Meer, L., & Kagohara, D. (2015). Children with autism spectrum disorder from bilingual families: A systematic review. *Review Journal of Autism and Developmental Disorders*, 2(1), 26–38. <https://doi-org.10.1007/s40489-014-0032-7>
- DuBay, M., & Watson, L. R. (2019). Translation and cultural adaptation of parent-report developmental assessments: Improving rigor in methodology. *Research in Autism Spectrum Disorders*, 62, 55–65. <https://doi.org/10.1016/j.rasd.2019.02.005>
- Dumont, D. E. (2021). Facing adulthood: Helicopter parenting as a function of the family projection process. *Journal of College Student Psychotherapy*, 35(1), 1-14, <https://doi.org/10.1080/87568225.2019.1601049>

- Dunlop-Bennett, E. (2019). *Through their eyes: A Samoan perspective on child wellbeing* (Unpublished doctoral thesis). University of Otago. <http://hdl.handle.net/10523/9242>
- Durie, M. (2019). Understanding whānau leadership. In Wai Research/Te Pou Matakana (Eds.), *Proceedings of the Whānau Ora Hui 2018: Affirming whānau aspiration Whānau Eke Panuku*. https://whanauora.nz/wp-content/uploads/2021/06/TPM-Whanau-Ora-Magazine_web.pdf
- Durie, M. (1994). *Whaiora Māori Health Development* (2nd edition.). Oxford University Press. <https://www.health.govt.nz/our-work/populations/maori-health/maori-health-models/maori-health-models-te-whare-tapa-wha>
- Dyches, T. T., Wilder, L. K., Sudweeks, R. R., Obiakor, F. E., & Algozzine, B. (2004). Multicultural issues in Autism. *Journal of Autism & Developmental Disorders*, 34(2), 211–222. <https://doi.org/10.1023/B:JADD.0000022611.80478.73>
- Echeita, G., Cañadas, M., Gutiérrez, H., & Martínez, G. (2021). From cradle to school. The turbulent evolution during the first educational transition of Autistic students. *Qualitative Research in Education*, 10(2), 116–143. <https://doi.org/10.17583/qre.2021.7934>
- Eggleston, M. J. F., Thabrew, H., Frampton, C. M. A., Eggleston, K. H. F., & Hennig, S. C. (2019). Obtaining an Autism Spectrum Disorder diagnosis and supports: New Zealand parents' experiences. *Research in Autism Spectrum Disorders*, 62, 18–25. <https://doi.org/10.1016/j.rasd.2019.02.004>
- Enabling Good Lives. (2022). Key characteristics. <https://www.enablinggoodlives.co.nz/about-egl/egl-approach/key-characteristics/>
- Enari, D. & Taula, L. (2022). Tattoo my mouth: Samoan language survival in Australia. *AlterNative: An International Journal of Indigenous Peoples*, 18(1), 215–218. <https://doi-org.ezproxy.massey.ac.nz/10.1177/11771801221084884>
- Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, 196(4286), 129–136. <https://doi.org/10.1126/science.847460>
- Erwin, J., Paisi, M., Neill, S., Burns, L., Vassallo, I., Nelder, A., Facenfield, J., Devalia, U., Vassallo, T., & Witton, R. (2022). Factors influencing oral health behaviours, access and delivery of dental care for autistic children and

- adolescents: A mixed-methods systematic review. *Health Expectations*, 25(4), 1269–1318.
<https://doi.org/10.1111/hex.13544>
- Esera, F. I. (2001). *If a client is operating from a Samoan world view how can s/he be holistically and appropriately treated under the western medical model?* (Unpublished master's thesis). Victoria University of Wellington, New Zealand.
- Evans, J. (2021). *Reawakened: traditional navigators of Te Moana-nui-a-Kiwa*. Massey University Press.
- Evans, K., · van der Meer, L., · Eggleston, M. J. F., · Taylor, L. J., · Thabrew, H., Waddington, H. & · Whitehouse, A. J. O. (2022). Survey of Autistic adults from New Zealand on the Autism diagnostic process during adolescence and adulthood. *Journal of Autism and Developmental Disorders*, 52, 771–781. <https://doi.org/10.1007/s10803-021-04983-0>
- Fa'alogo-Lilo, C., & Cartwright, C. (2021). Barriers and supports experienced by Pacific Peoples in Aotearoa New Zealand's mental health services. *Journal of Cross-Cultural Psychology*, 52(8/9), 752–770.
<https://doi.org/10.1177/00220221211039885>
- Fa'avae, D., Jones, A., & Manu'atu, L. (2016). Talanoa'i 'a e Talanoa—Talking about Talanoa: Some dilemmas of a novice researcher. *AlterNative: An International Journal of Indigenous Peoples*, 12(2), 138–150.
<https://doi.org/10.20507/AlterNative.2016.12.2.3>
- Fairbairn-Dunlop, P. (1991). *'E au le inailau a tamaitai': women, education and development*. Western Samoa.
- Figiel, S. (1996). *Where we once belonged*. Pasifika Press.
- Firestone, R., Cheng, S., Dalhousie, S., Hughes, E., Funaki, T., Henry, A., Vano, M., Grey, J., Schumacher, J., Jull, A., Whittaker, R., Te Morenga, L., & Mhurchu, C. N. (2020). Exploring Pasifika wellbeing: findings from a large cluster randomised controlled trial of a mobile health intervention programme. *The New Zealand Medical Journal*, 133(1524), 82–101. <https://pubmed.ncbi.nlm.nih.gov/33119572/>
- Fleming, A. H. (2018). Ngā tāpiritanga: Secure attachments from a Māori perspective. *Ata: Journal of Psychotherapy Aotearoa New Zealand*, 22(1), 23-36. <https://doi.org/10.9791/ajpanz.2018.03>

- Fleming, T., Peiris-John, R., Crengle, S., Archer, D., Sutcliffe, K., Lewycka, S., & Clark, T. (2020). *Youth19 Rangatahi Smart Survey, Initial Findings: Introduction and Methods*. The Youth19 Research Group, The University of Auckland and Victoria University of Wellington, New Zealand.
- Fletcher-Watson, S. (2022). Transdiagnostic research and the neurodiversity paradigm: commentary on the transdiagnostic revolution in neurodevelopmental disorders by Astle et al. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 63(4), 418–420. <https://doi.org/10.1111/jcpp.13589>
- Florence, H., & Mikahere-Hall, A. (2019). Creating a groundswell for change: Integrating religion, spirituality and Indigenous responses in psychotherapy. *Psychotherapy & Politics International*, 17(2), N.PAG. <https://doi.org/10.1002/ppi.1491>
- Foley, K.-R., Pollack, A. J., Britt, H. C., Lennox, N. G., & Trollor, J. N. (2018). General practice encounters for young patients with autism spectrum disorder in Australia. *Autism*, 22(7), 784–793. <https://doi.org/10.1177/1362361317702560>
- Foliaki, S. A., Kokaua, J., Schaaf, D., & Tukuitonga, C. (2006). Twelve-month and lifetime prevalences of mental disorders and treatment contact among Pacific people in Te Rau Hinengaro: The New Zealand Mental Health Survey. *The Australian and New Zealand Journal of Psychiatry*, 40, 924–34. <https://doi.org/10.1111/j.1440-1614.2006.01912.x>.
- Foliaki, S. A., Nosa, V., Birkenhead, S., Kanongata'a, H., & Fa'amoe, T. A. (2009). *Qualitative study of elderly Pacific informal caregivers of a young person with an illness or disability*. Clinical Research Unit: Vaka Tautua. [https://www.moh.govt.nz/notebook/nbbooks.nsf/0/5E3CED02D023E6CECC25764D007600B2/\\$file/pacific-caregivers-report.pdf](https://www.moh.govt.nz/notebook/nbbooks.nsf/0/5E3CED02D023E6CECC25764D007600B2/$file/pacific-caregivers-report.pdf)
- Folkema, T. (2022, May 19). *Autistic Language Preferences 2022*. [PowerPoint presentation]. Seminar presented at the meeting of Parent2Parent/Altogether Autism Northland, New Zealand.
- Fombonne, E. S. (2020). The epidemiology of autism spectrum disorders part 1 of 2: History and current estimates. Henry Stewart Talks. <http://ezproxy.massey.ac.nz/login?url=>.

- Foulis, S. J., Rigby, K., Loftus, A., Satchidanand, N., & Holmes, D. (2022). Patient-centered addiction medicine: What patients say helps them the most in their recovery - the role of whole-person healthcare and prayer in opioid addiction recovery. *Current Psychology*. <https://doi.org/10.1007/s12144-022-03060-8>
- Fountain, C., & Bearman, P. (2011). Risk as social context: Immigration policy and Autism in California. *Sociological Forum*, 26(2), 215–240. <https://www.jstor.org/stable/23027316>
- Fraenkel, J. (2012). *Pacific Islands and New Zealand - Immigration and aid*. Te Ara - the Encyclopaedia of New Zealand. <https://teara.govt.nz/en/pacific-islands-and-new-zealand>.
- Fraser, G. (2019). *Supporting Aotearoa's rainbow people: A practical guide for mental health professionals*. Youth Wellbeing Study and RainbowYOUTH.
- Fuata'i, L. (2007). E sui faiga, 'ae tūmau fa'avae: Practices change but foundations remain. In A. So'o (Ed.), *Changes in the matai system. O Suiga i le Fa'amatai* (pp. 173–185). Center for Samoan Studies, National University of Samoa.
- Fuluifaga, A. R. (2017). *O Feosofa'iga o le Vā: Samoan women negotiating vā relations in and around an art centre in rural Samoa*. (Unpublished master's thesis). Auckland University of Technology, Auckland, New Zealand.
- Gaines, A. (1991). Cultural constructivism: Sickness histories and the understanding of ethnomedicines beyond critical medical anthropologies. In Pfleiderer, B., & Bibeau, G. (Eds.), *Anthropologies of medicine : a colloquium on West European and North American perspectives*, 7(91), 221–258. <https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=cat09011a&AN=mul.oai.edge.mass.ey.folio.ebsco.com.fs00001086.408525e7.81e8.512d.8882.53c6d2bce6a6&site=eds-live&scope=site>
- Gasteiger, N., Vedhara, K., Massey, A., Jia, R., Ayling, K., Chalder, T., Coupland, C., & Broadbent, E. (2021). Depression, anxiety and stress during the COVID-19 pandemic: results from a New Zealand cohort study on mental well-being. *British Medical Journal Open Access*, 11, e045325. <https://doi.org/10.1136/bmjopen-2020-045325>
- Gibbs, V., Aldridge, F., Sburlati, E., Chandler, F., Smith, K., & Cheng, L. (2019). Missed opportunities: An investigation of pathways to autism diagnosis in Australia. *Research in Autism Spectrum Disorders*, 57, 55–62. <https://doi.org/10.1016/j.rasd.2018.10.007>

- Gibson, K., Haslam, N., & Kaplan, I. (2019). Distressing encounters in the context of climate change: Idioms of distress, determinants, and responses to distress in Tuvalu. *Transcultural Psychiatry*, 56(4), 667–696. <https://doi.org/10.1177/1363461519847057>
- Glasgow, A. (2019). *Ko toku reo ko toku ia mana: My language, my identity - The Pacific-Indigenous language nest: How language, culture and traditions are supported and promoted for the Pacific-Indigenous communities of the Cook Islands, Niue and Tokelau in Aotearoa New Zealand*. (Unpublished doctoral thesis). Victoria University of Wellington, New Zealand.
- Goodyear-Smith, F., & 'Ofanoa, M. (2022). Fa'afaletui: A Pacific research framework. *Journal of Mixed Methods Research*, 16(1), 34–46. <https://doi.org/10.1177/1558689820985948>
- Gossage, L., Narayanan, A., Dipnall, J. F., Iusitini, L., Sumich, A., Berk, M., Wrapson, W., Tautolo, E.-S., & Siegert, R. (2022). Risk factors for depression in Pacific adolescents in New Zealand: A network analysis. *Journal of Affective Disorders*, 311, 373–382. <https://doi.org/10.1016/j.jad.2022.05.076>
- Gray, D. E. (2001). Accommodation, resistance and transcendence: Three narratives of autism. *Social Science & Medicine*, 53(9), 1247–1257.
- Grebe, S. C., Mire, S. S., Kim, H., & Keller-Margulis, M. A. (2022). Comparing Fathers' and Mothers' perspectives about their child's Autism Spectrum Disorder. *Journal of Autism & Developmental Disorders*, 52(4), 1841–1854. <https://doi.org/10.1007/s10803-021-05077-7>
- Guerrero, A. D., Rodriguez, M. A., & Flores, G. (2011). Disparities in provider elicitation of parents' developmental concerns for US children. *Pediatrics*, 128(5), 901–909. <https://doi.org/10.1542/peds.2011-0030>
- Halapua, S. (2008). Talanoa process: The case of Fiji. (UNpan). www.unpan1.un.org/intradoc/groups/public/documents/UN/UNPAN022610.pdf
- Hamley, L., Le Grice, J., Greaves, L., Groot, S., Latimer, C. L., Renfrew, L., Parkinson, H., Gillon, A., & Clark, T. C. (2022): Te Tapatoru: a model of whanaungatanga to support rangatahi wellbeing, *Kōtuitui: New Zealand Journal of Social Sciences*. <https://doi.org/10.1080/1177083X.2022.2109492>

