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GUIDELINE DEVELOPMENT APPROACH

The Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Guidelines for Aotearoa (New Zealand)

2024

Ehara taku toa i te toa takitahi engari he toa takitini.
Success is not the work of an individual, but the work of many.

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The combined efforts of the many were needed to create this guideline.

HĀPAI TE HAUORA
MĀORI PUBLIC HEALTH

The Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Guidelines for Aotearoa (NZ) 2024

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GUIDELINE DEVELOPMENT APPROACH

The Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Guidelines for Aotearoa (New Zealand) 2024

Project Scope

This project developed Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Guidelines for Aotearoa (NZ) to assist clinicians in the diagnosis, referral and management of FASD. During this process we recognised the need to consider alternative diagnoses and impact of other pre- and post-natal factors including exposure to trauma.

The project team agreed that these Guidelines will be embedded within the cultural and health context of Aotearoa (NZ) and as such must be grounded within a Te Tiriti o Waitangi framework. Te Tiriti has also informed this project and includes, but is not limited to project leadership, structure or key personnel, and consultation with whānau and healthcare practitioners.

The revised Canadian, and the first Australian, diagnostic guidelines for FASD were both published in 2016. The Australian guidelines have been reviewed concurrently to the establishment of this guideline. Information from the Australian revision was considered in the establishment of these FASD diagnostic guidelines for Aotearoa (NZ). This included consideration of their systematic reviews of the literature, and reflections of their clinical interpretation of the research evidence. Consideration was also given to guidelines and literature from Canada and other countries. Differences in the health, education, justice and child welfare systems in Australia and other countries have been taken into consideration.

Exploring Te Ao Māori models of care through consultation, with whānau and health professionals, enabled the development of a diagnosis and assessment criteria which can be used by the wider workforce to work with whānau, hapū, iwi and hapori who are affected by FASD. Co-design and refinement was undertaken to develop guidelines in partnership with tāngata whenua, to ensure it is appropriate for use in Aotearoa (NZ) and meets the Ministry of Health and Government's commitment to improving outcomes for Māori, health equity, and child health and well-being. The final Aotearoa (NZ) guidelines were endorsed by key stakeholders (as listed below).

Key Project Outcomes

For this project, the key outcomes identified from the Service Specifications were;

- Formation of Steering Group and Advisory Groups to guide the development of the guidelines.
- Engagement with key stakeholders via consultations and survey to co-design and refine guidelines.
- Literature/Guideline review and critique of current FASD Clinical Diagnostic practice.
- FASD Clinical Diagnostic Guidelines, including a consultation process for endorsement of guidelines.
- Final report including recommendations and further areas for research.
- Deliver one publicity output to introduce the guideline to the intended user groups i.e. podcast, webinar, seminar, article in relevant publication or forum.

Guideline development process

The Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Guidelines for Aotearoa (NZ) was developed by a team to assist clinicians, professionals, and families in the diagnosis, referral and management of FASD. From the start the team agreed that these FASD Diagnostic Guidelines will be embedded within the distinct context of Aotearoa (NZ) and grounded within a Te Tiriti o Waitangi framework. The following details the methodological framework and workstreams undertaken to develop these guidelines.

Approach

Kaupapa Māori

Kaupapa Māori as a methodology provides the space in which Māori ideals, values and experiences can be fully understood. The development of the guidelines has been guided by Linda Smith's Kaupapa Māori explanation (2015) that states that instead of fitting research methods into a Māori framework, using this methodology from the beginning assumes the existence and validity of Māori knowledge, language and culture throughout all parts of the project. The approach to the guidelines has been founded upon the following Kaupapa Māori principles:

- Tino Rangatiratanga: the relative autonomy principle
- Taonga tuku iho: the cultural aspirations principle
- Ako Māori: culturally preferred pedagogy
- Kia piki ake i ngā raruraru o te kāinga: the mediation of socio-economic factors
- Whānau: the extended family management principle
- Kaupapa: the collective vision principle. (Smith, 1992, pp. 13-14)

Te Tiriti o Waitangi

These guidelines are embedded within the cultural and health context of Aotearoa (NZ) and grounded within Te Tiriti o Waitangi. Application of Te Tiriti o Waitangi included, but was not limited to, project leadership and governance, process and design, and consultation with whānau and healthcare practitioners. Co-design was undertaken to develop the guidelines in partnership with tāngata whenua, to ensure it is appropriate for use in Aotearoa (NZ) and meets the Ministry of Health and Government's commitment to improving outcomes for Māori, health equity, and child health and well-being. Whānau voice has been prioritised and Māori models are applied throughout this guideline. This guideline also aligns with Whānau Ora outcomes which centre whānau having self-determination for their health and well-being journey.

