

Original Research

OPEN ACCESS

Examining case complexity among Pasifika with autism/Takiwātanga in Aotearoa New Zealand: a national cross-sectional study

Troy RUHE,¹ Betty KOLOSE-PULEFOLAU,² Siale FOLIAKI,³ Nicholas BOWDEN,⁴ Rosalina RICHARDS,¹ Jesse KOKAUA¹

ABSTRACT

Introduction: Autism is a lifelong neurodevelopmental condition that is estimated to impact 1 in 44 children. In Aotearoa New Zealand, the rate of autism among Pasifika children and young people (38.6 per 10,000 people) is substantively lower than other ethnic groups (67.5 for European and 47.2 for Māori); however, the complexities associated with Autism diagnosis in Pasifika is unknown.

Aim: We compared rates of Autism and co-occurring diagnoses of conditions as a proxy for Autism case complexity between Pasifika and NMNP young people (aged 0-24 years) in Aotearoa New Zealand.

Methods: This national, cross-sectional study was undertaken using data from a national database; the Integrated Data Infrastructure (IDI). Three separate indicators were created to reflect different types of complexity for someone with autism: Asperger's syndrome (identifies those with lower complexity with fewer demands on support services); intellectual disability (higher needs/greater complexity); ORS funding (higher needs/greater complexity).

Findings: In this present study, Pasifika in Aotearoa New Zealand had much lower autism identification rates in comparison to Non-Māori Non-Pasifika (NMNP) (53.3 per 10,000 vs 83 per 10,000). After adjusting for socioeconomic differences, Pasifika had significantly lower odds (Odds Ratio (OR) = 0.47) of having an Asperger's syndrome diagnosis. However, Pasifika had significantly higher odds of having an intellectual disability (OR = 2.23) and being Ongoing Resources Scheme funded (OR = 2.18).

Conclusions: Using this method within the IDI, Pasifika children in Aotearoa continue to have lower rates of Autism diagnosis; however, they are more likely to have a higher complexity of autism diagnosis.

Keywords: autism, Pasifika, high need, complexity, big data

INTRODUCTION

Autism is a lifelong neurodevelopmental condition that is estimated to impact 1 in 44 children (2.3%).¹ It is characterised by long-term challenges with social and communication skills, sensory sensitivities, and restricted repetitive patterns of behaviour or interests.² There are several strengths of autism including abilities to think logically, strong adherence to rules, visual thinking, reliability and honesty^{2,3} however the effects of autism can impact on how individuals can manage the everyday demands of life, and this can require a range of supports required to enable autistic people to live their daily lives.

In this study, identity first language is preferred in recognition that this is the growing preference among autistic communities in Aotearoa New Zealand and with advice from the cofounder of

Corresponding author: Troy Ruhe

troy.ruhe@otago.ac.nz

1. Centre for Pacific Health, Va'a O Tautai, Division of Health Sciences, University of Otago,
2. Pasifika Autism Support Group, <http://www.asdpasifika.org.nz/>
3. Te Whatu Ora, Counties Manukau
4. Big Data Theme, A Better Start National Science Challenge, Women and Children's Health, Dunedin School of Medicine, University of Otago

Rec: 22.11.2022 **Accept:** 18.12.2022 **Publish:** 20.12.2022

Citation: Ruhe T, et al. Examining case complexity among Pasifika with autism/Takiwātanga in Aotearoa New Zealand: a national cross-sectional study. Pacific Health Dialog 2022; 21(10): 673-682. DOI: 10.26635/phd.2022.144

Copyright: © 2022 Ruhe T, et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Pasifika Autism Group. However, where necessary, terms such as 'person with autism' are also used. The authors also recognise that no single term is preferred by all autistic people.