- Hampton, S., Rabagliati, H., Sorace, A., & Fletcher-Watson, S. (2017). Autism and bilingualism: A qualitative interview study of parents' perspectives and experiences. *Journal of Speech, Language & Hearing Research*, 60(2), 435–446. https://doi.org/10.1044/2016_JSLHR-L-15-0348
- Happé, F. (2019). What does research tell us about girls on the autism spectrum? In Carpenter, B., Egerton, J., & Happé, F. (Eds.), *Girls and autism: educational, family and personal perspectives* (pp. 10–15). Routledge. <https://www-taylorfrancis-com.ezproxy.massey.ac.nz/books/edit/10.4324/9781351234429/girls-autism-barry-carpenter-francesca-happ%C3%A9-jo-egerton>
- Hastedt, I., Eisenhower, A., Sheldrick, R. C., & Carter, A. S. (2022). Bilingual and monolingual Autistic toddlers: Language and social communication skills. *Journal of Autism and Developmental Disorders*, Advance online publication. <https://doi.org/10.1007/s10803-022-05504-3>
- Hau'ofa, E. 1994. Our Sea of Islands. *The Contemporary Pacific*, 6(1), 148–61. <http://hdl.handle.net/10125/12960>
- Havea, S., Alefaio-Tugia, S., & Hodgetts, D. (2021). “Kainga” (families) experiences of a Tongan-Indigenous faith-based violence-prevention programme. *AlterNative: An International Journal of Indigenous Peoples*, 17(1), 83–93. <https://doi.org/10.3316/informit.789087717974303>
- Health Research Council of New Zealand (2004). *Guidelines on Pacific Health Research* (2nd edition). https://www.wipo.int/export/sites/www/tk/en/databases/creative_heritage/docs/pacific_health.pdf
- Henderson, A. K. (2016). The I and the We: Individuality, collectivity, and Samoan artistic responses to cultural change. *The Contemporary Pacific*, 28(2), 316–345. <https://doi.org/10.1353/cp.2016.0027>.
- Henrich, J., Heine, S. J., & Norenzayan, A. (2010). The weirdest people in the world? *Behavioural and Brain Sciences*, 33, 61–135. <https://doi.org/10.1017/S0140525X0999152X>
- Higgins, L., Mannion, A., Chen, J. L., & Leader, G. (2022). Adaptation of parents raising a child with ASD: The role of positive perceptions, coping, self-efficacy, and social support. *Journal of Autism and Developmental Disorders*, 1–19. <https://doi.org/10.1007/s10803-022-05537-8>
- Higgins, R. & Keane, B. (2015). Te reo Māori – the Māori language - Language decline, 1900 to 1970s. Te Ara - the Encyclopedia of New Zealand. <http://www.TeAra.govt.nz/en/te-reo-maori-the-maori-language/page-4>

- Holingue, C., Jang, Y., Landa, R., & Azad, G. (2022). Key stakeholder perspectives on obstacles to an autism-specific Medicaid waiver service delivery model. *Journal of Applied Research in Intellectual Disabilities*, 35(1), 205–216. <https://doi.org/10.1111/jar.12940>
- Holmes, A. G. D. (2020). Researcher positionality – A consideration of its influence and place in qualitative research - A new researcher guide. *Shanlax International Journal of Education*, 8(4), 1–10. <https://doi.org/10.34293/education.v8i4.3232>
- Holy Bible. (2011). New International Version. (Original work published 1973). <https://www.biblica.com/online-bible/> Biblica, Inc.
- Holy Bible. (2021). New Living Translation. (Original work published 1996). <https://www.tyndale.com/nlt/search> Tyndale.
- Hopner, V., & Liu, J. H. (2021). Relational ethics and epistemology: The case for complementary first principles in Psychology. *Theory & Psychology*, 31(2), 179–98. <https://doi.org/10.1177/0959354320974103>.
- Howard, K. B., Katsos, N., & Gibson, J. L. (2021). Practitioners' perspectives and experiences of supporting bilingual pupils on the autism spectrum in two linguistically different educational settings. *British Educational Research Journal*, 47(2), 427–449. <https://doi.org/10.1002/berj.3662>
- Ioane, J., & Lambie, I. (2016). Pacific youth and violent offending in Aotearoa New Zealand. *New Zealand Journal of Psychology*, 45(3), 23–29. <https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=pbh&AN=122738434&site=eds-live&scope=site>
- Ioane, J., & Tudor, K. (2017). The fa'asamoa, person-centered theory and cross-cultural practice. *Person-Centered and Experiential Psychotherapies*, 16(4), 287–302. <https://doi.org/10.1080/14779757.2017.1361467>
- Jacobs, D., Steyaert, J., Dierickx, K., & Hens, K. (2020). Parents' multi-layered expectations when requesting an Autism Spectrum Disorder assessment of their young child: an in-depth interview study. *BMC Psychiatry*, 20(1), 1–11. <https://doi.org/10.1186/s12888-020-02806-7>

- Jang, J., White, S. P., Esler, A. N., Kim, S. H., Klaiman, C., Megerian, J. T., Morse, A., Nadler, C., & Kanne, S. M. (2022). Diagnostic evaluations of Autism Spectrum Disorder during the COVID-19 pandemic. *Journal of Autism & Developmental Disorders*, 52(2), 962–973. <https://doi.org/10.1007/s10803-021-04960-7>
- Janke, T. (1999). *Our culture, our future. A report on Australian cultural and intellectual property rights*. Frankel & Co.
- Jenkins, J. H. (2015). *Extraordinary conditions: Culture and experience in mental illness*. University of California Press.
- Johnson, N., Frenn, M., Feetham, S., & Simpson, P. (2011). Autism spectrum disorder: Parenting stress, family functioning and health-related quality of life. *Families Systems & Health*, 29(3), 232–252. <https://doi.org/10.1037/a0025341>
- Johnson, C. P., & Myers, S. M. (2007). American Academy of Pediatrics Council on Children with Disabilities: Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, 120(5), 1183–1215.
- Johnson-Jennings, M., Billiot, S., & Walters, K. (2020). Returning to our roots: Tribal health and wellness through Land-Based Healing. *Genealogy*, 91(4), 1–21. <https://doi.org/10.3390/genealogy4030091>
- Kalavite, T. (2019). Tongan translation realities across Tā ('Time') and Vā ('Space'). *Journal of New Zealand & Pacific Studies*, 7(2), 173–183. https://doi.org/10.1386/nzps_00004_1
- Kapeli, S. A., Manuela, S., & Sibley, C. G. (2020). Understanding Pasifika mental health in New Zealand. *MAI Journal*, 9(3), 249–271. <https://doi.org/10.20507/MAIJournal.2020.9.3.7>
- Kapp, S. (2011). Navajo and autism: the beauty of harmony. *Disability & Society*, 26(5), 583–595. <https://doi.org/10.1080/09687599.2011.589192>
- Kasilingam, N., Waddington, H., & Van Der Meer, L. (2021). Early intervention for children with Autism Spectrum Disorder in New Zealand: What children get and what parents want. *International Journal of Disability, Development and Education*, 68(4), 521–537. <https://doi.org/10.1080/1034912X.2019.1696949>
- Kerslake, T. D. (2010). *Samoa and New Zealand's special relationship: More than a friendship*. (Unpublished master's thesis). University of Waikato.

- Khanlou, N., Haque, N., Mustafa, N., Vazquez, L. M., Mantini, A., & Weiss, J. (2017). Access barriers to services by immigrant mothers of children with Autism in Canada. *International Journal of Mental Health and Addiction*, 15(2), 239–259. <https://doi.org/10.1007/s11469-017-9732-4>
- Kingi-Ulu'ave, D., & Mati, E. (2020). Le Va's 'Trouble in the bubble? #CatchYourself' online educational campaign for maintaining respectful relationships while in lockdown. New Zealand Psychological Society Virtual Conference.
- Kirkwood, J. (2021). *Pasifika research, June 2021 : a research report about Pasifika people in Tāmaki Makaurau for the Teu Le Vā - Auckland Unlimited Pasifika Work Programme*. Auckland Unlimited.
- Koegel, L. K., Bryan, K. M., Su, P. L., Vaidya, M., & Camarata, S. (2020). Definitions of Nonverbal and Minimally Verbal in Research for Autism: A Systematic Review of the Literature. *Journal of Autism and Developmental Disorders*, 50(8), 2957–2972. <https://doi.org/10.1007/s10803-020-04402-w>
- Kopua, D. M., Bracken, P. J., & Kopua, M. A. (2019). Mahi a Atua: A Māori approach to mental health. *Transcultural Psychiatry*, 57(2), 375–383. <https://doi.org/10.1177/1363461519851606>
- Lai, M. C., Lombardo, M. V., Auyeung, B., Chakrabarti, B., & Baron-Cohen, S. (2015). Sex/gender differences and autism: setting the scene for future research. *Journal of the American Academy of Child and Adolescent Psychiatry*, 54(1), 11–24. <https://doi.org/10.1016/j.jaac.2014.10.003>
- Le Couteur, A. & Szatmari, P. (2015). Autism Spectrum Disorder. In Thapar, A., Pine, D. S., Leckman, J. F., Scott, S., Snowling, M. J., Taylor, E. (Eds.), *Rutter's Child and Adolescent Psychiatry* (6th ed., pp. 665–682). John Wiley & Sons Ltd. <https://doi.org/10.1002/9781444300895>
- Lee, D. D., Goedeke, S., & Krägeloh, C. U. (2019). Spirituality and religion in clinical practice: The experiences of psychologists in the integration of spirituality and religion in therapy in Aotearoa New Zealand. *New Zealand Journal of Psychology*, 48(2), 82–90.
- Lefale, P. F. (2010) Ua 'afa le aso Stormy weather today: traditional ecological knowledge of weather and climate: The Samoa experience. *Climatic Change*, 100(2), 317–335, <https://doi.org/10.1007/s10584-009.9722-z>

- Legg, H, & Tickle, A. (2019). UK parents' experiences of their child receiving a diagnosis of autism spectrum disorder: A systematic review of the qualitative evidence, *Autism*, 23(8) 1897–1910.
<https://doi.org/10.1177/1362361319841488>
- Le Va. (2014). *Organisational Guidelines for Disability Support Services: Working with Pasifika People with Disabilities and their Families*. Le Va.
- Le Va. (2019). Weaving together knowledge for wellbeing: Trauma informed approaches.
<https://www.leva.co.nz/resources/a-trauma-informed-approach-when-working-with-pasifika-people/>
- Le Va. (2020a). Engaging Pasifika: Quick Reference. https://www.leva.co.nz/wp-content/uploads/2020/05/EP_R_quickguide.pdf
- Le Va. (2020b). Rainbow/LGBTI. <https://www.leva.co.nz/our-work/suicideprevention/finding-help/support-services/Rainbow>
- Le Va. (2022a). Engaging Pasifika Live Online. [PowerPoint presentation]. https://www.leva.co.nz/wp-content/uploads/2021/09/EPLiveOnline_Slides-1.pdf
- Le Va. (2022b). Supporting the public health workforce. <https://www.leva.co.nz/training-education/public-health-workforce-grants/>
- Levy, M. P. (2018). *Indigenous psychology in Aotearoa: reaching our highest peaks*. National Standing Committee for Bicultural Interests, New Zealand Psychological Society & New Zealand College of Clinical Psychologists.
https://natlib-primo.hosted.exlibrisgroup.com/primo-explore/fuldisplay?docid=NLNZ_ALMA11372619710002836&context=L&vid=NLNZ&search_scope=NLNZ&tab=catalogue&lang=en_US
- Lewis-Fernández, R., Kirmayer, L. J., Guarnaccia, P. J., & Ruiz, P. (2017). Cultural concepts of distress. In Sadock, B. J., Sadock V. A., & Ruiz, R. (Eds.), *Kaplan & Sadock's Comprehensive Textbook of Psychiatry*, (10th ed., Vol 2, pp. 2443–2460). Lippincott Williams & Wilkins.
<https://eds.s.ebscohost.com/eds/ebookviewer/ebook/bmxlYmtfXzE4NTc1OTFfX0FO0?sid=016ad98c-91bb-49fd-9098-fdd5e98b6d5e@redis&vid=16&format=EK&rid=1>

- Lewis-Fernández, R., & Kirmayer, L. J. (2019). Cultural concepts of distress and psychiatric disorders: Understanding symptom experience and expression in context. *Transcultural Psychiatry*, 56(4), 786–803. <https://doi.org/10.1177/1363461519861795>
- Lilley, R., Sedgwick, M., & Pellicano, E. (2020). Inclusion, acceptance, shame and isolation: Attitudes to Autism in Aboriginal and Torres Strait Islander communities in Australia. *Autism: The International Journal of Research and Practice*, 24(7), 1860–1873. <http://dx.doi.org/10.1177/1362361320928830>
- Lilomaiaava-Doktor, S. (2009). Beyond 'migration': Samoan population movement (malaga) and the geography of social space (va). *The Contemporary Pacific*, 21(1). http://libproxy.unitec.ac.nz:2048/login?url=http://go.galegroup.com/ps/i.do?id=GALE%7CA192101753&v=2.1&u=per_unit&it=r&p=AONE&sw=w&asid=e7a1e8188954e1703f4035f3d400ccb5
- Lim, N., O'Reilly, M. F., Sigafoos, J., & Lancioni, G. E. (2018). Understanding the linguistic needs of diverse individuals with Autism Spectrum Disorder: Some comments on the research literature and suggestions for clinicians. *Journal of Autism and Developmental Disorders*, 48(8), 2890–2895. <https://doi.org/10.1007/s10803-018-3532-y>
- Lim, N., O'Reilly, M. F., Sigafoos, J., Ledbetter-Cho, K., & Lancioni, G. E. (2019). Should heritage languages be incorporated into interventions for bilingual individuals with neurodevelopmental disorders? A systematic review. *Journal of Autism & Developmental Disorders*, 49(3), 887–912. <https://doi.org/10.1007/s10803-018-3790-8>
- Lindblom, A. (2014). Under-detection of autism among First Nations children in British Columbia, Canada. *Disability and Society*, 29(8), 1248–1259. <https://doi.org/10.1080/09687599.2014.923750>
- Lindblom, A. (2017). Exploring autism and music interventions through a first nations lens. *AlterNative: An International Journal of Indigenous Peoples*, 13(4), 202–209. <https://doi.org/10.3316/informit.296698506160905>
- Listopad, I. W., Esch, T., & Michaelsen, M. M. (2021a). An empirical investigation of the relationship between spirituality, work culture, and burnout: The need for an extended health and disease model. *Frontiers in Psychology*, 12, 1–23. <https://doi.org/10.3389/fpsyg.2021.723884>

