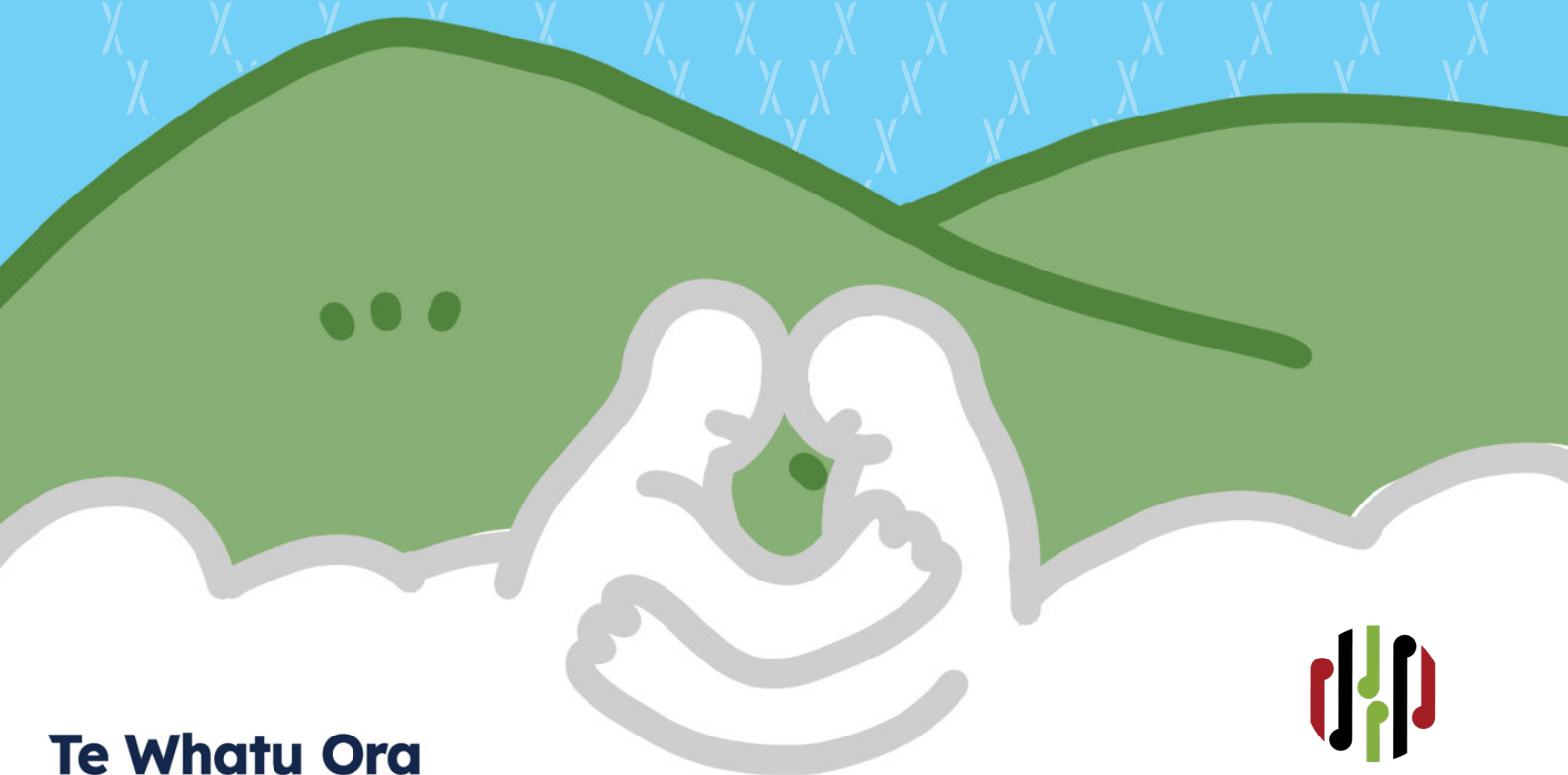




# The Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Guidelines for Aotearoa (New Zealand) 2024

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





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

Whakakotahitanga | Unity

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<b>Artwork:</b>	Hāpai Te Hauora



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

2024



# Honouring the voices

The following voices were heard during wānanga and hui and have guided the development of these guidelines. We thank all those who have contributed to the development process.