Symptoms of autism typically present during the second year of life but in high need cases may be seen earlier than 12 months, or after 24 months if symptoms are less pronounced.⁴ This is reflected in the updated description of autism in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), which for the first time, now includes levels of severity of autism.⁽⁵⁾ Autism also frequently co-occurs with other conditions. Most notably, about one third of individuals with autism have an intellectual disability, and approximately 70% have at least one co-occurring mental health condition, in particular attention-deficit hyperactivity disorder (ADHD), mood disorders, and anxiety.^{1,5-9}

In an application of a recently developed autism case identification method using administrative health data in Aotearoa New Zealand, the rate of autism among Pasifika children and young people (38.6 per 10,000 people) was substantively lower than other ethnic groups (67.5 for European and 47.2 for Māori).¹⁰ This lower relative rate for Pasifika is consistent with previous Aotearoa New Zealand studies.^{11,12} However, while ethnic disparities in autism prevalence rates are not uncommon, temporal evidence from the United States indicates that these are unlikely to reflect true ethnic based differences in prevalence¹³ and more likely reflect other factors such as access to diagnostic services, racism, and different cultural values.^(1, 13)

In Aotearoa New Zealand, one possible explanation for this comparatively lower rate of identified autism in Pasifika is that there may be a preference to use a family or community-based model of care for their children.^{14,15} Thus, the initial responsibility for childcare would be within the confines of family or community before seeking professional help, especially if that outside help was foreign to the cultural values of a Pacific community.¹⁰ On the other hand, inequitable access to health services, lack of cultural competency of care, and systemic racism may also affect receiving an autism diagnosis for Pasifika. Less complex cases of autism (lower need) might get misdiagnosed as behavioural problems, or even overlooked completely.¹⁶ Such explanations lend themselves to the possibility that one of the reasons for differences in ethnic-based autism prevalence

rates in Aotearoa New Zealand may be that the complexity of identified cases of autism varies by ethnicity. Therefore, Pasifika children and young people that are identified with autism might have higher needs on average than non-Pasifika, and lower needs individuals are less likely to be diagnosed.

METHODS

Study Design

This was a national cross-sectional study using linked administrative health data contained within the IDI. These data are probabilistically linked at the individual level and available for research deemed to be for the public good. The study was approved by the University of Otago Human Research Ethics (Reference: HD17/004). Clearance for this study and access to data was also approved by Statistics New Zealand. In addition, a 'Tivaivai research framework' was used for appropriate and culturally sensitive interpretations of the data.¹⁷

Participant population

The study participants were a national cohort of children and young people in Aotearoa New Zealand, aged 0-24 years. The cohort was defined as those in the Aotearoa New Zealand estimated resident population (ERP) for the 2017/18 fiscal year (1 July, 2017 until 30 June, 2018) utilising an established method for identifying the ERP using the IDI.¹⁸ To be included in the IDI-based ERP, individuals must have used key government services in Aotearoa New Zealand over the previous two-year period. It excludes those who died or moved overseas prior to the end of the 2017/18 fiscal year.

Autism

Autism status was determined using an existing IDI-based case identification method by Bowden et al.¹⁰ This method draws on three health datasets: hospital admissions information from the National Minimum Dataset (NMDS); specialist mental health services data from the programme for the integration of mental health (PRIMHD), and needs assessment information from Socrates, the Ministry of Health's disability support services dataset. Autism was indicated utilising appropriate diagnostic coding from within each dataset. Specifically: Diagnostic and Statistical Manual of Mental Disorders (4th ed.; DSM-IV) codes for autistic disorder (299.00), childhood disintegrative disorder (299.10), and Asperger's disorder/pervasive development disorder NOS (299.80) from PRIMHD; ICD-10-AM codes for autistic disorder (F84.0), atypical

autism (F84.1), other childhood disintegrative disorder (F84.3), Asperger's syndrome (F84.5) other pervasive developmental disorders (F84.8), and pervasive developmental disorder, unspecified (F84.9) from NMDS and PRIMHD; and assigned diagnosis codes of autism (1211), Asperger's syndrome (1206) and other autism spectrum disorders (1207) from Socrates. Autism was identified in those who received at least one of the above-listed diagnostic codes, in any of the datasets, across eight years of data from 1 July, 2010 until 30 June, 2018.

Outcomes measures

Three separate indicators were created to reflect different types of complexity for someone with autism: Asperger's syndrome (identifies those with lower complexity with fewer demands on support services); intellectual disability (higher needs/greater complexity); ORS funding (higher needs/greater complexity).

