Cultural appropriateness of t**he use of Autism Diagnostic & Observation Schedule (ADOS-2)**

**assessment tool for Māori: Whānau perspectives**

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Iris Pahau, OTBNZ Pou Tikanga Mentor.

# Te Tiriti o Waitangi

Te Tiriti o Waitangi (te Tiriti) was signed in 1840 between [[1]](#footnote-1)Tangata Whenua and the Crown. To work within the true spirit and intent of te Tiriti, the Crown’s responsibility is best stated in the **translated** version of te Tiriti o Waitangi (Māori text). The translation of the appropriate Māori text relative to this kaupapa is below:

### [[2]](#footnote-2)Ko te tuatoru

Hei wakaritenga mai hoki tenei mo te wakaaetanga ki te Kawanatanga o te Kuini – Ka tiakina e te Kuini o Ingarani nga tangata maori katoa o Nu Tirani ka tukua ki a ratou nga tikanga katoa rite tahi ki ana mea ki nga tangata o Ingarani.

signed] W. Hobson Consul & Lieutenant Governor

For this agreed arrangement therefore concerning the Government of the Queen, the queen of England will protect all the ordinary people of New Zealand and will give them the same rights and duties of citizenship as the people of England.

signed] W. Hobson Consul & Lieutenant Governor

# Background

Autism (ASD)/ Takiwātanga affects how a child acts, communicates, learns and interacts with others. The global prevalence of Autism/ Takiwātanga is rising with an estimated worldwide prevalence of 1-2% (Baxter Etal 2015). While the prevalence rate has been reported as 1 in 59 children in the USA (Baio etal 2018) it is thought to affect 1 in 100 New Zealanders as reported in the Ministry of Health NZ website. The rate of new ASD diagnoses in the Hutt Valley area is similar to international rates (Heather etal 2020) The Findings from Māori and autism: A scoping review (Jessica Tupou etal 2021) suggest broad differences in Māori and Western understandings of autism and slightly higher autism prevalence rates for Māori than for non-Māori New Zealanders.

The “gold standard” observational assessment for Autism (ASD)/Takiwātanga diagnosis (Kanne etal 2008) is Autism Diagnostic Observation Schedule -2 (ADOS-2). New Zealand Autism Spectrum Disorder Guideline 2016 also recommends ADOS to be used for ASD assessment. It is a semi structured, standardised assessment of social interaction, communication, play, imaginative use of materials and restricted and repetitive behaviours. The primary focus of the ADOS-2 is on the interactive social behaviour between the participant and one examiner.

The ADOS-2 was developed in the United Kingdom and United States, but used in many countries with many different cultures. New Zealand is a multicultural country with Māori population of 16.5% and European population of 70.2% (2018 census ethnic group report) plus some other ethnicities. Research suggest that ADOS-2 is a reliable tool in the Western context and some non-European cultures. However, its fitness for Māori has not been studied to date. . We know that before the arrival of European in the late 18th century, Tangata Whenua had their own lifestyle, beliefs, values, socio-economic circumstances, spiritual beliefs and their own whanau and hapu infrastructure. . Although there is a strong western influence, whānau continue to strongly practice their culture.

When tools designed in the western world are used outside this context, cultural factors may present as challenges during tool administration. Although some non-European population like Asians (So Hyun Kim et al., 2016) and Afrikaans (Lesia Smith et al., 2017) have identified cultural appropriateness of ADOS-2, this has unfortunately not been explored among Tangata Whenua. The research published on 2005 on “Māori perspectives of Autistic Spectrum Disorder” reports that some whānau expressed the wish to have more culturally appropriate assessment measures for Tamariki. The Māori and autism: A scoping review published in June 2021 also highlights a need for research to directly examine Māori autism prevalence rates. This may require the development of a rigorous system for collecting ASD diagnostic data from the Ministry of Health and/or District Health Boards (Drysdale & van der Meer, 2020). In line with this, the benefit of future research in evaluating the cultural appropriateness of current diagnostic tools for Māori has been highlighted as current diagnostic tools may not be appropriate for use with non-Western populations (Masi et al., 2017)

Furthermore, ADOS-2 testing uses many different toys and materials. Some of them may be unfamiliar to individuals being assessed (Norbury and Sparks 2013) or be culturally inappropriate. This was raised by one of the mothers in the recent Autism Hui organized in Gisborne - Marae based Takiwātanga Wānanga: Autism Spectrum from a Māori perspective. Certain social interaction that are assessed in ADOS-2 such as eye contact with an adult while talking/communicating can be culturally inappropriate for individuals being assessed (Norbury and Sparks 2013). The way ADOS-2 assessment is structured is an unfamiliar adult interacts with a child, often during play activities or social conversations for the entire assessment. This is in conflict with the Māori social structure where building connection and working with Whānau is central.

This study aims to explore the cultural appropriateness of ADOS-2, as a diagnostic tool for Autism, for Māori families referred to Hutt Valley District Health Board. The long term impact of using inappropriate tools and methods could result in inaccurate diagnosis.