## Whānau/Living Experience Voice

"I guess that approach of you are all in it together would be much more effective, and you would feel much more like you were moving as a team rather than you were just out on your own."

"I think it is absolutely crucial that the families are supported in the system and that we are advocating and empowering them with whatever resources are there".

"I think it is crucial to make sure all potential and current health and education providers are totally FASD informed."

"Recognise FASD as a disability for funding and resources, worthy of support."

"It helps to give you the language to advocate. Because the reality is we're always going to have to be advocates. And we have to get really smart at it whether we're in schools, or hospitals, it doesn't matter where we are, we have to be really good at it. So, anything that helps you get better at that language that's where the diagnosis is definitely helpful for those things."

"We need government acknowledgement of FASD as a major disability."

"I think it's really important that you understand the people that you're communicating with and deliver the information in a number of ways because everyone learns and absorbs differently. And I think one size isn't going to fit all."

"Tino rangatiratanga is about for whānau, by whānau approach, which means our whānau language for instance is used, health literacy means us using correct whānau language"

"The journey is long and the need for support continues well after that feedback appointment."

"It's not just about getting a diagnosis and explanation for us. I think it did a number of things. I had become quite separated from the whānau because of the way I approached raising my mokopuna. But once we had the diagnosis and we all sat down, and we all got a joint understanding of what was happening, it brought us back together. It brought us on the same page and the same approach, which meant that I then got more support."

## Kaimahi voice

"Relationships are the most important. If you get that right the rest just flows"

"There may be elements of trauma and guilt and so people need a lot of awhi and support and understanding with regard to having a child that is different"

"Have the whānau and tamariki voice in the diagnosis and treatment"

"Need for cross sector co-ordination"

"I think we need a panel. I think they need to be reviewed. I think we need a standardisation in New Zealand, where we're starting to clinically set a bar so that we're developing an expertise. [...] "if I got a diagnosis wrong, or if I missed something, I'd want to be picked up a bit earlier than not."

"Support for people carrying out assessment work is really complex, burnout in this group is high. Need for a team."

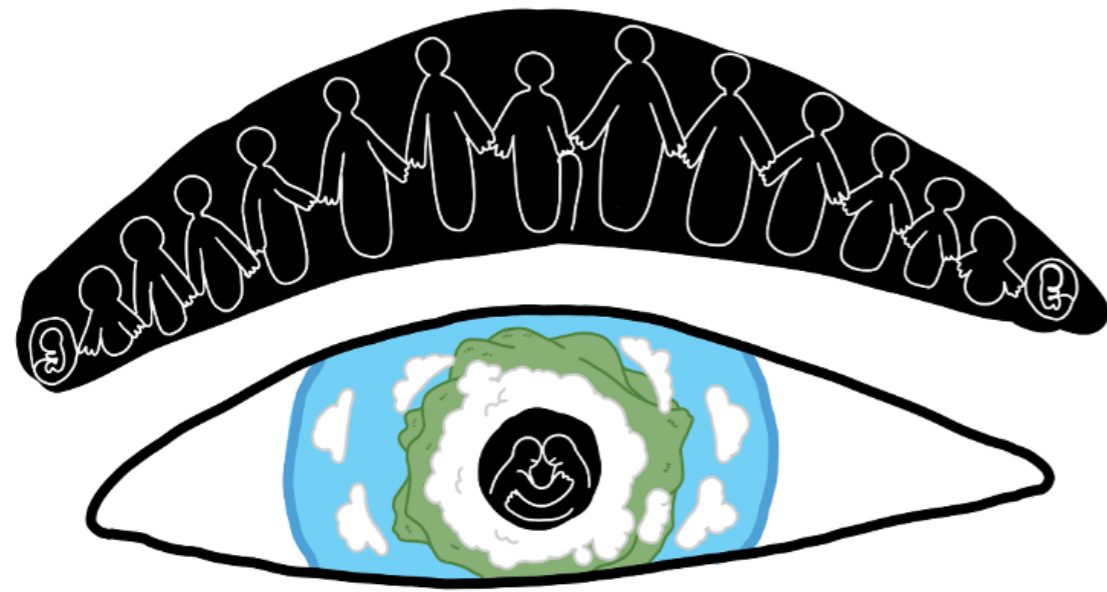
"Language – current guidelines very clinical – need to see people as people"

"Need for a culturally safe, Māori-led space to have these tapu [sacred] conversations with whānau."