Asperger's syndrome

Prior to DSM-V when Asperger's syndrome was a diagnosis of its own, it has often been referred to as 'high functioning' autism. It is differentiated as an absence of language impairment, no delay in cognitive development or age-appropriate self-help skills or adaptive behaviour further suggesting that complexity may be the catalyst for seeking specialist attention. While the term 'high functioning' autism is now generally avoided^{19,20} and despite Asperger's syndrome now being consumed into the DSM-V diagnosis of autism, there is still merit in examining its prevalence as a proxy for case complexity. ICD-10-AM Asperger's syndrome (F84.5) (NMDS), DSM-IV Asperger's disorder/pervasive development disorder NOS (299.80) (NMDS and PRIMHD), and the assigned diagnosis code of Asperger's syndrome (1206) (Socrates) were used. Asperger's syndrome was identified among the cohort if at least one of these diagnostic codes was identified across any of the datasets during the eight-year period.

Intellectual disability

In the present study, intellectual disability was identified in much the same way as autism, using an existing IDI-based case identification method.⁽¹⁰⁾ Specifically, intellectual disability was identified from the presence of any of the following codes over the eight-year period: DSM-IV codes 317* 319*, 3180, 3181, 3182 in PRIMHD; ICD-10-AM codes, F70-F79 in NMDS or PRIMHD; team type code, 12 (Intellectual Disability Dual Diagnosis Team) in PRIMHD; and assigned diagnosis codes, 1208 (intellectual

disability, type not specified), 1209 (learning disability, type not specified), 1210 (developmental delay, type not specified) and 1299 (other intellectual, learning or developmental disorder) in Socrates.

Ongoing Resource Scheme (ORS) funding

ORS funding information was extracted from the Ministry of Education student interventions table. ORS is a needs-based funding support provided via the Ministry of Education.^{21,22} ORS typically provides support to 1.2% of school aged children meaning it is a contested fund and only those with the highest needs receive funding. For this reason, we believe the presence of ORS funding provides a robust indication for high needs (complex) cases of autism. An indicator reflecting whether an individual had received ORS funding was constructed. An individual was recorded as having received ORS funding if an intervention for ORS (intervention code = 25) was present in the student interventions table. Analysis of ORS was restricted to those who were at least school aged, five years and over.

Ethnicity

An indicator for Pasifika ethnicity was extracted from the personal details table of the IDI. Ethnicity data is total ethnicity, meaning each person could identify with multiple ethnicities. All those who identified as Pasifika were included as Pasifika, regardless of the other ethnic groups they identify with. For the purposes of this study, Pasifika individuals were compared to a composite ethnic group of those who identified as non-Māori and non-Pasifika. This group is comprised of those from level 1 major ethnic groups of: European; Asian; Middle Eastern, Latin American, African (MELAA); and other but does not include those also identified as either Māori or Pasifika. Consequently, this study excludes those who were Māori and not Pasifika. Māori, who command a unique position in Aotearoa New Zealand as indigenous peoples, are deserving of independent research. However, they also share a heritage with people from the Pacific that mean their presence in a comparison cohort would moderate many characteristics inherent in Pasifika.

Sociodemographic characteristics

Sex (boys/girls) and age (0-4, 5-9, 10-14, 15-19, 20-24 years) chosen to align with the original autism case identification method were extracted from the IDI personal details table. A local neighbourhood indicator of socioeconomic deprivation was established using the New Zealand Deprivation Index (NZDep) 2013.²³

Urban/rural profile of residence was measured using Statistics New Zealand's classifications.⁽²⁴⁾ NZDep and urban/rural are each based on the meshblock (neighbourhood) an individual lives in as at 30 June, 2018. Meshblocks were determined using the address notification table in the IDI. NZDep scores were collapsed into quintiles with 1 representing the least deprivation and 5 the greatest. A binary variable was created reflecting urban/rural profile of residence, 1 indicating urban areas (populations 1,000 or more), and 0 indicating rural areas (less than 1,000 people).