- Listopad, I. W., Michaelsen, M. M., Werdecker, L., & Esch, T. (2021b). Bio-Psycho-Socio-Spirito-Cultural factors of Burnout: A systematic narrative review of the literature. *Frontiers in Psychology*, 12, 1–23. <https://doi.org/10.3389/fpsyg.2021.722862>
- Luft, J. & Ingham, H. (1955). *The Johari window, a graphic model of interpersonal awareness*. Proceedings of the Western Training Laboratory in Group Development. University of California, Los Angeles.
- Luong, J., Yoder, M. K., & Canham, D. (2009). Southeast Asian parents raising a child with Autism: A qualitative investigation of coping styles. *Journal of School Nursing*, 25(3), 222–229. <https://doi.org/10.1177/1059840509334365>
- Lutz, H. R., Patterson, B. J., & Klein, J. (2012). Coping with Autism: A journey toward adaptation. *Journal of Pediatric Nursing*, 27(3), 206–213. <https://doi.org/10.1016/j.pedn.2011.03.013>
- Macfarlane A. & Macfarlane S. (2014) Māori epistemology. In Coughlan, D. & Brydon-Miller, M. (Eds.), *Encyclopaedia of Action Research*, 519–530. Sage Publications Ltd.
- Macfarlane, A., Macfarlane, S., & Gillon, G. (2014). Inclusion, disability and culture: The nexus of potential and opportunity for policy development. In Wills, R., Morton, M., McLean, M., Stephenson, M., & Slee, R. (Eds.), *Tales from school: Learning disability and state education after administrative reform* (pp. 255–270). Sense Publishers.
- Macfarlane, S., Macfarlane, A., & Gillon, G. (2015). Sharing the food baskets of knowledge: creating space for a blending of streams. In Macfarlane, A., Macfarlane, S., & Webber, M. (Eds.), *Sociocultural realities: exploring new horizons* (pp. 52–67). Canterbury University Press.
- Macpherson, C. (2015). Belonging in Oceania: movement, place-making and multiple identification. *The Journal of Pacific History*, 50(3), 376–377. <https://doi.org/10.1080/00223344.2015.1071184>
- MacPherson, L. (2014). 2013 New Zealand Disability Survey. <https://www.stats.govt.nz/information-releases/disability-survey-2013>
- Macpherson, C., & Macpherson, L. (1990). *Samoan medical belief and practice*. Auckland University Press.
- Maenner, M. J., Shaw, K. A., Bakian, A. V., Bilder, D. A., Durkin, M. S., Esler, A., Furnier, S. M., Hallas, L., Hall-Lande, J., Hudson, A., Hughes, M. M., Patrick, M., Pierce, K., Poynter, J. N., Salinas, A., Shenouda, J., Vehorn, A., Warren,

- Z., Constantino, J. N., & DiRienzo, M. ... & Cogswell, M. E. (2021). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years -- Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. *MMWR Surveillance Summaries*, 70(11), 1–16.
- Makasiale, C. O. (2007). The use of symbol and metaphor in Pasifika counseling. In Makasiale, C. O., Agee, M. N., & Culbertson, P. (Eds.), *Penina uliuli: contemporary challenges in mental health for Pacific peoples*. University of Hawaii Press.
- Makasiale, C. O. (2013). The whole person and the heart: supervision the Pacific way. In Agee, M. N., McIntosh, T., Culbertson, P. L., & Makasiale, C. O. (Eds.), *Pacific identities and well-being: cross-cultural perspectives* (pp. 206–267). Otago University Press.
- Mallon, S. (2012). Little-known lives: Pacific Islanders in nineteenth-century New Zealand. In Mallon, S., Māhina-Tuai, K. U., & Salesa, D. I. (Eds.), *Tangata o le moana: New Zealand and the people of the Pacific*, (pp. 77-96). Te Papa Press.
- Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, 26(13), 1753–1760. <https://doi.org/10.1177/1049732315617444>
- Mandell, D. S., Ittenbach, R. F., Levy, S. E., & Pinto-Martin, J. A. (2007). Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder. *Journal of Autism & Developmental Disorders*, 37(9), 1795–1802. <https://doi.org/10.1007/s10803-006-0314-8>
- Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with Autism. *Journal of the American Academy of Child & Adolescent Psychiatry*, 41(12), 1447–1453. <https://doi.org/10.1097/00004583-200212000-00016>
- Mandell, D., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation & Developmental Disabilities Research Reviews*, 11, 110–115. <https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=eric&AN=EJ904459&site=eds-live&scope=site>

- Mandy, W. (2018). The Research Domain Criteria: A new dawn for neurodiversity research? *Autism*, 22(6), 642–644.
<https://doi.org/10.1177/1362361318782586>
- Manuela, S., & Sibley, C. (2013). The Pacific-Indigenous Identity and Wellbeing Scale (PIWBS): A culturally-appropriate self-report measure for Pacific-Indigenous Peoples in New Zealand. *Social Indicators Research*, 112(1), 83–103.
<https://doi.org/10.1007/s11205-012-0041-9>
- Marsden, M., & Henare, T. (1992). *Kaitiakitanga: A definitive introduction to the holistic world view of the Māori*. Ministry of the Environment.
- Martel, R., Shepherd, M., & Goodyear-Smith, F. (2022). He awa whiria—A “Braided River”: An Indigenous Māori approach to mixed methods research. *Journal of Mixed Methods Research*, 16(1), 17–33.
<https://doi.org/10.1177/1558689820984028>
- Matapo, J., & Enari, D. (2021). Re-imagining the dialogic spaces of talanoa through Samoan onto-epistemology. *Waikato Journal of Education. Special Issue: Talanoa Vā: Honouring Pacific Research and Online Engagement*, 26, 79–88. <https://doi.org/10.15663/wje.v26i1.770>
- Matapo, J., & McFall-McCaffery, J. T. (2022). Towards a Va knowledge ecology: Mobilising Pacific philosophy to transform Higher Education for Pasifika in Aotearoa New Zealand. *Journal of Higher Education Policy and Management*, 44(2), 122–137. <https://doi.org/http://www.tandfonline.com/loi/cjhe20>
- Matapo, J., & Teisina, J. (2021). Reimagining teacher subjectivity in Pacific Early Childhood Education in New Zealand. *Policy Futures in Education*, 19(4), 493–506. <http://dx.doi.org/10.1177/1478210320960890>
- Maua-Hodges, T. (2000). *Ako pai ki aitutaki: Transporting or weaving cultures: Research report of field experiences to the Cook Islands*. Wellington College of Education.
- Mauigoa-Tekene, L., Howie, L., & Hagan, B. (2013). *Understanding special education from the perspectives of Pasifika families, Report to the Ministry of Education*. Ministry of Education.
- McFadgen, B. G., & Adds, P. (2019). Tectonic activity and the history of Wairau Bar, New Zealand’s iconic site of early settlement. *Journal of the Royal Society of New Zealand*, 49(4), 459–473.
<http://www.tandfonline.com/doi/pdf/10.1080/03036758.2018.1431293>

- McPartland, J., Reichow, B., & Volkmar, F. (2012). Sensitivity and specificity of proposed DSM-5 diagnostic criteria for Autism Spectrum Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(4), 368–383.
<https://doi.org/10.1016/j.jaac.2012.01.007>
- Menezes, M., Robinson, M. F., Harkins, C., Sadikova, E., & Mazurek, M. O. (2021). Unmet health care needs and health care quality in youth with Autism Spectrum Disorder with and without Intellectual Disability. *Autism: The International Journal of Research and Practice*, 25(8), 2199–2208.
<http://dx.doi.org/10.1177/13623613211014721>
- Meo-Sewabu, L. (2014). Cultural discernment and ethics. *Asia Pacific Viewpoint*, 55, 345–354.
<https://doi.org/10.1111/apv.12059>
- Mila, K. (2017). Deconstructing the Big Brown Tails/Tales: Pasifika peoples in Aotearoa New Zealand. In McIntosh, T., Elizabeth, V., Bell, A., & Wynyard, M. (Eds.), *A land of milk and honey?: making sense of Aotearoa New Zealand* (pp. 68-76). Auckland University Press.
- Mila-Schaaf, K. (2010). Polycultural capital and the Pasifika second generation: negotiating identities in diasporic spaces (Unpublished doctoral thesis). Massey University. <http://mro.massey.ac.nz/xmlui/handle/10179/1713>
- Mila-Schaaf, K. (2013). Not another New Zealand-born identity crisis. In Agee, M. N., McIntosh, T., Culbertson, P., & Makasiale, C. O. (Eds.), *Pacific Identities and Well-being: Cross-cultural Perspectives* (pp. 49-64). Otago University Press.
- Mila-Schaaf, K., & Hudson, M. (2009). *Negotiating space for Indigenous theorising in Pacific mental health and addictions*. Le Va Pasifika within Te Pou.
- Ministries of Health and Education (2016). *New Zealand Autism Spectrum Disorder Guideline* (2nd edition). Ministry of Health. <https://www.health.govt.nz/publication/new-zealand-autism-spectrum-disorder-guideline>
- Ministry for Culture and Heritage (2020). Influenza in Samoa. <https://nzhistory.govt.nz/culture/1918-influenza-pandemic/samoa>
- Ministry of Education. (2020). Early intervention services (EIS). <https://www.education.govt.nz/early-childhood/teaching-and-learning/early-intervention/>

- Ministry of Education. (2021). How the Ministry's learning support works. <https://parents.education.govt.nz/learning-support/learning-support-needs/how-the-ministrys-learning-support-works/>
- Ministry of Education. (2022). Early intervention service. <https://parents.education.govt.nz/learning-support/early-learning-support/services-and-support-available/#early-int>
- Ministry of Health. (1995). *Pacific Islands Peoples' understanding of mental health. Strategic directions for the mental health services for Pacific Islands people.* Ministry of Health. [https://www.moh.govt.nz/notebook/nbbooks.nsf/0/0E79FEE76226D65E4C2565D70018A4B6/\\$file/mental-health-services-PI-people.pdf](https://www.moh.govt.nz/notebook/nbbooks.nsf/0/0E79FEE76226D65E4C2565D70018A4B6/$file/mental-health-services-PI-people.pdf)
- Ministry of Health. (2008a). *Pacific Peoples and Mental Health: A paper for the Pacific Health and Disability Action Plan review.* Ministry of Health. <https://www.health.govt.nz/publication/pacific-peoples-and-mental-health-paper-pacific-health-and-disability-action-plan-review>
- Ministry of Health. (2008b). *Pacific Peoples' Experience of Disability: A paper for the Pacific Health and Disability Action Plan review.* Ministry of Health. <https://www.health.govt.nz/system/files/documents/publications/pacific-peoples-experience-of-disability-may08.pdf>
- Ministry of Health. (2012). *What does ASD look like? Quickcard - Samoan.* <https://www.health.govt.nz/publication/what-does-asd-look-quickcard-samoan>
- Ministry of Health. (2013). *Disability Workforce Action Plan 2013-2016.* Disability Workforce. <https://www.health.govt.nz/our-work/disability-services/disability-projects/disability-workforce>
- Ministry of Health. (2016). *About Disability Support Services.* <https://www.health.govt.nz/our-work/disability-services/about-disability-support-services>
- Ministry of Health. (2017). *Faiva Ora 2016–2021: National Pasifika Disability Plan.* https://www.health.govt.nz/system/files/documents/publications/faiva-ora-2016-2021-national-pasifika-disability-plan-aug17_0.pdf
- Ministry of Health. (2018a). *Annual Data Explorer 2017/18: New Zealand Health Survey* [Data File]. <https://minhealthnz.shinyapps.io/nz-health-survey-2017-18-annual-data-explorer/>

- Ministry of Health. (2018b). Autism spectrum disorder support. <https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/autism-spectrum-disorder-support>
- Ministry of Health. (2018c). Child Development Services. <https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/child-development-services>
- Ministry of Health. (2018d). *Living Guideline Group: Keeping the ASD Guideline up to date*. <https://www.health.govt.nz/our-work/disability-services/disability-projects/autism-spectrum-disorder-guideline/living-guideline-group-keeping-asd-guideline-date#papers>
- Ministry of Health. (2019). *Demographic Report for Clients Allocated the Ministry of Health's Disability Support Services: 2018 update*. Ministry of Health. <https://www.health.govt.nz/publication/demographic-report-clients-allocated-ministry-healths-disability-support-services-2018-update>
- Ministry of Health. (2020). *'Ola Manuia: Pacific Health and Wellbeing Action Plan 2020-2025*. Ministry of Health. https://www.health.govt.nz/system/files/documents/publications/ola_manuia-phwap-22june.pdf
- Ministry of Health. (2021). *Annual Data Explorer 2020/21: New Zealand Health Survey* [Data File]. <https://minhealthnz.shinyapps.io/nz-health-survey-2020-21-annual-data-explorer/>
- Ministry of Health. (2022a). *Adults' Dietary Habits – Findings from the 2018/19 and 2019/20 New Zealand Health Survey*. Ministry of Health. <https://www.health.govt.nz/publication/adults-dietary-habits>
- Ministry of Health. (2022b). Carer support. <https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/respite/carers-support>
- Ministry of Health. (2022c). *Position statement and working definitions for racism and anti-racism in the health system in Aotearoa New Zealand*. Ministry of Health. <https://www.health.govt.nz/publication/position-statement-and-working-definitions-racism-and-anti-racism-health-system-aotearoa-new-zealand>
- Mirfin-Veitch, B., Jalota, N., & Schmidt, L. (2020). *Responding to neurodiversity in the education context: An integrative review of the literature*. Donald Beasley Institute. <https://parent2parent.org.nz/wp-content/uploads/2020/07/Responding-to-neurodiversity-Beasley-Institute.pdf>
- Moana Research. (2021). Pacific Data Sovereignty. <https://www.moanaresearch.co.nz/pacific-data-sovereignty/>

- Mo'a, V. (2014). Le aso ma le taeao – The day and the hour: Life or demise for “Whispers and Vanities”? In Suaalii Sauni, T. M., Wendt, M. A., Mo'a, V., Fuamatu, N., Va'ai, U. L., Whaitiri, R., & Filipo, S. L. (Eds.), *Whispers and Vanities: Samoan indigenous knowledge and religion* (pp. 45–57). Huia Publishers.
- Mo'a, V. (2015). Culture as a foundation for care. In. Pacific Perspectives Limited (Ed.), *Aniva Pacific Health Workforce Fono* (pp. 1–6). https://www.pacificperspectives.co.nz/files/ugd/840a69_da1886ebb72841068fe683307b035666.pdf
- Moon, K., and Blackman, D. (2014). A Guide to Understanding Social Science Research for Natural Scientists. *Conservation Biology*, 28, 1167–1177. <http://onlinelibrary.wiley.com/doi/10.1111/cobi.12326/full>
- Musharbash, Y. (2019). A Story in and on signs: Making resistance and acquiescence legible as forms of resilience. In L. Dousset & M. Nayral (Eds.), *Pacific Realities: Changing Perspectives on Resilience and Resistance* (1st ed., Vol. 6, pp. 23–43). Berghahn Books. <https://doi.org/10.2307/j.ctvw04bg3.5>
- Myers, J., Chavez, A., Hill, A., Zuckerman, K., & Fombonne, E. (2019). Epidemiological surveys of Autism Spectrum Disorders. In F. Volkmar (Ed.), *Autism and Pervasive Developmental Disorders* (pp. 25–60). Cambridge University Press. <https://doi.org/10.1017/9781108297769.003>
- Nabobo-Baba, U. (2006). *Knowing and learning: an indigenous Fijian approach*. Institute of Pacific Studies, University of the South Pacific.
- New Zealand Public Health and Disability Amendment Act 2020. <https://www.legislation.govt.nz/act/public/2020/0061/latest/LMS298000.html>
- Nord, M. I. (2022). Thinking like a bricoleur: New forms of rigor in research on information experience. *Library and Information Science Research*. (in press) <https://doi.org/10.1016/j.lisr.2022.101197>
- NZ Herald. (2002, June 4). Full text: Helen Clark's apology to Samoa. <https://www.nzherald.co.nz/nz/full-text-helen-clarks-apology-to-samoa/65TV2LDV6S7HHIYRDCFSC5YOZI/>
- O'Keefe, V. M., Fish, J., Maudrie, T. L., Hunter, A. M., Tai Rakena, H. G., Ullrich, J. S., Clifford, C., Crawford, A., Brockie, T., Walls, M., Haroz, E. E., Cwik, M., Rumbaugh Whitesell, N., & Barlow, A. (2022). Centering Indigenous knowledges and worldviews: Applying the Indigenist Ecological Systems Model to youth mental health and

wellness research and programs. *International Journal of Environmental Research and Public Health*, 19, 6271.