Process

The development of the guidelines was carried out in a number of phases. These phases were separated into different workstreams, which were overseen firstly by Hāpai te Hauora, then as the project progressed, were reviewed by the Steering Group Committee and advisory groups.

Phase 1 – Establishment of project and recruitment of project team

This phase involved engagement with Te Whatu Ora Health NZ on the nature and scope of project along with the appointment of Hāpai Te Hauora (Māori Public Health) to oversee the project. The project leads Sarah Goldsbury and Andi Crawford, with the support of Hāpai te Hauora, were responsible for the initial developmental stages of the project including the utilisation of a Kaupapa Māori approach (see above) and the grounding of the project and the guidelines within Te Tiriti o Waitangi. Recruitment of the project team was carried out by the project leads and in line with Te Tiriti o Waitangi consisted of both tāngata whenua and tāngata tiriti.

Phase Two – Establishment of guiding principles and workstreams

Phase two consisted of establishing the guiding principles for the project along with project process, and workstreams.

Table 1. Project Team Guiding Principles

Be led by both tāngata whenua and tāngata tiriti.
Be developed in consultation with relevant stakeholder groups–professionals, people affected by FASD including adults who have been diagnosed with FASD, this includes parents, caregivers, and whānau.
Support diagnostic services and processes that are accessible, culturally and age appropriate i.e. youth friendly.
Support consistent and standardised diagnostic tools and/or processes.
Support Kaupapa Māori approaches i.e., weaved into and alongside biomedical/technical tools and processes.
Build on international evidence and recommendation as applicable in Aotearoa (NZ).

Task allocation

The project team met once a week (or as necessary) in order to update on work progress and assign tasks. Minutes were completed for each hui and circulated via email with the project team. Recruitment of experts was sought when required to support the project team on task completion. A documents register was maintained to ensure all pertinent communication from various stakeholders and experts were recorded and easily accessible. Work streams were identified to cover the main components of the guidelines. See Table 2 for a breakdown of work stream, task and who they were allocated to.

Table 2. Phase 2 - Workstreams

Work Stream	Task	Completed by/Reviewed by
Work Stream One	Establish Steering Group Committee.	Project Team.
Work Stream Two	Literature Review.	Completed by the project team and reviewed by Hāpai Te Hauora and Steering Group.
Work Stream Three	Critical Tiriti Analysis	Completed by Haami Harmer and reviewed by Steering Group.
Work Stream Four	Stakeholder Engagement and thematic analysis.	Completed by the project team and reviewed by Steering Group.
Work Stream Five	Establish and seek guidance from Clinical Advisory Group.	Project Team.
Work Stream Six	Collaboration with the Australian Review.	Sarah Goldsbury, Andi Crawford with review by Steering Group and Clinical Advisory Group.

Work Stream One – Establish Steering Group

A Steering Group was convened by inviting people with living experience of FASD, those caring for people with FASD, professionals providing supports to those with FASD (including clinical and diagnostic support) and academics with expertise about FASD to participate in the development of the guideline. Their role was to review the available information and inform and advise on the development of the Aotearoa (NZ) FASD Diagnostic Guide. Within the Steering group there was a tāngata whenua rōpū and a tāngata tiriti rōpū. Equal representation in each rōpū was sought for whānau and all professional groups. Disciplines represented included Psychology, Speech-language Therapy, Occupational Therapy, Paediatrics, and other key experts in health, justice and disability services, as well as cultural experts.

Wherever possible the project team sought to ensure the members of the Steering Group were:

- from diverse geographical regions, including those in rural settings
- from diverse discipline areas acknowledging that many different professions provide support to families and individuals living with FASD
- diverse in terms of ethnicity, culture and gender; and
- people with living experience of FASD or supporting someone with FASD.

The process for selecting members of the Steering Group were as follows:

- Stakeholders were contacted via phone to explain the guidelines development project and then invited via email to join the steering group.
- Direct approaches were made by the project team to cultural experts; adults with lived experience; and whānau members of those with FASD.

Steering group participants were given the Conflicts of Interest Policy and asked to complete an Interests Register. On agreement a background document was shared to outline the purpose, scope and project process.

Steering Group Wānanga

A total of seven online wānanga were held, firstly to discuss the project and then to update the group on progress and gather guidance and feedback. Prior to the hui an agenda was sent out. Minutes were recorded and sent out to the Steering Group after each hui. Table 3 outlines the focus of each Steering Group Wānanga.