Procedure

The June 2020 refresh of the IDI was used to access all data. These data were extracted using SAS version 7.1 (SAS Institute Inc., 2014) and analysed in Stata MP version 15 (StataCorp, 2017). All Statistics New Zealand confidentiality requirements were adhered to, including rounding to base 3, and suppression of any data where counts were less than 6. Analysis and reporting of analyses were informed by the Reporting of Studies Conducted using Observational Routinely collected health Data (RECORD) guidelines.²⁵

Statistical Analysis

The autistic cohort, as at 2017/18, was described descriptively by socio-demographic sub-group, with comparisons made between Pasifika and non-Māori/non-Pasifika (NMNP). Crude rates of AS, ID, and ORS funding were then derived at both the population level and among autistics, stratified by Pasifika/NMNP. Unadjusted and adjusted odds ratios (OR) were generated for Pasifika on each of the complexity measures. Variables in the adjusted models included sex, age, NZDep2013, and urban/rural profile. Two-tailed $\alpha=0.05$ is the threshold adopted in the study to determine significance.

RESULTS

Participant population

The full New Zealand ERP of 0–24-year-olds for the 2017/18 fiscal year contains 1,565,505 children and young people. Of those, 211,116 identified as Pasifika, and 1,009,563 as NMNP. Overall, 9,504 young people were identified with

autism, representing an identification rate of 77.9 per 10,000 population. Among eight-year-olds, the identification rate was 119.4 per 10,000 population (or 1 in 84).

Among Pasifika 1,125 were identified with autism reflecting an identification rate of 53.3 per 10,000 population. In contrast, 8,379 NMNP were identified with autism, yielding a substantively higher identification rate of 83.0 per 10,000 people. The sociodemographic characteristics of these children are presented in **Table 1** alongside associated population identification rates.

Males comprised just over 80% of the sample of children and young people with autism among Pasifika, slightly more than NMNP. The majority (67.7%) of the Pasifika sample were aged 5-14, while only 11.7% were aged 0-4 years, 13.6% 15-19 years, and 6.7% 20-24 years. In contrast, the age distribution among the NMNP group was older. Almost all autistic Pasifika children and young people (96.3%) resided in urban areas, compared to 88.7% of NMNP. Autism identification rates were lower among Pasifika across all sociodemographic subgroups except among those age 0-4 years (30.9 per 10,000 people compared to 24.8). In contrast, the largest difference in autism identification rates between Pasifika and NMNP were in the older age groups (60.1% lower in those aged 15-19 years and 62.7% lower among those aged 20-24 years). Identification rates among Pasifika were also particularly low relative to NMNP among females (43.2% lower), and those living in the most deprived areas (62.8% lower).

Autism complexity

In crude analyses, among the autistic cohort, observed rates of Asperger's syndrome were approximately three times higher among NMNP (20.9%) compared to Pasifika (7.5%) (**Table 2**). In contrast, observed rates of intellectual disability and ORS funding were almost twice as high among autistic Pasifika (48.3% and 49.4% respectively) compared to NMNP (25.7% and 27.5%). For reference, observed rates among the full ERP are also presented in **Table 2**.

Table 1: Sociodemographic characteristics and Autism case identification^a rates of the 211,116 Pasifika and 1,009,563 non-Māori/non-Pasifika children and young people (per 10,000 people), 2017/18

	Pasifika		Non-Māori/Non-Pasifika (NMNP)	
	No. (%)	Autism per 10,000 population	No. (%)	Autism per 10,000 population
Total	1,125	53.3	8,379	83
Sex				
Male	909 (80.8)	84.2	6,576 (78.5)	126.3
Female	216 (19.2)	20.9	1,800 (21.5)	36.8
Age				
0-4	132 (11.7)	30.9	456 (5.4)	24.8
5-9	477 (42.4)	101.5	2,241 (26.7)	112.4
10-14	285 (25.3)	67.2	2,529 (30.2)	129.5
15-19	153 (13.6)	37.8	1,941 (23.2)	96.8
20-24	75 (6.7)	19.5	1,209 (14.4)	52.4
Deprivation ^b				
1 (least deprived)	63 (5.6)	51.4	1,992 (23.8)	76.4
2	114 (10.1)	64.6	1,815 (21.7)	79.9
3	147 (13.1)	57.7	1,719 (20.5)	83.9
4	243 (21.6)	56.5	1,599 (19.1)	87.7
5 (most deprived)	558 (49.6)	49.8	1,203 (14.4)	95.5
Urban/Rural ^c				
Urban	1,083 (96.3)	53.4	7,431 (88.7)	85.9
Rural	39 (3.5)	49.7	909 (10.8)	65.9

a. autism rates presented in this table are not intended to estimate autism prevalence. They are identification rates based on health service utilisation data and will likely undercount true prevalence

b. Values missing for 9,084 (0.74%) young people in total, 789 (0.37%) Pasifika, and 8,295 (0.82%) NMNP.

c. Values missing for 6,654 (0.55%) young people in total, 636 (0.30%) Pasifika, and 6,016 (0.60%) NMNP.