<https://doi.org/10.3390/ijerph19106271>

Ooi, K. L., Ong, Y. S., Jacob, S. A., & Khan, T. M. (2016). A meta-synthesis on parenting a child with autism.

Neuropsychiatric Disease and Treatment, 12, 745-762. <http://dx.doi.org/10.2147/NDT.S100634>

Opai, K. (2017). A time and space for Takiwātanga. *Altogether Autism Journal*, 2.

https://issuu.com/lifeunlimited1/docs/altogether_autism_journal_issue_2

Ouellette-Kuntz, H. M. J., Coe, H., Lam, M., Yu, C. T., Breitenbach, M. M., Hennessey, P. E., Holden, J. J. A., Brown, H.

K., Noonan, A. L., Gauthier, R. B., & Crews, L. R. (2009). Age at diagnosis of Autism Spectrum Disorders in four regions of Canada. *Canadian Journal of Public Health / Revue Canadienne de Santé Publique*, 100(4), 268–273.

<https://www.jstor.org/stable/41995266>

Pacheco, J., Garvey, M. A., Sarampote, C. S., Cohen, E. D., Murphy, E. R. and Friedman-Hill, S. R. (2022), Annual

Research Review: The contributions of the RDoC research framework on understanding the neurodevelopmental origins, progression and treatment of mental illnesses. *Journal of Child Psychology and Psychiatry*, 63, 360–376.

<https://doi-org.ezproxy.massey.ac.nz/10.1111/jcpp.13543>

Paralikar, V. P., Deshmukh, A., & Weiss, M. G. (2020). Qualitative Analysis of Cultural Formulation Interview: findings and

implications for revising the outline for cultural formulation. *Transcultural Psychiatry*, 57(4), 525–541.

<https://doi.org/10.1177/1363461518822407>

Patall, E. A. & Hooper, S. Y. (2017). The role of choice in understanding adolescent autonomy and academic functioning.

In Soenens, B., Vansteenkiste, M., & Van Petegem, S. (Eds.), *Autonomy in Adolescent Development: Towards conceptual clarity* (1st ed., pp. 145–167). <https://doi-org.ezproxy.massey.ac.nz/10.4324/9781315636511>

Paterson, J., Tautolo, E-S., Iusitini, L., & Taylor, S. (2016). Pacific Islands Families Study: psychological distress among

mothers of Pacific children living in New Zealand. *Australian and New Zealand Journal of Public Health*, 40(2), 110–114. <https://doi.org/10.1111/1753-6405.12491>

- Paterson, J., Tautolo, E-S., Iusitini, L., & Sisk, R. (2018). Cultural, individual, and familial risk and protective factors associated with depressive symptoms in Pacific youth living in New Zealand. *Social Work in Mental Health*, 16(6), 728–745, <https://doi.org/10.1080/15332985.2018.1497566>
- Patton, M. Q. (2015). *Qualitative research & evaluation methods: integrating theory and practice* (4th edition). SAGE.
- Payakachat, N., Long, C. R., McElfish, P. A., Narcisse, M.-R., Felix, H. C., Bursac, Z., & Hudson, T. J. (2019). Prevalence, health and resource utilization, and unmet healthcare needs of Native Hawaiian and Pacific Islander children with developmental disabilities. *American Journal on Intellectual & Developmental Disabilities*, 124 (3), 234–247. <https://doi.org/10.1352/1944-7558-124.3.234>
- Pearson, J. N., Stewart-Ginsburg, J. H., Malone, K., & Avent Harris, J. R. (2022). Faith and FACES: Black parents' perceptions of Autism, faith, and coping. *Exceptional Children*, 88(3), 316–334. <https://doi.org/10.1177/00144029211034152>
- Pere, R. (1997). Māori Health Models – Te Wheke. Ministry of Health. <https://www.health.govt.nz/our-work/populations/maori-health/maori-health-models/maori-health-models-te-wheke>
- Pesco, D., MacLeod, A. A. N., Kay-Raining Bird, E., Cleave, P., Trudeau, N., de Valenzuela, J. S., Cain, K., Marinova-Todd, S. H., Colozzo, P., Stahl, H., Segers, E., & Verhoeven, L. (2016). A multi-site review of policies affecting opportunities for children with developmental disabilities to become bilingual. *Journal of Communication Disorders*, 63, 15–31. <https://doi.org/10.1016/j.jcomdis.2016.05.008>
- Pitama, S. G., Haitana, T. N., Beckert, L., Palmer, S. C., Huria, T. M., Lacey, C. J., Bennett, S. T., Valentine, H., Pahina, J., Taylor, J. E., Tassell-Matamua, N., Rowe, L., Waitoki, W., & McLachlan, A. (2017). A proposed Hauora Māori clinical guide for psychologists: Using the Hui Process and Meihana Model in clinical assessment and formulation. *New Zealand Journal of Psychology*, 46(3), 7–19.
- Pitama, S., Huria, T., & Lacey, C. (2014). Improving Māori health through clinical assessment: Waikare o te Waka o Meihana. *New Zealand Medical Journal*. https://ndhadeliver.natlib.govt.nz/delivery/DeliveryManagerServlet?dps_pid=IE20388314

- Pitama, S., Robertson, P., Cram, F., Gillies, M., Huria, T., & Dallas-Katoa, W. (2007). Meihana Model: A clinical assessment framework. *New Zealand Journal of Psychology*, 36(3).
- Pituch, K. A., Green, V. A., Didden, R., Lang, R., O, R. M. F., Lancioni, G. E., & Sigafos, J. (2011). Parent reported treatment priorities for children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(1), 135–143. <https://doi.org/10.1016/j.rasd.2010.03.003>
- Polson, H. (2016). The development of a Makaton resource for Samoan children. In Bevan-Brown, J. & Dharan, V. (Eds.), *Autism spectrum disorder in Aotearoa New Zealand: Promising practices and interesting issues* (pp. 49–67). NZCER Press.
- Prescott, S. M., & Johansson Fua, S. (2016, July). *Enhancing educational success through Talanoa: A framework for the Pacific*. A. Kautoke (Ed.), Vaka Pasifiki Education Conference (pp.1–27). <https://hdl.handle.net/10652/3676>
- Priest, J. B. (2021). *The science of Family Systems Theory* (1st ed.). Routledge. <https://doi-org.ezproxy.massey.ac.nz/10.4324/9780367854591>
- Pulotu-Endemann, F. K. & Faleafa, M. (2017). Developing a culturally competent workforce that meets the needs of Pacific People living in New Zealand. In Smith, M., & Jury, A. (Eds.), *Workforce development theory and practice in the mental health sector* (pp. 165–180). IGI Global. <https://www-igi-global-com.ezproxy.massey.ac.nz/gateway/chapter/full-text-pdf/171510>
- Pulotu-Endemann, F. K., Suaali'i-Sauni, T., Lui, D., McNicholas, T., Milne, M., & Gibbs, T. (2007). *Seitapu Pacific mental health and addiction cultural and clinical competencies framework*. National Centre of Mental Health Research and Workforce Development.
- Ramsey, E., Kelly-Vance, L., Allen, J. A., Rosol, O., & Yoerger, M. (2016). Autism Spectrum Disorder prevalence rates in the United States: Methodologies, challenges, and implications for individual states. *Journal of Developmental and Physical Disabilities*, 28(6), 803–820. <https://doi.org/10.1007/s10882-016-9510-4>
- Ravindran, N., & Myers, B. J. (2012). Cultural influences on perceptions of health, illness, and disability: A review and focus on Autism. *Journal of Child and Family Studies*, 21(2), 311–319.

<https://search.ebscohost.com/login.aspx?direct=true&AuthType=sso&db=eric&AN=EJ959168&site=eds-live&scope=site>

- Ravulo, J., Mafile'o, T., & Yeates, D. B. (2019). Introduction to Pacific social work: Places, peoples, perspectives and practices. In Ravulo, J., Mafile'o, T., & Yeates, D. B. (Eds.), *Pacific Social Work* (pp. 3–10). Routledge.
- Reid, P., & Robson, B. (2007). Understanding health inequities. *Hauora: Maori Standards of Health IV. A Study of the Years 2000-2005*. University of Auckland.
- Rice, G. W. (2019). Remembering 1918: Why did Māori suffer more than seven times the death rate or non-Māori New Zealanders in the 1918 Influenza pandemic? *New Zealand Journal of History*, 53(1), 90–108.
- Rodgers, M., Simmonds, M., Marshall, D., Hodgson, R., Stewart, L. A., Rai, D., Wright, K., Ben-Itzhak, E., Eikeseth, S., Eldevik, S., Kovshoff, H., Magiati, I., Osborne, L. A., Reed, P., Vivanti, G., Zachor, D., & Le Couteur, A. L. (2021). Intensive behavioural interventions based on Applied Behaviour Analysis for young children with Autism: An international collaborative individual participant data meta-analysis. *Autism: The International Journal of Research and Practice*, 25(4), 1137–1153. <http://dx.doi.org/10.1177/1362361320985680>
- Roy, R., Greaves, L. M., Peiris-John, R., Clark, T., Fenaughty, J., Sutcliffe, K., Barnett, D., Hawthorne, V., Tiatia-Seath, J., & Fleming, T. (2021). *Negotiating multiple identities: Intersecting identities among Māori, Pacific, Rainbow and Disabled young people*. The Youth19 Research Group, The University of Auckland and Victoria University of Wellington, New Zealand.
- Ryan, P. (2019). *Enhancing clinical case formulation*. Routledge. <https://doi-org.ezproxy.massey.ac.nz/10.4324/9780429486418>
- Salesa, D. I. (2012). In Mallon, S., Māhina-Tuai, K. U., & Salesa, D. I. (Eds.), *Tangata o le moana: New Zealand and the people of the Pacific* (pp. 97–122). Te Papa Press.
- Samoa Voyaging Society. (2012, April 7). *Lines, paths, houses and songs* [Blog post]. Blogger. <https://samoavoyagingsociety.blogspot.com/2012/04/>
- Samu, L.-J. V., Barnes, H. M., Asiasiga, L., & McCreanor, T. (2019). "We are not privileged enough to have that foundation of language": Pasifika young adults share their deep concerns about the decline of their ancestral/heritage

languages in Aotearoa New Zealand. *AlterNative: An International Journal of Indigenous Peoples*, 15(2), 131–139. <https://doi.org/10.3316/informit.583981657019833>

Sanga, K. (2004). Making Philosophical Sense of Indigenous Pacific Research. In T. [et al] Baba (Ed.), *Researching Pacific and indigenous peoples: issues and perspectives*. <http://trove.nla.gov.au/version/40187999>

Sanga, K. F., & Reynolds, M. (2017). To know more of what it is and what it is not: Pacific research on the move. *Pacific Dynamics*, (1)2, 198–204. <https://ir.canterbury.ac.nz/bitstream/handle/10092/14973/1Kabini%20Sanga.pdf?sequence=1&isAllowed=y>

Sansosti, F. J., Lavik, K. B., & Sansosti, J. M. (2012). Family experiences through the Autism diagnostic process. *Focus on Autism and Other Developmental Disabilities*, 27(2), 81–92.

Schluter, P. J., Kokaua, J., Tautolo, E. S., Iusitini, L., Richards, R., & Ruhe, T. (2022). Parental education related to their children's health in late childhood and early adolescence for Pacific families within New Zealand. *Scientific Reports*, 12, 5313. <https://doi.org/10.1038/s41598-022-09282-x>

Schofield, G., & Beek, M. (2014). *The secure base model: promoting attachment and resilience in foster care and adoption*. British Association for Adoption & Fostering.

Schwichtenberg, A. J., & Poehlmann, J. (2007). Applied behaviour analysis: Does intervention intensity relate to family stressors and maternal well-being? *Journal of Intellectual Disability Research*, 51, 598–605.