Table 3. Outline of Steering Group Discussions

Hui #	Date	Items Discussed
Steering Group Hui 1	2.2.2022	Whakawhanaungatanga – meet the team. Outline of project and contextual factors impacting on current diagnostic and assessment practice as well as update on Australian FASD diagnostic guidelines project.
Steering Group Hui 2	5.4.2022	Terms of reference established including mātāpono (guiding principles)
Steering Group Hui 3	5.7.2022	Project updates – MOH, Australian Guidelines project, literature review. Stakeholder engagement process.
Steering Group Hui 4	6.9.2022	Project updates – Stakeholder engagement. Presentation of Critical Tiriti Analysis. Use of Mātauranga Māori within guidelines.
Steering Group Hui 5	5.11.2022	Project updates – Stakeholder Engagement (Themes), CTA and Literature Review.
Steering Group Hui 6	22.5.2023	Project updates. Presentation from Dr Natasha Reid: Review of Australian FASD Diagnostic Guidelines.
Steering Group Hui 7	29.8.23	Mihi to Sarah Goldsbury and welcome to Dr Raewyn Mutch joining the Project Team. Mihi to Dr Streissguth. Project update – plan for next phase, Stakeholder engagement findings, Australian Guidelines update.
Steering Group Hui 8	19.2.2024	Presentation of creative brief. General discussion and feedback to draft guideline documents.

Work Stream Two – Literature Review

A comprehensive literature review was undertaken and consisted of three sections:

- Comparison of current international guidelines from Canada, Australia, Scotland and the 4-digit FASD assessment guidelines from the United States.
- Review and identification of contextual factors impacting on the current provision of FASD diagnostic and assessment services in Aotearoa (NZ), including clinical, cultural and social factors.
- Inclusion of data from the Australian FASD Guidelines project which conducted an extensive systematic review considering the evidence across the diagnostic criteria.

The rationale for including the Australian literature was that this rigorous review provided an up to date systematic analysis of relevant research using a GRADE (Grading of Recommendations, Assessment, Development and Evaluation) system of evaluation (GRADE; Schünemann et al., 2013). This contribution increased the capacity of this project to provide clinically sound recommendations.

Search strategy

Online databases including PsycINFO, Scopus, Web of Science and Google Scholar were searched using the descriptors "fetal alcohol spectrum disorder", "FASD", "prenatal alcohol exposure" or "PAE", searches were also undertaken to seek material on FASD diagnostic pathways and processes and effective practice.

The criteria for selection of studies were as follows:

For a comparison of the guidelines:

- FASD specific guidelines
- published 2015 (within previous 8 years) or later.
- be in common/current use

For Aotearoa (NZ) literature review:

- Published in peer reviewed journal – 2015 or later
- Focused on FASD diagnostic pathways, processes and practice

Australian Evidence Review:

The Australian evidence review determined the following research questions to guide the Aotearoa (NZ) evidence review:

1. What is the available evidence for each of the components of the diagnostic criteria (i.e., prenatal alcohol exposure, dysmorphology, neurodevelopment and physical size)?
2. What are the experiences of individuals with FASD/ND-PAE and their families of the assessment and diagnostic process?
3. What broader factors (i.e., in addition to the diagnostic criteria) should be considered as part of a holistic assessment when considering FASD/ND-PAE as one possible outcome?
4. What are the costs, other resource implications and models of care to be considered when undertaking assessments that consider FASD/ND-PAE as one possible outcome?

See "Australian clinical practice guidelines for the assessment and diagnosis of fetal alcohol spectrum disorder or neurodevelopmental disorder associated with prenatal alcohol exposure. Association between prenatal Alcohol Exposure Physical Size, Dysmorphology and Neurodevelopment: Systematic Review Report." (Hayes et al. 2024) for detail regarding the evidence review search strategy and selection of the evidence. Certainty of evidence was established using the GRADE Grading of Recommendations, Assessment, Development and Evaluation approach (Schünemann, et al. 2013). This evidence was included in the Aotearoa (NZ) literature review and formed the basis of information to be considered in establishing the clinical criteria. Process of this review is detailed below in Workstream five – Clinical Advisory Group.

Work Stream Three – Critical Tiriti Analysis:

As the result of questions raised within the Steering Group about ensuring the project upholds Te Tiriti o Waitangi within a kāwanatanga space and within tangata tiriti clinical spaces the application of a Critical Tiriti Analysis (CTA) (Came et al., 2023) was proposed. Team members attended CTA training in August 2022 and were further supported by consultation with Tim McCreanor and Heather Came (authors of CTA).