# Cultural Appropriateness

The cultural appropriateness of an Indian practitioner examining the appropriateness of tools relative to Maori may be in question. I, however, am very confident that Meenakshi can competently undertake this study with the help and assistance of Maori whanau. The first occasion that Meenakshi questioned the appropriateness of this tool, it felt uncomfortable to her in relation to her own culture. She has attempted to locate a Maori Occupational Therapist who may work with the ADOS tool but has been unsuccessful. As a Tikanga Advisor and a Maori practitioner that has worked in an advisory capacity to both the Capital & Coast DHB and Hutt Valley DHB, I am available to Meenakshi throughout her research.

Nga manaakitanga

Iris M Pahau

# Method

*Ethical Considerations*

Ethical approval for conducting this study will be gained from Health and Disability Ethical Committee NZ.

*Occupational Therapy Board Tikanga Advisor*

The Occupational Therapy Board’s Tikanga Advisor will be -advising the researcher about the appropriate process.

*Participants*

A total of n = 30 primary caregivers whose children have been referred to Child Development Service, Hutt Hospital for developmental assessment and who include parents, grandparents and carers will be recruited. Children can be between the age group of 0-16 years in line with Child Development Service specifications. Participants will be divided into two groups based on the ADOS-2 module administered:

* Group A will be caregivers whose children are administered ADOS-2 Module 1 and 2, and
* Group B will be caregivers whose children are administered ADOS-2 Module 3 and 4.

*Measures ADOS-2.*

*Procedure*

One child and his/her whānau member will be seen at time in a private room with a camera for recording purpose. The ADOS-2 will be administered by the investigator. Information sheet and consent form will be given to the whānau in the previous session. Phone calls will be made by the investigator to make sure whānau understand the process and clarify any doubts. On the ADOS assessment day a blank paper will be given to whānau to make notes about their likes and dislikes while watching the assessment. Following the assessment a questionnaire will be given to whānau to complete at home and bring it back in the next appointment. Phone calls will be made during this time to help whānau complete the questionnaire and clarify doubts. All the completed questionnaires will be returned to the sealed box during the next appointment. The box will be opened for analysis at the end of the study. This process will be followed for both Group A and Group B.

Group A: In this group whānau will be allowed to sit and watch in the same room where assessment takes place. ADOS module 1 and 2 will be administered.

Group B: in this group whānau will be asked to sit and watch from the adjacent room. This room is provided with a two-way mirror window and speaker. ADOS module 3 and 4 will be administered.

Aims of the project

Main Aim:

To investigate cultural appropriateness of ADOS-2 for tamariki and rangatahi Māori and improve Autism assessment outcomes.

Secondary aims:

* To ensure Māori families feel valued and comfortable for their children to be assessed using a culturally appropriate assessment tool for Māori whānau, tamariki and rangatahi.
* To inform ADOS trainers about the cultural preferences of whānau and provide guidance when considering adaptation of the ADOS assessment process and training.
* To increase/improve awareness amongst health professionals about cultural considerations (tikanga Māori) and encourage them to make an effort in administering ADOS in culturally appropriate way.
* To supports Enabling Good Life, Ministry of Health, objectives and principles - Individuals and their families/ whānau have increased control over their lives.

# Inclusion/Exclusion Criteria

# Inclusion Criteria

# Whānau /families identifying themselves as NZ Māori

# Referred to Child Development Service (CDS) Hutt Valley for developmental assessment

# NZ Māori families waiting for ADOS-2 administration

1. Children with age range from 2 -16 years.

# Exclusion criteria:

# Whānau /families not identifying as NZ Māori

# Whānau /families not referred to CDS developmental assessment team

# Whānau /families not wanting ADOS-2 assessment

1. Where ADOS assessment not indicated

Informed Consent

Statistical Analysis

Victoria University statistician

# Publications

Following are possible publication options

OT Insight/Maramatanga Whakaora Ngangahau - best practice magazine for occupational therapists Aotearoa: <https://www.otnz.co.nz/publications/ot-insight/>

Research in Autism Spectrum Disorders: journal homepage: [www.elsevier.com/locate/rasd](http://www.elsevier.com/locate/rasd)

# Review Journal of Autism and Developmental Disorders: <https://www.springer.com/journal/40489>

Appendix 1

To whom it may Concern

Meenakshi Panda approached me concerned about the cultural appropriateness of the ADOS Tool in assessing Māori tamariki and rangatahi. I was very humbled that someone

References

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Schedule-2 in Afrikaans

Anne Masi1, Marilena M. DeMayo1, Nicholas Glozier1, Adam J. Guastella1 (2017) An Overview of Autism Spectrum Disorder, Heterogeneity and Treatment Options

Norbury CF and Sparks A (2013) Difference or disorder? Cultural issues in understanding neurodevelopmental disorders. Developmental Psychology 49(1): 45–58

1. [↑](#footnote-ref-1)
2. Translation by Professor I H Kawharu, published in Report of the Royal Commission on Social Policy, Wellington, 1988

   **Tangata Whenua:** Generic term for Māoricomprising those with Mana Whenua responsibilities (Māori who are tied culturally to an area by whakapapa and whose ancestors lived and died there) together with Taura Here (Māori resident in an area, but who below to waka and Iwi from other parts of Aotearoa) [↑](#footnote-ref-2)