Searing, B., Graham, F., & Grainger, R. (2015). Support needs of families living with children with Autism Spectrum Disorder. *Journal of Autism & Developmental Disorders*, 45(11), 3693–3702. <https://doi.org/10.1007/s10803-015-2516-4>

Shaw, K. A., Maenner, M. J., Baio, J., Washington, A., Christensen, D. L., Wiggins, L. D., Pettygrove, S., Andrews, J. G., White, T., Rosenberg, C. R., Constantino, J. N., Fitzgerald, R. T., Zahorodny, W., Shenouda, J., Daniels, J. L., Salinas, A., Durkin, M. S., & Dietz, P. M. (2020). Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years -- Early Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2016. *MMWR Surveillance Summaries*, 69(3/4), 3–11. <https://doi.org/10.15585/mmwr.ss6903a1>

- Shochet, I. M., Orr, J. A., Kelly, R. L., Wurfl, A. M., Saggars, B. R., & Carrington, S. B. (2020). Psychosocial resources developed and trialled for Indigenous people with autism spectrum disorder and their caregivers: a systematic review and catalogue. *International Journal for Equity in Health*, 19(1), 1–19. <https://doi.org/10.1186/s12939-020-01247-8>
- Shpigler, H. Y., Saul, M. C., Corona, F., Block, L., Ahmed, A. C., Zhao, S. D., & Robinson, G. E. (2017). Deep evolutionary conservation of autism-related genes. *Proceedings of the National Academy of Sciences of the United States of America*, 114(36), 9653–9658. www.pnas.org/cgi/doi/10.1073/pnas.1708127114
- Shyu, Y. I., Tsai, J. L., & Tsai, W. C. (2010). Explaining and selecting treatments for autism: parental explanatory models in Taiwan. *Journal of Autism and Developmental Disorders*, 40(11), 1323–1331. <https://doi.org/10.1007/s10803-010-0991-1>
- Simi, T. (1992). *A deeper song: Poems by Tate Simi*. Samoa Observer.
- Simpson, H. A. (2021). Forming strong cultural identities in an intersecting space of indigeneity and autism in Canada, the United States, Australia, and New Zealand. *AlterNative*, 17(3), 416–424. <https://doi.org/10.1177/11771801211039274>
- Smith, H., & Wolfgramm-Foliaki, E. (2022). Vā-kā: Igniting the space between Mana Whenua and Mana Moana research relations. *New Zealand Sociology*, 37(1), 20–41. <https://eds.p.ebscohost.com/eds/pdfviewer/pdfviewer?vid=2&sid=3513e46d-1082-45a9-ae91-845a50092d4d%40redis>
- Smith, L. T. (2021). *Decolonizing methodologies: Research and Indigenous peoples*. Zed Books. <http://dx.doi.org.ezproxy.massey.ac.nz/10.5040/9781350225282.0013>
- Soenens, B., Vansteenkiste, M., Van Petegem, S., Beyers, W., & Ryan, R. (2017). How to solve the conundrum of adolescent autonomy. On the importance of distinguishing between independence and volitional functioning. In Soenens, B., Vansteenkiste, M., & Van Petegem, S. (Eds.), *Autonomy in adolescent development: Towards conceptual clarity* (1st ed., pp. 1–32). <https://doi-org.ezproxy.massey.ac.nz/10.4324/9781315636511>
- Sommers-Flanagan, J., & Sommers-Flanagan, R. (2017). *Clinical interviewing* (6th edition). John Wiley & Sons, Inc.

- Stats NZ. (2014, June 17). Disability Survey 2013. <https://www.stats.govt.nz/information-releases/disability-survey-2013>
- Strauss-Hughes, A., Heffernan, R., & Ward, T. (2019). A cultural–ecological perspective on agency and offending behaviour. *Psychiatry, Psychology and Law*, 26(6), 938–958. <https://doi.org/10.1080/13218719.2019.1644250>
- Suaalii Sauni, T., & Fulu-Aiolupotea, S. M. (2014). Decolonising Pacific research, building Pacific research communities and developing Pacific research tools: The case of the talanoa and the fa'afaletui in Samoa. *Asia Pacific Viewpoint*, 55(3), 331–344. <https://doi.org/10.1111/apv.12061>
- Suaalii Sauni, T., McTaggart, S., & Von Randow, M. (2009). *Pacific families now and in the future: A qualitative snapshot of household composition, wellbeing, parenting and economic decision-making among Pacific families in Auckland, 2008*. Report 2/2 to the Families Commission. Auckland Uniservices Ltd.
- Suaalii Sauni, T. M., Wendt, M. A., Mo'a, V., Fuamatu, N., Va'ai, U. L., Whitiri, R., & Filipino, S. L. (2014). *Whispers and Vanities: Samoan indigenous knowledge and religion*. Huia Publishers.
- Su'a-Tavila, A. (2019). Contemporary Pacific Values and Beliefs. In Ravulo, J., Mafle'o, T., & Yeates, D. B. (Eds.), *Pacific Social Work* (pp. 11–21). Routledge.
- Swensen, L. D., Kelley, E., Fein, D., & Naigles, L. R. (2007). Processes of language acquisition in children with Autism: Evidence from preferential looking. *Child Development*, 78(2), 542–557. <https://doi.org/10.1111/j.1467-8624.2007.01022.x>
- Tager-Flusberg, H., & Kasari, C. (2013). Minimally verbal school-aged children with autism spectrum disorder: The neglected end of the spectrum. *Autism Research*, 6(6), 468–478. <https://doi.org/10.1002/aur.1329>
- Taleni, T. O., Macfarlane, S., Macfarlane, A. H., & Fletcher, J. (2018). Tofa liuliu ma le tofa saili a ta'ita'i Pasefika: Listening to the voices of Pasifika community leaders. *New Zealand Journal of Educational Studies*, 53(2), 177–192. <https://doi.org/10.1007/s40841-018-0114-7>
- Tamaira, A. M. (2009). *The Space Between: Negotiating Culture, Place, and Identity in the Pacific*. Occasional Paper Series 44. Center for Pacific Islands Studies, School of Pacific and Asian Studies, University of Hawai'i at Mānoa. <https://scholarspace.manoa.hawaii.edu/server/api/core/bitstreams/2bfd999a-b05b-45b9-87c3-4350f0eb0795/content>

- Tamasese, T. K. (2002). Honouring Samoan ways and understandings: Towards culturally appropriate mental health services. *International Journal of Narrative Therapy & Community Work*, 2002(2), 64–71.
- Tamasese, T. K., Parsons, T. L., & Waldegrave, C. (2014). *Pacific perspectives on ageing in New Zealand*. Wellington: Family Centre Social Policy Research Unit.
[https://www.massey.ac.nz/massey/fms/Colleges/College%20of%20Humanities%20and%20Social%20Sciences/Psychology/HART/publications/reports/Pacific_Elders_NZLSA_2014.pdf?6A68389EA6EAB37148E4AE22BA963822#:~:text=The%20Pacific%20population%20in%20New,Statistics%20New%20Zealand%2C%202013b\).](https://www.massey.ac.nz/massey/fms/Colleges/College%20of%20Humanities%20and%20Social%20Sciences/Psychology/HART/publications/reports/Pacific_Elders_NZLSA_2014.pdf?6A68389EA6EAB37148E4AE22BA963822#:~:text=The%20Pacific%20population%20in%20New,Statistics%20New%20Zealand%2C%202013b).)
- Tamasese, K., Peteru, C., & Waldegrave, C. (1997). *Ole taeao afua = The new morning: a qualitative investigation into Samoan perspectives on mental health and culturally appropriate services*. Family Centre.
- Tamasese, K., Peteru, C., Waldegrave, C., & Bush, A. (2005). Ole Taeao Afua, the New Morning: A qualitative investigation into Samoan perspectives on mental health and culturally appropriate services. *Australian and New Zealand Journal of Psychiatry*, 39(4), 300–309. <https://doi.org/10.1080/j.1440-1614.2005.01572.x>
- Tamasese Taisi Efi, T. A. T. (2005). In search of harmony: in the Samoan indigenous religion. <https://www.library.auckland.ac.nz/external/ebooks/TupuolaEfiTuiatuaColloquiumpaperDec05.pdf>
- Tamasese Taisi Efi, T. A. T. (2007). *Samoan Jurisprudence and the Samoan Lands and Titles Court: the perspective of a litigant* (public lecture). http://www.head-of-state-samoa.ws/pages/speech_jurisprudence.html
- Tamasese Taisi Efi. (2009). Bioethics and the Samoan Indigenous Reference. *International Social Sciences Journal*, 60(195), 115–124.
- Tuia, T. T., & Cobb, D. (2021). Decolonizing Samoan fa’afaletui methodology: taking a closer look. *AlterNative*, 17(2), 275–283. <https://doi.org/10.1177/11771801211016854>
- Whetu, T., & Best, E. (1893). Te Haerenga mai o Kupe i Hawaiki / The Coming of Kupe from Hawaiki to New Zealand. *The Journal of the Polynesian Society*, 2(3), 147–151. <http://www.jstor.org/stable/20701292>
- Te Tai Tokerau Tarai Waka Inc. (n.d.). Star positions. Te Aurere. http://teaurere.org.nz/star_positions.htm
- Taonui, R. (2005). Canoe navigation - Ocean voyaging, *Te Ara - the Encyclopedia of New Zealand*, <https://teara.govt.nz/en/canoe-navigation/page-2>

- Te Pou. (2020). Disability Word Collection. Te Reo Hāpai. <https://www.tereohapai.nz/Browse/Collections/3/mi-NZ>
- Te Pou o te Whakaaro Nui. (2010). *Talking therapies for Pasifika peoples: best and promising practice guide for mental health and addiction services*. Te Pou o te Whakaaro Nui.
- Te Pou o te Whakaaro Nui. (2016). *Determining the workforce development needs of New Zealand's autism workforce: Results of an information-gathering exercise undertaken in November 2015*. Te Pou o te Whakaaro Nui.
- Thaman, K. H. (2014). No need to whisper: Reclaiming Indigenous knowledge and education in the Pacific. In Suaalii Sauni, T. M., Wendt, M. A., Mo'a, V., Fuamatu, N., Va'ai, U. L., Whaitiri, R., & Filipo, S. L. (Eds.), *Whispers and Vanities: Samoan indigenous knowledge and religion* (pp. 301–313). Huia Publishers.
- The Fono. (2020). *About The Fono*. <https://thefono.org/about/>
- Tiatia-Seath, J., Fleming, T., Peiris John, R., Roy, R., Chinn, V., & Clark, T. (2021). *A Youth19 Brief: Pacific young people with a disability or chronic condition*. The Youth19 Research Group, Victoria University of Wellington and the University of Auckland, New Zealand.
- Toffoli, D. (2016). Attachment theory: Insights into student postures in autonomous language learning. In Gkonou, C., Tatzl, D., & Mercer, S. (Eds.), *New directions in language learning psychology* (pp. 55–70). <https://doi.org/10.1007/978-3-319-23491-5>
- Tokona te Raki. (2022). Whiria te Muka Tangata. Ministry of Health. <https://www.health.govt.nz/system/files/documents/publications/whiria-te-muka-tangata-aug22.pdf>
- Trezona, C. (2018, November 27). By autistics, for autistics. Altogether Autism. <https://www.altogetherautism.org.nz/by-autistics-for-autistics/>
- Tualaulelei, E., & McFall-McCaffery, J. (2019). The Pacific research paradigm: opportunities and challenges. *MAI Journal* (Online). <http://www.journal.mai.ac.nz/content/pacific-research-paradigm-opportunities-and-challenges>
- Tuitea, I. (2006). *Solution focused nursing: An alternative model for assessing psychosis and mai aitu in mental health*. (Unpublished master's thesis). Victoria University of Wellington, New Zealand.
- Tu'itahi, S. (2007). Fonua: A model for Pacific health promotion. *Hauora: A newsletter of the health promotion forum*, 8–9.

- Tu'itahi, S. (2020). *Before Te Tiriti, there was Moana: Pacific perspectives on Te Tiriti & Pacific peoples in New Zealand*. [Webinar]. Te Tiriti-based Futures & Anti-racism. https://www.youtube.com/watch?v=nkAJq04wkps&ab_channel=TeTiritiBasedFutures%26AntiRacism
- Tu'itahi, S., Watson, H., Egan, R., Parkes, M. W., & Hancock, T. (2021). Waiora: the importance of Indigenous worldviews and spirituality to inspire and inform Planetary Health Promotion in the Anthropocene. *Global Health Promotion*, 28(4), 73–82. <https://doi.org/10.1177/17579759211062261>
- Tukuitonga, C. (2013). *Pacific people in New Zealand*. In St George, I. M. (Ed.). *Cole's medical practice in New Zealand* (12th edition). Medical Council of New Zealand.
- Tupou, J., Curtis, S., Taare-Smith, D., Glasgow, A., & Waddington, H. (2021). Māori and autism: A scoping review. *Autism: The International Journal of Research & Practice*, 25(7), 1844–1858. <https://doi.org/10.1177/13623613211018649>
- United Kingdom National Screening Committee. (2022). Child screening programme: Autism. <https://view-health-screening-recommendations.service.gov.uk/autism/>
- Vaiioleti, T. M. (2006). Talanoa research methodology: A developing position on Pacific research. *Waikato Journal of Education*, 12.
- Vaiioleti, T. (2013). Talanoa: Differentiating the talanoa research methodology from phenomenology, narrative, Kaupapa Māori and feminist methodologies. *Te Reo*, 56/57, 191–212.
- Vaka, S. L. (2014). *A Tongan talanoa about conceptualisations, constructions and understandings of mental illness*. (Unpublished doctoral thesis). Massey University.
- Vaka, S. L. (2016). Ūloa: A model of practice for working with Tongan people experiencing mental distress. *New Zealand Sociology*, 31(2), 123–148.
- Valicenti-McDermott, M., Seijo, R., & Shulman, L. (2019). Social differences between monolingual English and bilingual English-Spanish children with Autism Spectrum Disorders. *Pediatric Neurology*, 100, 55–59. <https://doi.org/10.1016/j.pediatrneurol.2019.07.001>

- Virués-Ortega, J., Lehnert, K., Swan, B., Taylor, M. W., Snell, R. G., Jacobsen, J. C., Southee, A., Dougan, D., Taylor, J., & Hill, R. (2017). The New Zealand Minds for Minds Autism Spectrum Disorder self-reported cohort. *Research in Autism Spectrum Disorders*, 36, 1–7. <https://doi.org/10.1016/j.rasd.2016.12.003>
- Waddington, H., Macaskill, E., Whitehouse, A. J. O., Billingham, W., & Alvares, G. A. (2022a). Parent-reported atypical development in the first year of life and age of autism diagnosis. *Journal of Autism and Developmental Disorders*, 1–12. <https://doi.org/10.1007/s10803-022-05506-1>
- Waddington, H., van der Meer, L., Powell-Hector, N., Wilson, E., Shepherd, D., & Barbaro, J. (2022b). Brief Report: Training New Zealand Well Child/Tamariki Ora nurses on early Autism signs using the Social Attention and Communication Surveillance-Revised. *Journal of Autism and Developmental Disorders*, 52(11), 5050–5057. <https://doi.org/10.1007/s10803-021-05344-7>
- Wallace-Watkin, C., Whitehouse, A. J. O., & Waddington, H. (2021). Early intervention delivery methods for New Zealand children with Autism: Current practices versus parental preferences. *Journal of Autism and Developmental Disorders*, 51, 3199–3211. <https://doi.org/10.1007/s10803-020-04777-w>
- Weastall, K. (2017). *Raising a child with an Autism Spectrum Disorder: the experience of stigma by association, its impact on caregiver wellbeing, the influence of signature strengths, and the experience of growth*. (Unpublished doctoral thesis). Massey University.
- Welterlin, A., & La Rue, R. H. (2007). Serving the needs of immigrant families of children with autism. *Disability and Society*, 22(7), 747–760. <https://doi.org/10.1080/09687590701659600>
- Wensley, D., & King, M. (2008). Scientific responsibility for the dissemination and interpretation of genetic research: Lessons from the “Warrior Gene” controversy. *Journal of Medical Ethics*, 34(6), 507–509. <https://doi.org/10.1136/jme.2006.019596>
- Whaikaha – Ministry of Disabled People and Ministry of Education. (2022). *Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau: Third Edition*. Wellington: Whaikaha – Ministry of Disabled People