An analysis of the project using CTA was undertaken by Haami Harmer in January 2023. The data was analysed within a Te Ao Māori framework based within the context of Mauri Ora. A second analysis was carried out in December 2023 and is found in related document Whakakotahitanga: Critical Tiriti Analysis. .

Workstream Four – Stakeholder Engagement

This section outlines the stakeholder consultation that was undertaken throughout Aotearoa (NZ) during 2022 and 2023. Multiple methods of engagement were utilised to ensure members of the community were able to share their views. Those with living experience of FASD, whānau and professionals were invited to a kanohi te kanohi community hui on developing Aotearoa (NZ) diagnostic guidelines for FASD. Four venues across Aotearoa (NZ) were selected. Participants were advised that if they were not able to attend the wānanga then additional online hui, interviews and surveys would be available. See Table 4 for details of the engagement process.

Table 4. Stakeholder Engagement

Engagement Method	Location	Venue	Date
Wānanga	1 Tāmaki Makaurau/ Auckland. 2 Whangārei . 3 Ōtautahi/ Christchurch. 4 Te Papaioea/Palmerston North.	Te Mahurehure Marae. Te Puna o Te Mātauranga Marae. Rehua Marae. Tuturu Pumau Te Hotu Manawa o Rangitāne o Manawatū Marae.	2 Sept 2022. 9 Sept 2022. 30 Sept 2022. 28 Oct 2022.
Online Hui	Pasifika Group. Whānau Group One. Whānau Group Two . Professional Group.	Online. Online. Online. Online.	11 Nov 2022. 22 Nov 2022. 28 Nov 2022. 19 Dec 2022.
Interview	Professional.	Online.	21 Nov 2022.
Survey.	Living experience. Whānau. Professional.	SurveyMonkey Online. SurveyMonkey Online. SurveyMonkey Online.	Dec 2022 – Feb 2023. Dec 2022 – Feb 2023. Dec 2022 – Feb 2023.

Engagement Process

Wānanga

Wānanga were advertised through clinical and professional networks, FASD-CAN and other organisations supporting families impacted by FASD. Wānanga were opened with Māori tikanga (cultural customs) including karakia (prayer) and whakawhanaungatanga (relationship building). This ensured tikanga was respected and set the context for a culturally safe and inclusive environment to encourage a free flowing of ideas and discussion. A short presentation by the project leads, proceeded large and small group discussions. Small group discussion enabled the prioritisation of ideas which were then reported back to the larger group for deliberation. Whole group reflection enabled stakeholders to consider and discuss what the most important factors in having an assessment and making a diagnosis for FASD were, along with barriers to diagnosis. Wānanga discussion was summarised with participants then closed with karakia.

Online hui and surveys

Online hui and surveys were also available for those who were unable to attend the wānanga and were advertised through FASDCan, and professional networks. Four two-hour online hui were held and are described below. Two were advertised as whānau/caregiver hui, although some professionals attended. A separate online hui for professionals was also held. Finally, to ensure Pasifika voice was present an online hui was held for representatives of this community. All online hui followed a similar structure as the wānanga including tikanga and rituals of encounter, followed by a presentation by the project leads before group discussion was undertaken. Three surveys, Caregiver, Professional, and Lived Experience were developed and shared through FASDCan's social media platform. These surveys contained demographic questions along with open-ended questions. Finally individual interviews were also provided for stakeholders who were unable to attend wānanga and hui but who wished to have a say.

Demographics

We talked to a wide range of stakeholders to guide the development of the first FASD diagnostic guideline for Aotearoa (NZ). Through wānanga, online hui, individual interview, and surveys we were able to hold space for the voices of people with FASD lived experience, their whānau, clinicians, academics and other supporting workers (such as Speech-language Therapists, Psychologists, Social Workers, Corrections Officers, General Practitioners and Occupational Therapists).

Data Analysis

As all four data streams (wānanga, online hui, interview and survey) provided qualitative data a thematic analysis was conducted to identify common themes. Four clear themes were identified across all data streams regarding the most important factors in having an assessment and making a diagnosis for FASD. Themes included the importance of whānau engagement, recognition of Te Ao Māori, development of clinical knowledge and practice, and the need for clear diagnostic pathways and communication (See Whakakotahitanga: Findings from stakeholders engagement for more detail).

Work Stream Five – Clinical Advisory Group

A clinical advisory group was established to review the available information, inform and advise on the development of the Aotearoa (NZ) FASD Diagnostic Guide. The clinical advisory group consisted of Psychologists, Paediatricians, Speech-language Therapists, Occupational Therapists and researchers.