"Incorporate models that look at the whole person and their whānau rather than medicalised, individual-focused western model."

"Just because it's in the guidelines does not always translate into real world practice. I think the key would be how do we enable our workforce to be culturally competent and responsive to meet Te Tiriti o Waitangi obligations."

# Creative Brief



A kōrero within Te Ao Māori is that the eye is the first to develop when in utero. There are many more pūrākau that speak to the importance of the eye and within this creative brief this was our starting point. The eye itself is not symmetrical, instead contouring in a natural, organic shape and does not conform to a symmetrical, artificial shape that sits within the paradigm of normal. Instead this symbol represents the push against the systemic inequities experienced by whānau whose needs are diverse requiring a whole of community approach.

In this creative expression the eye captures the experience of an individual undergoing the diagnostic process for Fetal Alcohol Spectrum Disorder (FASD). The reflection within the eye portrays a crucial aspect of this journey: the act of hariru, or sharing mauri, between the individual's whānau (family) and those tasked with the role of undertaking the diagnosis.

X X X X  
X X X X  
X X X X

The inner layer, depicted in white symbolizes mana, representing spiritual power and authority. Surrounding this is a layer of green, representing mauri, the life force and essence. Finally, the outer layer in blue symbolizes mātauranga, or knowledge.

There is a dual metaphor in the choice of representing green in the form of lush hills, and blue as a clouded sky. This retraces back to cosmology, where Papatūānuku-e-takoto-nei (earth mother, below) and Ranginui-e-tū-iho-nei (sky-father, above) are separated, illuminating te ao (the world) in white light. This space-between, illustrated as clouds, envelops and is catalysed by the central act of hariru.

The eyebrow in our illustration serves as a metaphor for the cyclical nature of life, illustrating the passage from kōhungahunga (foetus) to kaumātua (elderly age) and back again, signifying the timeless flow of existence in all directions and also that this disorder traverses the life span of those who are diagnosed. Another function of the eyebrow is that it protects the eye from falling debris and sweat. It is also the eyebrow that can communicate our emotions and thoughts.

Central to the narrative is the concept of kotahitanga or unity. Affirming the expectation that the experience of the individual is harmonious. This transcendence of time and space resulting in a puna wai of mana, mauri and mātauranga. It is from the source of this well spring initiated by the act of hariru, that Pae Ora can be achieved.

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# Dedications and Acknowledgements

The whakataukī “Ehara taku toa i te toa takitahi, engari he toa takitini,” that adorns the title page of the guidelines acknowledges the contributions of all who have gifted their time, stories, pūtea, knowledge, and aroha to this project. The project team extends our gratitude to you all.

Whānau voice has been central to the development of these guidelines and the positioning of the voice of whānau on pages 2-3 of this guideline affirms their significance as it is them we as clinicians serve. The generosity of whānau has been humbling. Heartfelt thanks to all whānau who shared their experiences, given their time and supported the development of these diagnostic guidelines in so many ways.

The development of these guidelines was supported by a steering group who provided guidance and advice across service, cultural and whānau contexts. The individuals in this steering group all played particular roles in developing these guidelines and our deepest thanks are given to them.

The steering group was comprised of a tāngata whenua rōpū (Kara Te Whata-Mayard, Haami Harmer, Dave Kaio, Tracy Karanui, Kiri Key, Mere Wawatai, Raewyn Mutch, Gavin Hutana) and tāngata tiriti rōpū (Kate Robertshaw, Anita Gibbs (2022), Rose Hawkins, Nicky Jordan, Sally Kedge,

Valerie McGinn, Fiona Langridge, Joanna Chu, Leigh Henderson) including Pacific representation from Dr Vili Nosa and Elizabeth Samuel.

We are thankful for wider support from Māori including marae and Hāpai te Hauora for upholding tikanga in navigating and sustaining the cultural context.

Many clinicians have given their time and generously shared important perspectives in ensuring these guidelines are grounded in evidence but also suited to the health context of Aotearoa (NZ). Thank you to those clinicians who formed the Clinical Advisory Group and attended wānanga across Aotearoa (NZ).