- Whitaker, R. C., Dearth-Wesley, T., Herman, A. N., van Wingerden, A. N., & Winn, D. W. (2022). Family connection and flourishing among adolescents in 26 countries. *Pediatrics*, 149(6), e2021055263. <https://doi.org/10.1542/peds.2021-055263>
- Work and Income (n.d.). Caring for a child with a health condition or disability. <https://www.workandincome.govt.nz/eligibility/carers/care-child-with-a-disability.html>
- Zhou, V., Munson, J. A., Greenson, J., Hou, Y., Rogers, S., & Estes, A. M. (2019). An exploratory longitudinal study of social and language outcomes in children with autism in bilingual home environments. *Autism: The International Journal of Research and Practice*, 23(2), 394–404. <https://doi.org/10.1177/1362361317743251>
- Zimmer-Gembeck, M., Van Petegem, S., Ducat, W., Clear, S., & Mastro, S. (2017). Parent-adolescent relationships and romantic development. A review and argument for research on autonomy-supportive parenting. In Soenens, B., Vansteenkiste, M., & Van Petegem, S. (Eds.), *Autonomy in Adolescent Development: Towards Conceptual Clarity* (1st ed., pp. 168–192). <https://doi-org.ezproxy.massey.ac.nz/10.4324/9781315636511>
- Zubler, J. M., Wiggins, L. D., Macias, M. M., Whitaker, T. M., Shaw, J. S., Squires, J. K., Pajek, J. A., Wolf, R. B., Slaughter, K. S., Broughton, A. S., Gerndt, K. L., Mlodoach, B. J., Lipkin, P. H. (2022). Evidence-informed milestones for developmental surveillance tools. *Pediatrics*, 149(3), 1–29. <https://doi.org/10.1542/peds.2021-052138>
- Zuckerman, K. E., Lindly, O. J., & Sinche, B. K. (2015). Parental concerns, provider response, and timeliness of autism spectrum disorder diagnosis. *Journal of Pediatrics*, 166, 1431–1439, e1431. <https://doi:10.1016/j.jpeds.2015.03.007>
- Zwaigenbaum, L., Bauman, M. L., Choueiri, R., Kasari, C., Carter, A., Granpeesheh, D., ... & Natowicz, M. R. (2015). Early intervention for children with autism spectrum disorder under 3 years of age: recommendations for practice and research. *Pediatrics*, 136(1), S60–S81. <https://doi.org/10.1542/peds.2014-366>

Appendices

Appendix A: Talanoa Guiding Questions

Child/rens name/s:.....

1. Tell me about yourselves.
2. and your family...
3. What is your understanding of mental illness within your Pacific culture/s?
4. And of autism?
5. Would you share a little bit about your journey to diagnosis for your child?
6. What was it like for you when you received the autism label over your child?
7. What do your families understand about autism?
8. How do you talk about autism with your family/friends?

Lived experiences

9. When thinking about how raising a child on the autism spectrum impacts many areas of your lives, do any of these words resonate with you? [using prompt words]
10. Could you please share some of your experiences in caring for your child?
11. How has autism changed the way your family organises itself?
12. How has it impacted your relationships with your parents? With your spouse? With your children? With your siblings? Wider family members?
13. Can you think back to a specific 'win' that you had with your child on the spectrum?
14. Can you think of a specific challenge you had to overcome related to having a child on the spectrum?
15. What are some of the blessings of having a child on the spectrum?
16. What are some of the challenges of having a child on the spectrum?
17. What are your hopes and dreams for your child?

Support

18. What supports from government ministries or other organisations have you accessed?
19. What supports are you not getting that would make life easier for you?
20. Is having culturally appropriate supports important to you? What kind of things would make you feel more culturally understood or supported?
21. What would you consider as Pacific ways of disability care?
22. What helps you be resilient in the face of all these challenges?

Culture and Language

23. How important to you is passing on your Pacific language and culture to your children?
24. How do you make decisions about which languages you will teach your child and in what order?
25. How traditional would you say your family is?
26. In what ways do you share your culture with your child?
27. In what ways do you teach your culture to your child?
28. In what ways do you teach your language to your child?
29. How does your child learn language best?
30. Does your child enjoy your culture/speaking your language?

Appendix B: Talanoa Word Prompts

Faith

Support crew

Church

Spiritual

Religion

Work

Extended Family

Culture/Language

Friends

Family Structure

Paid Carers

Family Relationships

Parents

Social Activity

Siblings

Financial Stability

Our other children

Physical Health

Parenting methods

Mental Health

Aspirations

Study/Training

Career	Sports
Law/Legal	Hobbies
Time	Exercise
Motivation	Me Time
Gratefulness	Quality Time
Marriage	Worries
Appreciation	Fears
Acceptance	Diversity
Tolerance	Prayer
Mental Illness	Serving
Burnout	Busy
Strength	Therapist

Family Carers

Curse

Teacher Experiences

Hardship

Grief/Grieving

Blessing

Loss

Lessons

Kindness

Change/d

Non/Judgmental

Gift/s

Inspiration

Independent

My/Our Reason

.....

Passion/s

.....

.....

.....

Appendix C: Lemalu Samau Tate Simi's Identity Poem

Educate yourself enough so you may understand the ways of other people

But not too much that you may lose your understanding of your own

Try things palagi Not so you may become palagi but so may see the value of things Sāmoan

Learn to speak Sāmoan not so you may sound Sāmoan but so you may feel the essence of being Sāmoan

Above all be aware and proud of what you are so you may spare yourself the agony of those who are asking

“What am I?”

O oe se a? A'oa'oina oe ia lava ina ia e malamalama ai i aga a isi atunu'u ia aua fo'i le aveā lou iloa ma mea e fa'agalo
ai lou iloa o tu ma aga a lou lava atunu'u.

Tofotofo i mea fa'apapalagi e le ina ia aveā ai oe o se papalagi a ia e iloa ai le taua o mea fa'a Sāmoa. A'oa'o e tautala i
le Gagana Sāmoa e le ina na ona fa'afoliga ai o oe o se Sāmoa a ia matua lagona ai le a'ano o le loto Sāmoa.

O le mea sili i ia mea o le iloa ma mitamita i lou tupuaga ia le pei ai oe o i latou o lo'o tu'ufesili pea

O a'u ea o se a? (Simi, 1992)

Appendix D: Research Case Study

Massey University
Clinical Psychology

CASE STUDY ONE

Reflections on the Impact of Conducting Research on Clinical Practice

Candidate : Rochelle Nafatali
Clinical Psychology Programme Massey University
Student ID : [REDACTED]
Setting : Department of Corrections
Primary Supervisor : Dr Siautu Alefaio

This case was completed during internship at the Department of Corrections Tai Tokerau Psychologists' Office in 2021 and represents the work of the candidate.

Supervisor

Dr Siautu Alefaio
Primary Supervisor

Student

Rochelle Nafatali
[REDACTED]

Date : 31/05/2021

Abstract

This case study outlines the contributions to clinical practice that have resulted from engagement in doctoral research prior to entering internship. The opening section positions the researcher in terms of whakapapa/gafa (genealogy) and place within Aotearoa. Then follows an outline of the doctoral research project and description of engagement with Pacific families raising children on the autism spectrum. The final sections describe working as an intern psychologist at the Department of Corrections Tai Tokerau Psychologists' Office with tāne in prison. Parallels and links are drawn to highlight the contribution that doctoral research makes to a developing intern psychologist's practice. These contributions include strengthening protocols for engagement, raising awareness of client autonomy, increasing cultural competence, and centering Pacific voices.

Positioning the Researcher / Tūranga o te Kairangahau / Tulaga o le Tagata Su'esu'e

Malo lava le soifua maua ma le lagi e mamā.

E muamua ona ou si'i le vi'iga ma le fa'afetai i le Atua.

O le 'āiga o lo'u tamā e o mai le lua nu'u o Luatuanu'u ma Lauili'i (Upolu, Samoa).

O le 'āiga o lo'u tinā e o mai le atunu'u o Niu Sila.

O le 'āiga o la'u to'alua e o mai le lua nu'u o Lotofaga (Upolu, Samoa) ma Sala'ilua (Savai'i, Samoa).

E to'alua le fanau o māua.

O la'u igoa o Rochelle Nafatali.

In my Samoan introduction above, I acknowledge the reader and first give honour and thanks to God. I refer to the villages in Samoa where my Father's family hail from, as well as to the country of my Mother's birth and where I was born – Aotearoa New Zealand. The introduction continues on to acknowledge my husband's villages in Samoa, our two children, and then ends with my name. This is the appropriate way in which to introduce oneself in the fa'aSamoa or 'Samoan way'.

On my Father's side I am a second-generation New Zealand-born Samoan, and on my Mother's side I am third-generation New Zealand European, Kiwi/Pākehā, or Pālagi. Born in Ōtāhuhu, I was a tamariki whāngai, or child of informal intra-familial adoption, entrusted to my Grandparents on my Mother's side to raise. In Pākehā families, this is not that common. My connection to Tai Tokerau or the Bay of Islands is that my Great-Grandparents on my Mother's side would bring my Grandmother to Tai Tokerau from Te Atatu South every summer for boating and holidaying – my Great-Grandfather and later my Grandfather were both boat builders and racers. This led my Grandparents to move to Tai Tokerau in 1985. In 1990, when I was three years old, I moved to Tai Tokerau to live with my Grandparents. My family are visitors and newcomers to this whenua, we are *tauiwi* (new bones; Ioane & Tudor, 2017).

I went to a very small community-oriented kura called Ōpua School. My first Principal, Mr Tīpene, was Māori and a strong advocate for teaching tikanga and te reo Māori to all children from an early age, to the benefit of all former Ōpua students. Being in the early 1990's, his determination was probably encouraged by the 1987 legislative changes that recognised te reo Māori as an official language of Aotearoa. As a consequence, the use of te reo Māori, waiata Māori, karakia, tī rakau, hāngi, and kapa haka were all regular features of our school. Mr Tīpene and Ōpua School ignited in me a love for te reo Māori me ona tikanga. If I have any proficiency or understanding of Te Āo Māori or the Māori world at all, I owe it to Mr Tīpene who first modelled that for me and others.

It was against this bicultural Māori-Pākehā background that I learned of my Samoan heritage during my adolescent years. Following High School where te reo Māori was the focus, it was a challenge to juggle my desire to learn more about te Āo Māori with my desire to learn about my own heritage language and culture. Because of the opportunities available to me during my undergraduate years at university, I focused on learning about Samoan culture and the Samoan language. I then worked with Pacific peoples in the community and at the University over several years, learning and being mentored in various spaces by Pacific elders.

It was during this time that I discovered that Pacific peoples and tangata whenua descended from the same ocean and are connected through shared ancestors. Our languages and cultures, although unique, share similarities, and Aotearoa is often considered to be a Pacific Island. We are tagata o le moana (people of the sea) and Māori are tangata whenua (people of the land). My bicultural world now had to enlarge and "multicultural" or "diverse" became a better fit for my experiences.

Over the last 10 years, I have sought opportunities to re-engage with and to extend my understanding of te Āo Māori including te reo Māori. This has led me to engage in wānanga on tikanga Māori in the workplace,

on Te Tiriti o Waitangi's application, and in courses of te reo Māori language learning. Each of these learning experiences has enriched my understanding of te Āo Māori, of tangata whenua, and of ethical practice in general. My clinical training has also enabled me to grow deeper in my understanding of te Āo Māori through learning about the pōwhiri and whakawhānaungatanga processes, developing pēpēha, participating in noho marae, practicing waiata, and learning karakia. I consider it a life-long journey to learn more about te Āo Māori and the fa'aSamoa, a journey where I will never "arrive" but that with a growing understanding of both, I will become more comfortable moving within and between these cultures and the culture I was raised in, and potentially facilitate others to do the same.

In summary, in reflecting on my position as a New Zealander, a training clinical psychologist, and a doctoral student engaging in research, firstly I am tauiwī; I am not Indigenous to this land. My people are Indigenous to the Samoa islands and to Europe and have converged in Aotearoa through migration. However, because of the ancestral connection between tagata moana/tangata whenua, my early experiences, and the value I place on te Āo Māori I think of myself as an ally with tangata whenua. This position of whānaungatanga (connection, relationship) underpins my approach to my clinical training, my research, and to my work as an intern with all of my clients.

The Research Project / Te Rangahau / O le Su'esu'ega

My doctoral research project focuses on the lived experiences of Pacific parents raising children on the Autism spectrum in Aotearoa New Zealand. Specifically, the holistic experiences of parents are surveyed, including their use of supports both internal and external to the family, and how language and culture is maintained within these families. The following overview of the project describes the background to the project and outlines the project aim and methodology. The concept of relationship provides both the foundation for the research engagement process, and influenced whakawhānaungatanga with clients in the prison also.

Background

Globally and in Aotearoa New Zealand (NZ), prevalence rates of autism appear to have been increasing over time (Baio et al., 2018; Carr, 2016; Drysdale & van der Meer, 2020). It is unknown if these are real increases in numbers, or if the increase is due to factors such as raised awareness in the community, continually refined DSM diagnostic criteria for autism, highly specific assessment tools, and streamlined referral processes leading to more likely diagnosis (Drysdale & van der Meer, 2020; Le Couteur & Szatmari, 2015; MoH/MoE, 2016; Myers et al., 2019; Ooi et al., 2016), or perhaps a combination of all of these. Internationally the prevalence rate for autism is one percent across developed countries and lower in developing countries (Carr, 2016).