Table 2: Autism complexity indicators for Pasifika and Non-Māori/Non-Pasifika (NMNP), under 25 years of age: All young people and those with autism, 2017/18

	Within Autism No. (%)		Population %	
	Pasifika N=1,125	NMNP N=8,379	Pasifika N=211,116	NMNP N=1,009,563
Asperger's syndrome	84 (7.5)	1,755 (20.9)	0.04	0.174
Intellectual disability	543 (48.3)	2,154 (25.7)	0.257	0.213
	N=996	N=7,923	N=168,351	N=826,020
ORS (age 5-24)	492 (49.4)	2,181 (27.5)	0.292	0.264

Table 3 presents unadjusted and adjusted (sex, age deprivation and urban/rural profile) odds ratios (OR) for Pasifika on each of the autism complexity measures. After adjusting for socioeconomic differences, Pasifika had

significantly lower odds (OR= 0.47) of having an Asperger's syndrome diagnosis. In contrast, Pasifika had significantly higher odds of having an intellectual disability (OR = 2.23) and being ORS funded (OR = 2.18).

Table 3: Comparative odds ratios (ORs) across severity characteristics in Pasifika young people with autism, 2017/18

	Unadjusted ORs (95% CI)	Adjusted* ORs (95% CI)
Asperger's syndrome	0.30 (0.24, 0.37)	0.47 (0.37, 0.60)
Intellectual disability	2.68 (2.36, 3.04)	2.23 (1.94, 2.55)
ORS (age 5-24)	2.56 (2.24, 2.93)	2.18 (1.89, 2.51)

* Adjusted for gender, age, deprivation, and urban/rural profile of residence

DISCUSSION

In this present study, Pasifika in New Zealand have much lower autism identification rates in comparison to NMNP (53.3 per 10,000 vs 83 per 10,000). This is consistent with previous literature from New Zealand^{11,12} and has been seen in aboriginal children in Australia²⁶ and first nations children in Canada,²⁷ but not in migrant children in Sweden where rates are similar with Swedish born children.²⁸ Previous research on Pasifika families, like Maori and other indigenous groups, had suggested low autism diagnosis could reflect culturally different understandings from western notions of autism rather than an absence.^{29,30} It is not fully understood how accepted autism is in some indigenous groups.⁽³¹⁾ Some Pasifika families perceive it as a negative and is met with denial and shame as there is a social stigma with diagnosis for cultural and spiritual reasons.^{14,32} The social stigma may also arise from Pasifika families communicating symptoms to clinicians which is sometimes dismissed as bad parenting and children lacking discipline.²⁹ It is possible that the undercount in Pasifika families would mean families are going without adequate support unless the need is high.

The current study suggests that autistic Pasifika children appear to have more complex needs. Specifically, they have higher rates of co-occurring intellectual disability, are more likely to receive ORS funding, and less likely to have an Asperger's Syndrome diagnosis compared to NMNP. This finding is consistent with some migrant and indigenous populations reporting a reverse risk gradient with higher rates of diagnoses for those requiring high support needs (higher risk) and less with low support needs

(lower risk).^{28,33} Migrant parents were reported to have a significantly lower risk of autistic children with high low support needs.²⁸ Similarly, autistic children of migrant parents in another population-based study were at an increased risk of requiring high support needs with highest risk when parents were from areas of low human development index (HDI).^{34,35} Additionally, a more recent study of the same cohort found a higher likelihood of intellectual disability and autistic children with migrant parents from low and middle HDI countries.⁽³⁶⁾ Although these studies highlight a lower risk of autistic children with high support needs in these populations, it is possible that these findings are reflections of underdiagnosis in these migrant and indigenous groups unless high complexity and more clear symptoms are present that warrant specialist attention. New Zealand parents of autistic children with co-occurring ADHD described delays in help seeking for these groups as the symptoms were not typical and often resulted in diagnosis of autism much later than ADHD.⁽¹⁶⁾ In a study on aboriginal children in Australia, children were less likely to be diagnosed with Asperger's syndrome with the authors suggesting the lower complexity of symptoms was less likely to be recognised.³⁷