The Aotearoa (NZ) project team was incredibly grateful to Dr Natasha Reid and the Australian team for permitting us to utilise their guideline documentation. This contribution has allowed us to establish evidence based FASD diagnostic guidelines with rigour, attention to detail and holistic practice.

The development of these guidelines has also benefited from the previous work establishing Māori models of health. Tania Henderson's whānau model has created an important structure of holistic assessment. The Hui process and Meihana model also guides clinicians to consider the contextual factors that impact

X X X X  
X X X X  
X X X X

Māori as Indigenous people living on colonised lands. Particular thanks to Professor Suzanne Pitama and Dr Tracy Haitana for their permission to include the Meihana model within these guidelines. Likewise, important work by Dr Andre McLachlan ‘Te Whare o Oro’ provides a mātauranga Māori framework for understanding the brain and therefore FASD.

Over the last four years a number of people have contributed to the core project team. The team invested much time and aroha and all want a system that better supports those who experience FASD.

Finally, we wish to acknowledge Te Whatu Ora (Health NZ) who commissioned the development of these guidelines in (2020) and the project lead (Harsh Vardhan). We believe that this guideline aligns with the following priorities outlined in Te Pae Tata – Interim New Zealand Health Plan (2022, p. 9-10)

1. Place whānau at the heart of the system to improve equity.
2. Embed Te Tiriti o Waitangi across the health sector.
3. Develop an inclusive health workforce.
4. Keep people well in their communities.

**Ngā mihi nui ki tō tautoko i a mātou.**

# Terminology

This guideline is for use in Aotearoa (NZ) and as such kupu reo Māori have been prioritised. The word whānau is used for all families and its inclusive nature consists of not only genealogical connections but all other important familial connections. A glossary which includes definitions of te reo Māori, Pacific languages and specific clinical terms is provided in this main document. Where international research has been cited, the terminology used by those papers e.g., family instead of whānau has been used. The word family has been used with reference to Pacific People.

This document has followed terminology recommendations from CanFASD Common messages: Guidelines for talking and writing about FASD (Canada FASD Research Network 2023) who state "Respect, dignity, and inherent human worth should be promoted among individuals with FASD, women who use alcohol during pregnancy, and their families" (p.2). FASD-CAN has also provided important guidance and review of terminology used. Furthermore, the CanFASD guidelines also state:

*"It is important to remember that a 'one-size-fits-all' approach to language and messaging may not apply when writing and talking about FASD. The suggestions here are intended to be inclusive and respectful for all individuals with FASD and their families. However, recognizing the diversity and uniqueness of each person with FASD, we always recommend consulting at an individual level to ensure that language choices are reflective and respectful of each person's experience."*

(p. 2)

Use of prenatal alcohol exposure (PAE) is a specific choice to support de-stigmatisation of alcohol use and pregnancy. Use of PAE rather than drinking during pregnancy or alcohol use during pregnancy places the focus on the exposure, rather than on the behaviour of the individual, and aims to reduce blame and shame.

Further, these guidelines use gender inclusive language in recognition that not all people who are or can become pregnant identify as women. The wording of pregnant women and people (shortened in some instances to pregnant women/people) is to recognise that women and people of different gender identities can be pregnant.



# About the Aotearoa (NZ) FASD Diagnostic Guideline

## Forward

### Whakataukī: Nā tō rourou, nā tōku rourou, ka ora ai te iwi

*(With your food basket and my food basket the people will thrive)*

This whakataukī encapsulates the notion that while working in isolation might result in survival, working together can take people beyond survival and onto prosperity.

Kotahitanga – Whanaungatanga – Mahi Tahi are some of the kupu that come to mind when we describe the project team that have worked collectively on the development of 'Whakakotahitanga' – The Fetal Alcohol Spectrum Disorder Diagnostic Guidelines for Aotearoa (New Zealand) 2024. These guidelines are a true reflection of what a multidisciplinary team of experts looks like including the families and individuals who contributed their time and knowledge. The inclusion of whānau voice was always important to us as they are who we serve.

Ever aware of the needs from a cultural perspective, our project team had equal representation of both tāngata whenua and tāngata tiriti to ensure balance. The placing of Te Tiriti o Waitangi at the centre of this project gave a foundation with principles on which to guide us on this journey, ensuring that what we created was mana enhancing, whānau centred, and strengths based.