In NZ, no epidemiological or population-level published data exists on autism prevalence rates (Drysdale & van der Meer, 2020), however, Autism NZ's website estimates that there are now 80,000 people in NZ living on the spectrum (www.autismnz.org.nz). In addition, the latest aggregated NZ health data estimates that autism prevalence in children under the age of 14 years is 1.6%, or approximately 13,000 children (Ministry of Health, 2018). Within the NZ Pacific-Indigenous community, the current estimate suggests a prevalence rate of approximately 1.1% or numbering over 1,000 children (Ministry of Health, 2018).

While there is a body of published research discussing parents' experiences of raising a child on the autism spectrum, this research has not included Pacific families and their experiences. Specifically for autism, Bernier and colleagues state that "cultural beliefs and practices can affect identification and integration of individuals with ASD into a society" (2010, p. 856). Diversity in values, traditions, and socio-cultural experiences are important for health professionals to be cognisant of when working with families of children with disabilities (Macfarlane et al., 2014). It is pertinent, then, to deduce cultural factors at all levels of the ecological system that could lead to earlier recognition of children on the spectrum, improve the diagnostic process, and lead to early and effective intervention for autism families of all cultural backgrounds (Bernier et al., 2010).

Pacific-Indigenous peoples have differing conceptualisations of health, mental health, and psychopathology (mental illness/disorders/conditions/problems) to those of Western, mainstream

conceptualisations (Tamasese et al., 2005). An example of this key difference in views is highlighted by the following statement:

“when we [Samoans, Pacific-Indigenous people] talk about mental health, it is not seen as a separate category of health. It is a part of the total health and wellbeing of people, land, and sea” (Tamasese, 2002, p. 68).

Total health and wellbeing when conceptualised through a Pacific-Indigenous lens is more holistic than Western conceptualisations, incorporating the physical, spiritual, mental, familial, cultural, and other, including contextual factors, for example, as stated in the Fonofale model (MoH, 1995). Tukuitonga has described the Pacific-Indigenous health lens as “socioecological” (2013, p. 68).

Taking a wider, Pacific lens on health and wellbeing is likely to lead to differing understandings, meaning making, and lived experiences of Pacific autism families compared with other autism families. Accordingly, Pacific-Indigenous peoples’ lived experiences of health, illness, and disability need to be investigated holistically, using the same parameters which Pacific-Indigenous people equate to health and wellbeing. It seems obvious that if Pacific-Indigenous experiences and views are sought through a Western paradigm and guided by a Western (and therefore a constricted) conceptualisation, there will be several poles of the fale (referring to the Fonofale model) that will remain unsurveyed and therefore inaccessible to empirical research evidence, and furthermore untouchable by Western treatment approaches. Due to Pacific peoples being the largest and fastest-growing youth population in Aotearoa, research done with Pacific peoples will contribute to clinicians’ understanding and awareness of Pacific health in order to deliver services which are both responsive to the needs of Pacific peoples, and culturally competent (Ioane & Tudor, 2017).

Project Aim

The holistic lived experiences of Pacific-Indigenous autism families are imperative to seek and understand in research in order to design and deliver effective support services for these families, now, and in the future (MoH/MoE, 2016). This research project sought to explore the lived experiences of Pacific autism families through *talanoa* (Pacific way of conducting research interviews) with the parents in a more holistic way. Guiding questions facilitated the sharing of experiences, including specific topic areas which surveyed the families’ use of supports, and language and culture transfer within these families.

Method

The research utilised a Pacific-Indigenous methodological approach called *talanoa* (Vaiotele, 2006) to guide data collection. *Talanoa* - “to talk, to tell stories or relate experience” (Churchward, 1959, p. 447, as cited in Vaiotele, 2006) - as a framework facilitates the sharing of people’s stories and narratives as experienced by them, that is, their lived experiences, through trust, respect, and mutual relationship. In mainstream research methodologies the *talanoa* method is most akin to participatory action research and other narrative interview methodologies, particularly thematic analysis. However, *talanoa* is distinguished by the requirement of cultural connectedness between the researcher and participants, and the co-construction of knowledge that results in *talanoa* as opposed to Western qualitative methods (Vaiotele, 2006, 2013). In this sense, *talanoa* is collaborative, subjective, and resists outsider control of both data collection, and of the ensuing narrative (Vaiotele, 2006). Guiding questions were developed that were focused enough to bring out information on the desired topics (e.g., the families’ lived experiences), while allowing participants to be largely in control of the conversation and what was shared; in effect, enabling co-construction of the data from the participant’s unique Pacific-Indigenous epistemological viewpoint (Vaiotele, 2006). Within this study, the researcher shares both a broad Pacific cultural background and the status of an autism parent with *talanoa* participants and so is considered as being within the ‘in’ group of participants. This project was evaluated by peer review and judged to be low risk (Notification number: 4000020645). Consequently, it was not reviewed by one of the University’s Human Ethics Committees. The researcher named in this document was and is responsible for the ethical conduct of this research.

Participants

Participants were recruited members of the Pasifika Autism Support Group (PASG; a parent-led support group for parents raising Pacific-Indigenous children on the spectrum) in Auckland which the researcher is also a part of. The parents of eight autism families chose to participate in a research talanoa. The parents were raising at least one child with autism between the ages of two and 17 years old. Parents were defined widely as typically a heterosexual couple, either de facto or married, sole parents, grandparents raising the child, parents and grandparent/s together raising the child, or older siblings, aunties and uncles of the child with significant caregiving responsibilities. The resulting group of participants were 17 Pacific parents representing the Pacific nations of Samoa, Tonga, Niue, Kiribati, and Aotearoa.

Procedure

Talanoa allows and encourages the use of Pacific cultural engagement protocols to be used before, during, and following research talanoa. These protocols included the researcher using greetings and other phrases in the family's Pacific-Indigenous language from the point of the introductory and talanoa setup emails, continuing throughout contact with the family. On arrival at the families' homes and following greetings and an invitation to sit, an 'ava/kava bowl was set in the centre of the room which is symbolic of a talanoa about to begin and signified the changing of the space. Parent participants were given a participant information sheet and research consent form in English, each. The parents' informed consent was recorded once the study parameters and protocols were clearly stated and the participants had read through all the information to their satisfaction. Copies of the consent form were given to the participants, and the original copy of the consent forms were kept with the researcher and stored securely. Next the researcher facilitated the sharing of humour and small talk, and the drawing of genealogical and geographical connections between each other. Following this, the researcher offered for the parent participants or the most senior family member to begin talanoa sessions with a *lotu* (prayer) in the family's preferred language. According to talanoa protocol, once it was clear that feelings of *māfanafana* (warmth) and *malie* (humour) were established or sustained, the talanoa session naturally progressed into deeper levels of the talanoa, where sharing, with personal narrative elaboration and co-creation of shared stories and experiences, occurred. Talanoa sessions were voice-recorded with the prior permission of all of the participants to allow the researcher to participate fully in the talanoa. In this study, ample time was allowed for talanoa to continue until the sessions came to a natural place of rest; this was found to be between 1.5-3 hours; less for one parent, more for larger family groups. Further, food was shared at each talanoa with the presentation of Pacific baking to the family, which was later shared at a natural half-way point in the talanoa at the family's direction, or following the talanoa. Often the researcher left this as a gift for the family to share together. Once talanoa transcripts were acknowledged by the families, a *mea'alofa* (koha) was extended to the families in appreciation of their generosity and expertise shared with the researcher.

Data Analysis

The analysis of talanoa data in this study is to be carried out using a two-stage approach. Initially (phase one), talanoa recordings were transcribed by the researcher using the ExpressScribe v 8.26 software package. Checked transcripts were returned to the participants to check, add to, or otherwise amend to ensure their intent was fully captured. Phase two will involve analysis for shared narratives using qualitative thematic analysis within the NVivo software package, with associated coding into hierarchical themes.

Internship: Working in Prison / Whakamahi ki te Whare Herehere / O Galuega i Totonu o le Falepuipui

I began working at Ara Poutama – Department of Corrections in January 2021. I started in the Central Auckland team before moving my *whānau/āiga* back home to Tai Tokerau in February 2021 following the passing of my Grandmother mentioned earlier. The Kaikohe Psychologists' Office is located in Kaikohe town, five kilometres from the Northland Region Corrections Facility (known locally as "Ngawha" as it is adjacent to the Ngawha Springs). The team services Community Probation sites from Kaitiaki to Whangārei and Dargaville, and the Northland Region Corrections Facility (NRCF). Our primary purpose is the psychological assessment

and treatment of tāne in the prison and on sentence in the community. This includes the preparation of special reports such as psychological reports for the Parole Board, Health Assessments for the courts considering Extended Supervision Orders, Section 26 (sentencing options) and Fitness assessment reports. Risk assessment and treatment of criminogenic needs (factors that predict reoffending behaviour; Bonta & Andrews, 2016) are Ara Poutama psychologists' key tasks. As an intern, I am regularly involved in psychometric testing, assessment of individuals, and treatment. The following sections are reflections on research and practice that have occurred during my work as an intern for Ara Poutama so far.

Engagement

The process of building rapport to establish a therapeutic relationship is similar to processes and concepts which have existed for thousands of years within Māori and Pacific cultures as whakawhānaungatanga and vā (Lacey, 2011; Ioane & Tudor, 2017). The importance of establishing connections and maintaining relationships has long been important to these cultures. In my research, purposeful creating of research spaces and engagement in Pacific research protocols encouraged connection and relationship. In my work within the prison, many of these purposeful protocols are not possible within the specific custodial environment; it is an environment of deliberate restriction of freedom and luxuries. Within prison, it is not appropriate to bring in food and cultural items, and spaces where we see clients are most often not designed or conducive for therapy. Spaces used are often sparse rooms with only chairs and a table within them, no clock, no attention to décor, often have large windows which severely limit privacy, are usually more akin to storage rooms, and are locked for security.

The challenge then is to establish and maintain engagement with person-centred ideals in a place where the person has deliberately and consistently been de-centred. Engagement in appropriate cultural protocols or tīkanga, is one way of negating the inherent barriers to engagement within a prison. Engaging in tīkanga within prison can still follow the general hui process of Mihi, Whakawhānaungatanga, Kaupapa and Poroporoaki (Lacey, 2011). As examples, client preference around introduction of pēpēha during the Mihi stage, and the use of karakia to open and close sessions can be sought (Pitama et al., 2014).

The pēpēha is a vehicle for the listener to understand your whānaungatanga or whakapapa connections and the basic pēpēha which students learn follow a general structure. The individual is presented in reference to their collective and their connections to each of these aspects that make the individual who they are. The pēpēha is very similar to the introduction process in the fa'aSamoa I opened this case study with. In the Samoan culture when meeting someone new, the first question you are asked, or that is asked about you, is "what is your family name" and/or "who are your parents?". The responses to these questions instantly give the listener information about your family, village, and chiefly title connections, much the same as the pēpēha does for tangata whenua.

Bringing the pēpēha into clinical practice has several functions (Lacey et al., 2011). From a whakawhānaungatanga perspective, it offers the listener information with which they can place you within your wider connections, and where relevant, within shared whakapapa connections. The process of sharing pēpēha also implies a respect for and trust in the listener. Further, sharing pēpēha shows a humility to meet the client half-way through a willingness to learn and use appropriate tīkanga in the clinical space. In Aotearoa, the use of pēpēha is considered self-disclosure, and so is recommended to be used judiciously. This might mean using an appropriate abridged version, which offers information without impinging on personal safety (Lacey et al., 2011). In using pēpēha in my clinical practice, I have noticed the above benefits and felt the deepening of engagement following the use of pēpēha.

Autonomy vs. Self-Determination

Autonomy in the Māori and Pacific sense is different to that of autonomy from a Western perspective. From a Western perspective, autonomy is defined as "freedom from external control or influence; independence" (Oxford University Press, 2010). As postulated in Erikson's stages of psychosocial development, the more

autonomous and independent one becomes, the more mature and developed they are perceived to be (Ewalt & Mokuau, 1995). In clinical assessment and treatment, we typically seek to help clients gain awareness of their autonomy in the sense of personal agency as part of moving toward wellness (T. Moyers, personal communication, March 26, 2021).

However, therein lies a tension, as conversely from a Māori and Pacific perspective, identity is located within the collective (Ioane & Tudor, 2017; Pitama et al., 2007; Tamasese et al., 2014). Articulating further, Macfarlane and colleagues stated:

“in the same way that Indigenous people consider their lands and resources to be collective assets, they see their languages, cultural values, beliefs and practices as a function of the group, not individuals” (2014, p. 259).

This group cohesion speaks to a collective rather than individual autonomy. For example, the Samoan ‘self’ is a relational self, where one is only able to describe themselves in relation to others; in relation to those living, past, and ancestral (Tamasese, 2002), that is, the relationships that one enjoys defines the individual, rather than the individual defining the relationships. In this collective perspective where group affiliation is the basis of self-determination, the Western ideals of self-individuation and independence are not the goal, rather, a type of interdependence is (Ewalt & Mokuau, 1995). Self-determination is a better term because in collective cultures, self-determination is inclusive of the family and societal group influence (Ewalt & Mokuau, 1995).

In seeking to facilitate self-determination with Pacific research participants, Pacific parents are asked to choose whether they would like to participate and where suits them, are enabled to choose what experiences and narratives they share and create, are given the opportunity to vet their own information, and are valued for their time and expertise. In parallel, clients within NRCF undergoing treatment and assessment are in small ways facilitated to act in self-determining ways themselves. This is done through a choice whether or not to participate in assessment and treatment, the opportunity to collaborate on treatment goals, the opportunity to co-design interventions at times, choices within session such as whether karakia or whakataukī are used, choices around delivery style and narratives, whether or not between-session tasks are completed, the choice to complete psychometric instruments, the choice to attend and engage in sessions, and the choice to activate knowledge and skills learnt within session in their daily lives. Other ways in which self-determination is encouraged is through the therapy techniques used. For example, typical CBT highlights and challenges unhelpful patterns of thinking. However, the way in which this is done with clients is to ask questions which allow the client to discover or make links themselves between problem thinking and the consequences in their lives and generate new beliefs (Padesky & Mooney, 2012). This guided discovery allows clients to take ownership and be an active rather than passive agent in their change process.

Increasing Cultural Competence

Tēnā koutou katoa.