The majority of autistic Pasifika are being diagnosed between the ages of 5-9 and less so into adolescents and adulthood; compared to NMNP who are continuing to be diagnosed within those later stages. This is consistent with findings from Australia, where among indigenous families, autistic children with high support needs are diagnosed earlier in life, and those with low support needs are diagnosed later in life, or not at all.⁽³¹⁾ In another migrant group, higher parental levels of education increased the

odds of a diagnosis at a younger age similar child of non-migrant parents.³⁸ An understanding of these differences in age of diagnosis between Pasifika and NMNP children may reflect access to effective services and have important implications for equitable health outcomes.

Implications

For Pasifika parents, a dearth of literature around accessing services for autism remains; however, clear inequities in service access and diagnosis have been documented.^(10, 15, 29) Parents are typically the first to notice signs of behavioural patterns,^{39,40} thus it is essential that parents have the proper awareness to ensure early detection and direction of effective and timely services. For example, a recent study suggested that a more targeted support for autistic students receiving ORS funding in Aotearoa New Zealand was associated with decreased suspension rates.⁴¹

The findings of this study would suggest a systematic undercount of autistic Pasifika children and a number of Pasifika children and families not receiving the health care and support they are entitled. It is highly likely that those who face longer terms of undiagnosed or misdiagnosis could lead to poorer long-term outcomes in all facets of life such as social and adaptive functioning which could affect education outcomes as well as employment.^{42,43} Thus, without access to timely and effective services, the potential of exacerbation of inequities between Pasifika and NMNP children in Aotearoa may increase.

Strengths and limitations of the study

Key strengths of the study are the use of whole population health data making it possible to identify a national population of young Pasifika Autistic individuals for the first time. The extent of the data allowed for comparisons between sub-groups such as socio-economic, gender, age as well as a comparison between Pasifika and NMNP which provides meaningful information for future implications. Another strength with the method is the linking of health and non-health data, such as ORS funding, which provided a greater basis from which we could characterise autism complexity beyond diagnosis information alone.

The Bowden case identification method utilised for autism is unvalidated; however, it cannot be formally validated currently with the data available in the IDI. A formal validation would assist with the accuracy of diagnosis of Autistic individuals as well as the potential undercount;

thus, the extent to which the method undercounts autism and generates false positives is unknown. Likewise, the methods for capturing Asperger's syndrome and intellectual disability have the same limitations.

The measures we employed to capture autism complexity should be considered proxies. While autism severity is a part of the DSM-V diagnostic process these data are not available within the IDI. ORS is arguably the best proxy as it is needs based and involves various stakeholders in the application process which has been shown to be a much more equitable process with respect to ethnicity than disability support service funding which rests much more on the parent.⁴⁴

CONCLUSION

Pasifika children in Aotearoa/NZ continue to have lower rates of Autism diagnosis; however, they are more likely to have a higher complexity of autism diagnosis in the data within the IDI. These findings suggest that greater attention is required to make health services more accessible to ensure Pasifika families are afforded the support required for greater quality of life.

Disclaimer

These results are not official statistics. They have been created for research purposes from the Integrated Data Infrastructure (IDI) which is carefully managed by Stats NZ. For more information about the IDI please visit <https://www.stats.govt.nz/integrated-data/>.

Acknowledgements

We would like to acknowledge A Better Start National Science Challenge, funded by the New Zealand Ministry of Business, Innovation and Employment. Grant number = tranche 2 project, UOAX1901. JK, TR and RR received funding from two HRC funding grants (HRC 20/115, and 20/116).

Conflicts of interest:

None declared

Data availability statement

The data used by this study are only available from a Statistics New Zealand approved datalab. Restrictions apply to the availability of these data, used under license for this study. Access to confidential unit record data is restricted to analysts who follow strict protocols within the confines of the datalab – any data that has been checked and released by SNZ is available for use by external researchers.