Words of wisdom from Koka Areta Koopu (2024) and something we should consider on our hīkoi forward in life. 'We must remember, as we walk forward on our paths/our journeys to stop, turn around and see who is following us, for they are the ones who will continue the work you are doing, and who will support the work that needs to be done'.

Those words of wisdom resonated with me, as they reminded me of the many beautiful souls who have dedicated their time and energy to this project and who have a vested interest in the guidelines that have been created.

**Tania Henderson**  
**March 2024**

## Preface

Aptly, this seminal work is entitled Whakakotahitanga (Unity). The whakataukī that adorns the cover speaks of success being the work of many. Unity and collaboration are features of the guidelines themselves that makes them very special. Publication will mark a watershed moment in the fight for recognition of FASD and in the pursuit of appropriate supports and services for all who are affected by this disability.

FASD is a constant presence in my working life and has been throughout my 25 years as a Judge. It is there in the Family Court as a feature of the traumatic lives of many children in the care and protection system. It is there in the Youth Court for many children who come to police attention from an early age. It is there in the adult criminal courts for many who have been locked into the criminal justice system for years.

When I read the files of those affected by FASD, the all too common history is a sad one of disadvantage on so many levels. Lives of trauma even before birth. Early entry into a health system that does not adequately recognise this disability. Early exit from an education system that is not equipped to manage the challenging behaviour or meet the special needs. Entry first into the youth justice system, and then the adult criminal justice system. Once there, becoming rapidly entrenched, the symptoms of disability mistaken for being signs of delinquency. Misdiagnosed and therefore mistreated.

Part of the injustice for those with FASD is that they are the innocent victims of a preventable disability. Another injustice for them, and for the whole community, is that this disability is capable of being well managed with appropriate supports and services. If those were provided, the people affected would be able to lead happy, fulfilled lives and many would not end up in situations that keep bringing them to my attention.

I have long believed that to address these issues properly, the most important thing to get right first is diagnosis. So much good comes from doing that well. With it comes better recognition and understanding of the symptoms. Importantly, a proper diagnosis identifies the real needs and informs the right responses. Armed with that knowledge, we are better able to ensure those responses are provided. Otherwise, we can identify gaps that need filling in support and service provision and push for that.

These guidelines are therefore tremendously important and will help bring about much needed change. They are the result of extremely hard work, spanning years, by remarkably dedicated people who have been undeterred by obstacles placed in their path, including the pandemic and natural disaster.

The authors include those with scholarly knowledge whose careful research and experience has been fused with wisdom and guidance from cultural experts with the added and invaluable contribution of our Australian friends. It is a privilege of my interest in this area to know such wonderful people. In a sense, the authors also include those with lived experience of FASD, and those caring for and working with them, because the guidelines begin with their voices. That is in keeping with the spirit of inclusiveness and respect for diversity that permeates the whole document.

A great deal of thought and care has gone into upholding Te Tiriti o Waitangi in the preparation of the guidelines. The state of “Mauri Oho”, reflected in the Critical Te Tiriti Analysis, is testament to that. The

only improvement that can be made on the score achieved by the authors is dependent on things outside their control. This cultural proficiency is also reflected in the tikanga concepts and principles that are woven throughout the document including manaakitanga, whakawhanaungatanga, aroha, kotahitanga, mana, tika and pono.

This approach will help ensure that diagnosis will not be seen through a eurocentric lens. This will result in the avoidance of stigmatisation and a focus on care and wellbeing in a holistic way that is respectful of te ao Māori. It is also important to acknowledge the regard the authors have for all cultures including the special attention given to Pasifika people.

These guidelines will also be useful to a much wider audience than just those involved in diagnosis. There are various parts, including sections on barriers to care, good practice statements, cross-sector coordination and the importance of relationships, that will resonate with a much wider audience. They certainly did with me.

Finally, as I read this wonderful work, with its focus on the well-being of infants from before birth through to ensuring well-being for life, another whakataukī came to mind that captures what makes this a truly remarkable achievement. It is the people.