Wherever possible the Project Team sought to ensure the members of the Clinical Advisory Group:

- Were from diverse geographical regions, including those in rural settings
- Were divers in terms of ethnicity, culture and gender; and
- People with cultural expertise were present

The process for selecting members of the Clinical Advisory Group were as follows:

- Approaching steering group members who were interested were invited to take part in a clinical wānanga.
- Direct approaches were made by the project team where necessary to ensure cultural, regional, professional and private/public representation.
- Stakeholders who agreed to participate were sent an agenda before the wānanga.

Clinical Advisory Team

Dr Andi Crawford, Anna Baker, Dr Collette Mui, Cristina Fon, Elda Botes, Kara Te Whata-Maynard, Dr Kate Robertshaw, Dr Natasha Reid, Dr Nicky Jordan, Dr Raewyn Mutch, Sally Kedge, Tracy Karanui, Dr Valerie McGinn.

Clinical wānanga

A face-to-face clinical wānanga (with online option to attend) was held 4th October 2023 to establish clinical criteria, this included considering data presented by Dr Natasha Reid (Senior Research Fellow, Clinical Psychologist, University of Queensland) from the Australian diagnostic guidelines project including a systematic review of the literature and clinical interpretation of research evidence, along with comparison of four guidelines (Australian, Canadian, Scottish and 4-Digit Code) currently in use both locally and internationally. Feedback from stakeholder engagement was also considered.

The team focused on the following clinical criteria:

- Criterion A – Prenatal Alcohol Exposure
- Criterion B – Neurodevelopmental Domains
- Criterion C – Requirement of clinical distress or impairment
- Criterion D – Present in developmental period
- Criterion E – Other medical conditions
- Specifiers
- Associations
- At Risk Category

A summary of the clinical wānanga was completed and sent to members for review. A draft of the clinical criteria and the guidelines was sent to the advisory group for their feedback. Review comments were addressed, and the guidelines were adjusted whilst also centring Te Tiriti o Waitangi responsibilities and the voice of families and other stakeholders.

Workstream Six – Collaboration with Australian FASD Guidelines Review Project Team

The Aotearoa (NZ) guidelines team utilised a collaborative approach with their Australian counterparts. This collaboration entailed:

- Aotearoa (NZ) project team members were included in Australian Guideline groups. Sarah Goldsbury and Andi Crawford contributed to the Review of the Australian Guidelines, attending workshops, reviewing data from systematic reviews and GRADE evaluation, and contributing the drafting of the Australian clinical criteria.
- The Australian team generously shared their evidence reviews and GRADE evaluation. The diagnostic criteria were drafted by Dr Natasha Reid and the Australian Guideline Development Group and was incorporated into the Aotearoa Guidelines where was appropriate to our context.

Phase Three – Drafting clinical guidelines, Consultation and Dissemination.

Table 2. Phase 3 – Task Allocation

Work Stream	Task	Completed by/Reviewed by
Workstream One	Developing/Writing Guidelines.	Completed by the project team and reviewed by Hāpai Te Hauora and other experts as required.
Workstream Two	Consultation and Review.	Completed by the project team and reviewed by Hāpai Te Hauora, Steering Group and other subject experts.

Work Stream One – Developing/ Writing Guidelines

Writing the guidelines was completed by the project team with support from experts. The scope of the guidelines focused on the delivery of FASD diagnostic services. While outside of the scope of the guidelines the need for pre and post diagnostic services was also noted.

Who were involved:

- Project team
- Clinical advisory group
- Australian Review of FASD guideline contributors
- Steering group
- Whānau
- Hāpai te Hauora

Guidelines were drafted by the project team which centred feedback from the stakeholder engagement and evidence reviews. Collaboration with Australia was significant as this enabled clinical guidance based on the best available literature. Much of the clinical criteria benefited from applying the work developed from the Australian Guideline Development Group. Guidelines were shared to the clinical advisory group, key experts and whānau to be critiqued throughout the drafting phase. A wānanga was held in Ōtautahi/Christchurch where feedback on the draft guidelines was sought from stakeholders. Present at the meeting were whānau and professionals providing clinical and other support services. A full draft was shared with the Steering Group and subject experts in January 2024 for final review. Hāpai te Hauora provided oversight and guidance from a Māori research perspective and supported the project with visual artists and graphic designers.

Work stream two – Consultation and Dissemination

Final stage consultation was conducted in February 2024. This involved Steering Group, Clinical Advisory Group and other academic, health, care & protection, and cultural experts.

The final document was launched on 26th April 2024 at Papakura Marae.

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