REFERENCES

1. Maenner MJ, Shaw KA, Bakian AV, Bilder DA, Durkin MS, Esler A, et al. 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*. 2021;70(11):1.
2. *Altogether Autism. Strengths and abilities in autism*. 2020.
3. Meilleur A-AS, Jelenic P, Mottron L. Prevalence of clinically and empirically defined talents and strengths in autism. *Journal of autism and developmental disorders*. 2015;45(5):1354-67.
4. Association AP. *Diagnostic and Statistical Manual of Mental Disorders, 4th 6. Edition: Primary Care Version* Washington DC: American Psychiatric Association. 1995.
5. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders*. *Am Psychiatric Assoc*. 2013;21(21):591-643.
6. Lai M-C, Kasee C, Besney R, Bonato S, Hull L, Mandy W, et al. Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet Psychiatry*. 2019;6(10):819-29.
7. Matson JL, Shoemaker M. Intellectual disability and its relationship to autism spectrum disorders. *Research in developmental disabilities*. 2009;30(6):1107-14.
8. Simonoff E, Pickles A, Charman T, Chandler S, Loucas T, Baird G. Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry*. 2008;47(8):921-9.
9. Lugo-Marin J, Magan-Maganto M, Rivero-Santana A, Cuellar-Pompa L, Alviani M, Jenaro-Rio C, et al. Prevalence of psychiatric disorders in adults with autism spectrum disorder: A systematic review and meta-analysis. *Research in Autism Spectrum Disorders*. 2019;59:22-33.
10. Bowden N, Thabrew H, Kokaua J, Audas R, Milne B, Smiler K, et al. Autism spectrum disorder/Takiwātanga: An Integrated Data Infrastructure-based approach to autism spectrum disorder research in New Zealand. *Autism*. 2020;24(8):2213-27.
11. Eggleston MJ, Thabrew H, Frampton CM, Eggleston KH, Hennig SC. Obtaining an autism spectrum disorder diagnosis and supports: New Zealand parents' experiences. *Research in Autism Spectrum Disorders*. 2019;62:18-25.
12. Simpson J, Duncanson M, Oben G, Adams J, Wicken A, Morris S, et al. The health of children and young people with chronic conditions and disabilities in New Zealand 2016. 2018.
13. Yuan J, Li M, Lu ZK. Racial/ethnic disparities in the prevalence and trends of autism spectrum disorder in US children and adolescents. *JAMA Network Open*. 2021;4(3):e210771-e.
14. Mauigoa-Tekene L, Hogan B, Howie L. Families' talanoaga about building relationships with special education services. 2013.
15. Mauigoa-Tekene L, Howie L, Hagan B. Understanding special education from the perspectives of Pasifika families: Ministry of Education, New Zealand, Research Division; 2013.
16. Sainsbury WJ, Carrasco K, Whitehouse AJ, Waddington H. Parent-reported Early Atypical Development and Age of Diagnosis for Children with Co-occurring Autism and ADHD. *Journal of autism and developmental disorders*. 2022:1-12.
17. Kokaua J, Jensen S, Ruhe T, Camp J, Jensen W, Sorensen D, et al. An Application of a Tivaivai Research framework to a quantitative Pacific health research project using New Zealand's Integrated Data Infrastructure: Tivaivai framework for quantitative Pacific research. *Pacific Health Dialog*. 2020;21(5):206-15.
18. Gibb S, Bycroft C, Matheson-Dunning N. Identifying the New Zealand resident population in the integrated data infrastructure (IDI): Statistics New Zealand=Tatauranga Aotearoa; 2016.
19. Keating CT, Hickman L, Leung J, Monk R, Montgomery A, Heath H, et al. Autism-related language preferences across the globe: A mixed methods investigation. 2022.
20. Monk R. Autism terminology guidance from the autistic community of Aotearoa New Zealand: A living resource created by

autistic people with the support of autism New Zealand. Wellington: Autism New Zealand; 2022.