*Hutia te rito o te harakeke*

*Kei whea te kōmako e kō?*

*Kī mai ki ahau;*

*He aha te mea nui o te ao?*

*Māku e kī atu*

*He tāngata, he tāngata, he tāngata.*

*If the heart of the flax bush was removed, where would the bellbird sing?*

*If I was asked, what is the most important thing in the world?*

*I would say, it is people, it is people, it is people.*

**A J FitzGerald**

**District, Family and Youth Court Judge**

**Patron of FASD-CAN**

## About the Aotearoa (NZ) FASD Diagnostic Guideline

### Format of the Guideline

The guideline begins with outlining the vision of FASD diagnostic guidelines. The guideline is then organised into five sections.

- Section 1: Whakapapa of the knowledge and evidence. This section outlines the knowledge base that has guided the development of this guideline which includes Te Tiriti o Waitangi, themes from wānanga and hui, Te Ao Māori frameworks, existing diagnostic guidelines, research evidence and literature and other practice guidelines.
- Section 2: The diagnostic guideline. Section 2.1-2.7 includes an overview of diagnosis and assessment, referral considerations, guidance for a holistic assessment, Te Ao Māori and Pacific models, and considerations for other communities that may experience barriers to care. Sections 2.8-2.10 give clinical guidance to assessment principles and criteria whilst 2.11 outlines important considerations and resources for feedback and post diagnosis support.
- Section 3: Provides recommendations and next steps for future service development and research.
- Section 4: Evaluation. Provides a summary of evaluation methods. The first being Critical Tiriti Analysis and the second details the Grading of Recommendations, Assessment, Development and Evaluation framework (GRADE; Schünemann, et al., 2013) which helped to establish the clinical criteria.

A glossary and reference list follows before further guidance is outlined in Appendix A: Neurodevelopmental assessment considerations and Appendix B Communication assessment considerations.

The guideline is complimented with a series of four reports.

- **Whakakotahitanga: Guideline development approach**
- **Whakakotahitanga: Findings from stakeholder engagement**
- **Whakakotahitanga: Literature review**
- **Whakakotahitanga: Critical Tiriti Analysis**

# Vision

This guideline details recommendations and principles required for the diagnosis of Fetal Alcohol Spectrum Disorder (FASD) in Aotearoa (NZ). It is vital that guidelines are established that are responsive to the distinct context of Aotearoa (NZ). Guidelines provide a consistent and relevant framework for the diagnosis and confirmation of FASD. Whilst we have made reference of the pre and post diagnostic pathways the majority of this work is outside the scope of this document. This guideline is written for clinicians and professionals working in the assessment and diagnosis of FASD in a health context. We expect other areas such as education, justice and social development will need to consider how these guidelines will be implemented within those specific contexts. Furthermore, this guideline is a living document and will require regular review after implementation has occurred and more research evidence becomes available.

In 2022 Te Whatu Ora (Health NZ) and Te Aka Whai Ora (Māori Health Authority) developed Te Pae Tata – Interim New Zealand Health Plan (2022) “Embedding Te Tiriti o Waitangi across the health Sector.” (Pg 9). The project team endeavoured to embed the guidelines within Te Tiriti o Waitangi including, but was not limited to, project leadership and governance, process and design, and consultation with whānau and healthcare practitioners. Co-design were undertaken to develop guidelines in partnership between tāngata tiriti and 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 of health are applied throughout this guideline. This guideline also aligns with a Whānau Ora approach which centres whānau having self-determination for their health and well-being journey.



# Guiding Principles

Our guiding principles for the development of Aotearoa (NZ) guidelines for the diagnosis of FASD were that the project would:

- be led by both tāngata whenua and tāngata tiriti.
- be developed in consultation with relevant stakeholder groups including professional groups such as Paediatricians, Psychologists, Occupational therapists, Speech-language Therapists and others who will use the guideline (e.g., primary care/WCTO workforce for early identification/referral).
- be developed in consultation with people affected by FASD including adults who have been diagnosed with FASD, and including parents, caregivers, and whānau.
- support diagnostic services and processes that are accessible, culturally appropriate and age appropriate i.e. youth friendly.
- support consistent and standardised diagnostic tools and/or processes.
- support Te Ao Māori approaches i.e. woven into or alongside biomedical/technical tools and processes.
- build on international evidence and recommendations as applicable in Aotearoa (NZ).