Ko Ngāti Hāmoa me Ngāti Pākehā o ngā iwi.

Ko Moana-nui-a-Kiwa tōku moana.

I tupu ake ahau i Tai Tokerau. Ko Haruru taku kāinga inaianei.

I te taha o tōku matua nō Ingarangi, nō Hāmoa ia.

I te taha o tōku whāea nō Kōtarangi, nō Ingarangi, nō Tiamani ia.

Ko Max Yates tōku matua.

Ko Vicki Wedgwood tōku whāea.

Ko Junior Nafatali taku hoa rangatira.

Ko Israel raua ko Ramiyah āku tamariki.

Ko Rochelle Nafatali tōku ingoa.

Nō reira tēnā koutou, tēnā koutou, tēnā koutou katoa.

Throughout my clinical training I have been given the opportunity to increase my comfortability in te Te Ao Māori, or my cultural competence, in several practical ways. This began with learning about the karakia process, participating in the pōwhiri process, developing and later refining appropriate pēpēha, practicing waiata, and learning about Māori models of health, wellbeing, and clinical assessment. More than a tick-box exercise, these processes have been important in increasing my cultural competence as immersing yourself in another culture and language expands your ability to think in different ways and from various perspectives. For example, the concept of introducing oneself with a pēpēha as in the opening of this section is underpinned by a generational, collective perspective of making connections. In contrast to Western individual models, the individual is the last to be named, and is of the least importance in the pēpēha (H. Valentine, personal communication, April 11, 2019).

Within my research, increasing my cultural competence meant researching Samoan and Pacific worldviews and learning the downstream cultural protocols relevant to engagement, which I then needed to put into action within research talanoa. Similarly within my internship, cultural competence means learning more about te Ao Māori, learning the cultural protocols and processes relevant within a prison within my particular rohe, and putting these into action within the specific defined therapy environment at the prison. Both in my research and within the prison, I can see that increases in cultural competence lead to both increases in therapist confidence, and strengthened therapeutic alliance. This is evidenced by visible changes in body language and posture of both clients and therapist, increases in the level of responses from clients, and an increase in information given which then leads to further exploration of important therapeutic topics such as whānau, developmental history, client cultural connectedness and preferences, as examples.

Centering Client Voices / Arotia i ngā Reo o ngā Tangata Whaiora

Within my research, deliberate decisions were made to privilege Pacific parents' voices and allow these to be heard. Similarly in a prison environment, the voices of those in our care have often been silenced, not elicited, not valued, or dismissed. As an intern psychologist within Corrections, whenever we go through the consent process with a client, we are asking them to participate in providing their voice on matters where others are already speaking about them. We hold information about clients from their criminal histories and prior file information, including what the courts and Police have said about them, what their family members have said, what their employers have said about them, and what others involved in their management have said about them. Our challenge as psychologists is to join the client's voice with those of others, and encourage clients to speak on matters which they are the experts; their own lives and experiences.

Conclusion

While the impact of engaging in research on my internship is hypothesised to grow and transform over time, the major contribution over the past four months is of providing a prior model of cross-cultural ethics and an approach to cultural competence which I could then translate with adaptation into my current practice and environment. While both the environment and culture of the new situation (working in a prison with predominately Māori clients) are different to that of the research environment (collecting data within the family homes of Pacific peoples), it is clear to see the parallels between the experiences and the resulting advantages that engaging in culturally informed practice can bring. Although our approaches may differ in small or large ways, at the centre of both experiences is the focus on the client. In this way, we bring together our bodies of knowledge to be able to serve our community: *Nāu te rourou, nāku te rourou, ka ora ai te iwi* (with your basket and my basket, the people will live/be sustained: Māori whakataukī).

References

- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z. ... Dowling, N. F. (2018). Prevalence of Autism Spectrum Disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveillance Summary*, 67(6), 1-23. <https://www.cdc.gov/ncbddd/autism/addm-community-report/index.html>
- Bernier, R., Mao, A., & Yen, J. (2010). Psychopathology, families, and culture: Autism. *Child and Adolescent Psychiatric Clinics of North America*, 19(4), 855-867. <https://doi.org/10.1016/j.chc.2010.07.005>
- Bonta, J., & Andrews, D. A. (2016). *The Psychology of Criminal Conduct*, Taylor & Francis Group. ProQuest Ebook Central, <https://ebookcentral.proquest.com/lib/massey/detail.action?docID=4741995>.
- Carr, A. (2016). Autism Spectrum Disorders. In Carr, A. (Ed.). *The handbook of child and adolescent clinical psychology a contextual approach* (3rd ed.). (pp. 284-313). London, UK: Routledge. <https://doi-org.helicon.vuw.ac.nz/10.4324/9781315744230>
- Drysdale, H., van der Meer, L., & Kagohara, D. (2015). Children with autism spectrum disorder from bilingual families: A systematic review. *Review Journal of Autism and Developmental Disorders*, 2(1), 26-38. 10.1007/s40489-014-0032-7
- Ewalt, P. L., & Mokuau, N. (1995). Self-determination from a pacific perspective. *Social Work (United States)*, 40(2), 168-175. <https://doi.org/10.1093/sw/40.2.168>
- Lacey, C., Huria, T., Beckert, L., Gilles, M., & Pitama, S. (2011). The Hui Process: a framework to enhance the doctor-patient relationship with Māori. *The New Zealand Medical Journal*, 124(1347), 72-78.
- Le Couteur, A. & Szatmari, P. (2015). *Autism Spectrum Disorder*. In Thapar, A., Pine, D. S., Leckman, J. F., Scott, S., Snowling, M. J., Taylor, E. (Eds.). *Rutter's Child and Adolescent Psychiatry* (6th ed.), (pp. 665-682). Chichester, UK: John Wiley & Sons Ltd. <https://doi.org/10.1002/9781444300895>
- Ioane, J., & Tudor, K. (2017). The fa'asamoa, person-centered theory and cross-cultural practice. *Person-Centered and Experiential Psychotherapies*, 16(4), 287-302. <https://doi.org/10.1080/14779757.2017.1361467>
- Macfarlane, A., Macfarlane, S., & Gillon, G. (2014). *Inclusion, disability and culture: The nexus of potential and opportunity for policy development*. In Wills, R., Morton, M., McLean, M., Stephenson, M., & Slee, R. (Eds.), *Tales from school: Learning disability and state education after administrative reform*, 255-270. Sense Publishers.
- Ministry of Health. (2018). Annual Data Explorer 2017/18: New Zealand Health Survey [Data File]. <https://minhealthnz.shinyapps.io/nz-health-survey-2017-18-annual-data-explorer/> (Accessed 4 July, 2019)
- Ministry of Health. (1995). Pacific Islands Peoples' understanding of mental health. Strategic directions for the mental health services for Pacific Islands people. Wellington: Ministry of Health.
- Ministries of Health and Education (2016). New Zealand Autism Spectrum Disorder Guideline (2nd Edition). Ministry of Health. <https://www.health.govt.nz/publication/new-zealand-autism-spectrum-disorder-guideline>
- Myers, J., Chavez, A., Hill, A., Zuckerman, K., & Fombonne, E. (2019). *Epidemiological surveys of Autism Spectrum Disorders*. In F. Volkmar (Ed.), *Autism and Pervasive Developmental Disorders*, (pp. 25-60). Cambridge University Press. 10.1017/9781108297769.003
- Ooi, K. L., Ong, Y. S., Jacob, S. A., & Khan, T. M. (2016). A meta-synthesis on parenting a child with autism. *Neuropsychiatric Disease and Treatment*, 12, 745-762. <http://dx.doi.org/10.2147/NDT.S100634>

- Oxford University Press, 2010. Autonomy. In Stevenson, A. (Ed.), *Oxford Dictionary of English*: Oxford University Press. Retrieved 15 May. 2021, from https://www-oxfordreference-com.ezproxy.massey.ac.nz/view/10.1093/acref/9780199571123.001.0001/m_en_gb0050550.
- Padesky, C. A., & Mooney, K. A. (2012). Strengths-Based Cognitive-Behavioural Therapy: A Four-Step Model to Build Resilience. *Clinical Psychology & Psychotherapy*, 19(4), 283-290. <https://doi.org/10.1002/cpp.1795>
- Pitama, S., Huria, T., & Lacey, C. (2014). Improving Māori health through clinical assessment: Waikare o te Waka o Meihana. *New Zealand Medical Journal*, 127(1393). https://ndhadeliver.natlib.govt.nz/delivery/DeliveryManagerServlet?dps_pid=IE20388314
- Tamasese, K. (2002). Honouring Samoan ways and understandings: Towards culturally appropriate mental health services. *International Journal of Narrative Therapy & Community Work*, 2002(2), 64-71.
- Tamasese, K., Peteru, C., Waldegrave, C., & Bush, A. (2005). Ole Taeao Afua, the New Morning: A qualitative investigation into Samoan perspectives on mental health and culturally appropriate services. *Australian and New Zealand Journal of Psychiatry*, 39(4), 300-309. <https://doi.org/10.1080/j.1440-1614.2005.01572.x>
- Tukuitonga, C. (2013). *Pacific people in New Zealand*. In St George, I. M. (ed.). *Cole's medical practice in New Zealand*, 12th edition. Medical Council of New Zealand, Wellington.
- Vaioliti, T. M. (2006). Talanoa research methodology: A developing position on Pacific research. *Waikato Journal of Education*, 12.
- Vaioliti, T. (2013). Talanoa: Differentiating the talanoa research methodology from phenomenology, narrative, Kaupapa Maori and feminist methodologies. *Te Reo*, 56/57, 191-212.

Appendix E: Interventions Based on Principles of Applied Behaviour Analysis

It is important to note while mentioning ABA therapy, that although ABA appears to be the most common privately-funded autism intervention type available in Aotearoa (deduced from Google hits for organisations that provide autism intervention in Aotearoa) and has the largest empirical basis for effectiveness with autistic children (Anderson & Carr, 2021; Broadstock, 2011; Sigafoos & Schlosser, 2008), therapies and interventions based on ABA theory and principles are highly controversial within the autistic community (Kapp et al., 2019). This is in part due to the way that fundamental principles of ABA approach autistic behaviours as behaviours to be extinguished and replaced, and a deficit focus regarding autistic individuals and their learning (Folkema, 2022; Kapp et al., 2019). It is further due to the harmful methods of practice that were historically forced upon autistic individuals, including over-hand techniques, repetitive focused trials, gruelling and intensive therapy schedules, and aversive behaviour change techniques (Anderson & Carr, 2021; Banerjee et al., 2021). Further limitations include the non-generalisability of learning to non-clinical settings, and methodological weaknesses in empirical effectiveness studies, weakening overall effectiveness claims (Anderson & Carr, 2021; Rodgers et al., 2021). Opponents to the ABA approach also dismiss the body of empirical support for ABA as having a very narrow focus for effectiveness. For example, success was rated irrespective of whether the behaviour under focus was positive for overall psychosocial wellbeing, i.e. enriched the autistic person's quality of life, emotional or mental health and well-being, and irrespective of whether ABA processes caused distress or damage to the autistic individual's mental state (Anderson & Carr, 2021; Rodgers et al., 2021; Shochet et al., 2020).

Proponents of interventions based on ABA, retort that ABA is not a therapy or intervention in itself but a behavioural science based on the principles of operant and respondent conditioning, requiring expert knowledge to prescribe and deliver an appropriate programme for a specific child according to the functional analysis of the specific child's behaviour (Anderson & Carr, 2021; Sigafoos & Schlosser, 2008). In addition, proponents acknowledge the human rights abuses of institutionalised autistic people in the past, however, state that these were performed by rogue health professionals and not sanctioned by ABA developers (Anderson & Carr, 2021). ABA supporters acknowledge aversive mediators of behaviour (punishment) as being part of Lovaas' behavioural theory and associated interventions, however, note that since the US Individuals with Disabilities Education Act (IDEA; 1990), behaviour analysts are mandated to choose the least aversive and restrictive methods (Anderson & Carr, 2021). In 2021, Rodgers and colleagues did a comprehensive meta-analysis of outcomes from 10 studies testing therapies based on ABA and EIBI principles with autistic children using the original data rather than the published findings. The authors concluded that methodological weaknesses across the 10 studies put all studies at risk of bias across multiple domains. Further, early intensive ABA-based interventions led to positive increases in adaptive behaviour (as measured with an adaptive behaviour psychometric) and cognitive ability (as measured by intelligence testing) at two-year follow-up, however, the outcomes showed large confidence intervals and findings were stated to have varied widely across studies. Despite the controversy present in the field, and despite "little or no New Zealand-based research showing the appropriateness of ABA to the New Zealand context and population...[and]...a lack of knowledge about the suitability of ABA for persons with an Asperger Syndrome diagnosis, and for participants aged 15 years or above" the Autism Guideline supplementary paper on ABA (Broadstock, 2011) recommended that "Interventions and strategies based on applied behaviour analysis (ABA) principles should be considered for all children with ASD" (p. 13). The paper graded the evidence for this recommendation as Grade A, or "supported by GOOD evidence" (emphasis in original; Broadstock, 2011, p. 5).

Appendix F: Summary of Recommendations for Pacific Peoples from the Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau: Third Edition

Recommendation Number	Recommendation
8.1	The role of the family, extended family and community should be acknowledged and empowered by identifying attitudes and beliefs that the individual and family have surrounding ASD.
8.2	Appropriate educational material in language appropriate to each specific Pacific Island group should be provided to enhance understanding of ASD and support services they may be eligible for.
8.3	Pacific support workers, carers, teacher aides, cultural workers and/or clinicians should be involved from the point of assessment and diagnosis through to coordination and treatment.
8.4	The establishment of Pacific community support networks specific to ASD in appropriate geographical locations should be facilitated.
8.5	Services must be proactive in offering treatment.
8.6	Decision-making regarding assessment, treatment and coordination should be based on contextual information from a variety of sources and include specific Pacific input.
8.7	A programme of research that would provide baseline information regarding ASD and Pacific people should be developed.
8.8	A targeted recruitment and development strategy to support increasing the capacity and capability of the Pacific ASD-related workforce should be developed.
8.9	A strategy should be developed aimed at improving the cultural competency of the mainstream workforce to acquire knowledge and understanding of Pacific cultural values and world views and appropriately apply this to their work.

Note: From the Aotearoa New Zealand Autism Guideline: He Waka Huia Takiwātanga Rau: Third Edition (2022, p. 259).