21. Education Counts. Ongoing Resourcing Scheme (ORS). 2020.
22. Ministry of Education. Support available for children. 2021.
23. Atkinson J, Salmond C, Crampton P. NZDep2013 index of deprivation. Wellington: Department of Public Health, University of Otago. 2014.
24. Statistics New Zealand. Classifications and related statistical standards: Urban Area Statistics New Zealand. 2016.
25. Benchimol EI, Smeeth L, Guttmann A, Harron K, Moher D, Petersen I, et al. The REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) statement. *PLoS medicine*. 2015;12(10):e1001885.
26. Leonard H, Glasson E, Nassar N, Whitehouse A, Bebbington A, Bourke J, et al. Autism and intellectual disability are differentially related to sociodemographic background at birth. *PloS one*. 2011;6(3):e17875.
27. Lindblom A. Under-detection of autism among First Nations children in British Columbia, Canada. *Disability & Society*. 2014;29(8):1248-59.
28. Murray MJ. Children of migrant parents may be at greater risk of low-functioning autism spectrum disorder, but lower risk of high-functioning autism spectrum disorder. *Evidence-Based Mental Health*. 2013;16(1):24.
29. Masi L. Experiences of Pasifika Mothers' Caring for a Child With Autism Spectrum Disorder: Auckland University of Technology; 2022.
30. Tupou J, Curtis S, Taare-Smith D, Glasgow A, Waddington H. Māori and autism: A scoping review. *Autism*. 2021;25(7):1844-58.
31. Wilson K, Watson L. Autism spectrum disorder in Australian Indigenous families: Issues of diagnosis, support and funding. *Aboriginal and Islander Health Worker Journal*. 2011;35(5):17-8.
32. Capstick S, Norris P, Sopoaga F, Tobata W. Relationships between health and culture in Polynesia—A review. *Social Science & Medicine*. 2009;68(7):1341-8.
33. van der Ven E, Termorshuizen F, Laan W, Breetvelt E, van Os J, Selten J-P. An incidence study of diagnosed autism-spectrum disorders among immigrants to the Netherlands. *Acta Psychiatrica Scandinavica*. 2013;128(1):54-60.
34. Augereau N, Lagdas I, Kermarrec S, Gicquel L, Martin V, Xavier J, et al. Premigration social adversity and autism spectrum disorder. *BJPsych open*. 2020;6(5).
35. Magnusson C, Rai D, Goodman A, Lundberg M, Idring S, Svensson A, et al. Migration and autism spectrum disorder: population-based study. *The British Journal of Psychiatry*. 2012;201(2):109-15.
36. Morinaga M, Hollander AC, Heuvelman H, Lundberg M, Dalman C, Rai D, et al. Migration and risk of intellectual disability with and without autism: A population-based cohort study. *Acta Psychiatrica Scandinavica*. 2021;144(5):487-500.
37. Bent CA, Dissanayake C, Barbaro J. Mapping the diagnosis of autism spectrum disorders in children aged under 7 years in Australia, 2010–2012. *Medical Journal of Australia*. 2015;202(6):317-20.
38. Garcia Primo P, Weber C, Posada de la Paz M, Fellingner J, Dirmhirn A, Holzinger D. Explaining age at autism spectrum diagnosis in children with migrant and non-migrant background in Austria. *Brain sciences*. 2020;10(7):448.
39. Ozonoff S, Heung K, Byrd R, Hansen R, Hertz-Picciotto I. The onset of autism: patterns of symptom emergence in the first years of life. *Autism research*. 2008;1(6):320-8.
40. Ozonoff S, Young GS, Goldring S, Greiss-Hess L, Herrera AM, Steele J, et al. Gross motor development, movement abnormalities, and early identification of autism. *Journal of autism and developmental disorders*. 2008;38(4):644-56.
41. Bowden N, Gibb S, Audas R, Clendon S, Dacombe J, Kokaua J, et al. Association Between High-Need Education-Based Funding and School Suspension Rates for Autistic Students in New Zealand. *JAMA Pediatrics*. 2022.
42. Bailey B, Arciuli J. Indigenous Australians with autism: A scoping review. *Autism*. 2020;24(5):1031-46.
43. Whitehouse A, Varcin K, Waddington H, Sulek R, Bent C, Ashburner J, et al.

Interventions for children on the autism spectrum: a synthesis of research evidence. 2021.

44. Murray S, Kokaua, J, Bowden, N. Ethnic inequalities in children and young people's access to disability-related support. 2020.