The steering group gave guidance to values that would support the project throughout the development process. Key values expressed in English included: safety, belonging, equity, relationships, kindness, respect, partnership. Key values expressed in te reo Māori included: whakawhanaungatanga (a sense of connection and belonging), manaakitanga (to care and be cared for), aroha (giving and receiving love and respect), pono (to be honest), tika (making good decisions, what is right), whakamana (to be mana enhancing), kotahitanga (unity; working together), rangatiratanga (self-determination; Māori authority over Māori processes and knowledge), kāwanatanga (governance), tikanga (respecting and following Māori customs).

# Background

Fetal alcohol spectrum disorder (FASD) is a diagnostic term which indicates severe neurodevelopmental impairments in the brain and body resulting from alcohol exposure in pregnancy (Cook et al., 2016; Popova et al., 2023). People with FASD have impairments that impact their development, including their ability to think, learn, focus attention, and control behaviour and emotions across the lifespan (Streissguth, et al., 2004; McLachlan et al. 2020). Internationally, alcohol exposure in pregnancy is considered as the leading preventable cause of intellectual and developmental conditions (Popova et al., 2023). It is not known how many people in Aotearoa (NZ) have FASD, but it is estimated that between 3–5 percent of our population are affected (around 1,800 to 3,000 children born with FASD per year) (Rossen et al., 2018, Romeo et al., 2023). Further data is needed to gain a more accurate understanding of the health burden.

In Aotearoa (NZ), assessment and diagnosis of FASD requires clinical knowledge and experience of working with other neurodevelopmental disorders, trauma and attachment issues. People affected may also fail to be diagnosed because prenatal alcohol exposure is unknown, or because discussions about prenatal alcohol exposure are not conducted using methods recommended for this highly stigmatised and sensitive topic. FASD is often not identified early in life, if at all, and as a result people do not get recognition of their disability or access to support. When not supported, those with FASD are at high risk for developing difficulties at

school, with social situations, alcohol and other drug use, and having interactions with police and the justice system (Gibbs & Sherwood, 2017). It is important to note that while many individuals with FASD will experience challenges, they also have many unique strengths (Duquette et al., 2006; Duquette & Stodel, 2005; Flannigan et al., 2021; Sanders & Buck, 2010). Importantly, with appropriate supports individuals with FASD can achieve positive healthy outcomes (Flannigan et al., 2021; Grubb et al., 2021).



# Current Diagnostic Practice

At the time of writing this guideline, the practice of FASD assessment and diagnosis in Aotearoa (NZ) is inconsistent, and access is limited due to a lack of publicly funded service delivery (Bagley, 2019). Up until now clinicians have been working with international diagnostic guidelines from Canada, Australia and the United States of America. There are limited specialists with the capacity and capability to undertake FASD assessment and differential diagnosis. Clear diagnostic tools, specialist knowledge and skills are all required to assess, differentiate and diagnose neurodevelopmental conditions to identify the type of clinical interventions that are likely to be effective. Best practice involves a multidisciplinary approach however this is not always available, and the implications of working in a sole capacity must be considered. At the national level, more data and research are needed to better understand and respond to FASD in our distinct context. Establishing a consistent approach to assessment and diagnosis of FASD is a critical foundation and will assist at both the individual and system level, for practice and monitoring. Note the purpose of this guideline is to give guidance to the practice of diagnosing FASD using current evidence within the context of Aotearoa (NZ), it does not provide public health messaging regarding alcohol use in pregnancy.

The first Australian diagnostic guidelines for FASD were published in 2016 and are currently being revised. The Australian Guideline Development

project team were generous with sharing their evidence reviews and guideline development process (Australian Guideline Development Group, 2024). This collaboration has been reciprocated with members of the Aotearoa (NZ) project team participating in the revision project for Australia. Information from the current Australian revision, including the systematic review of the literature and clinical interpretation of research evidence was considered in the establishment of the FASD diagnostic guidelines for Aotearoa (NZ) (Australian Guideline Development Group, 2024; Hayes, 2024). We are extremely grateful for the sharing of their rigorous analysis of the literature and subsequent GRADE evaluation. We hope this collaborative process may be able to be replicated in other areas in order to gain more international diagnostic consistency whilst also reflecting each country's own cultural, health and disability system and legislative context.

Note at the time of publication of these guidelines 'Whakakotahitanga' the Australian review were in the process of seeking NHMRC approval. Any amendments that occur for the Australian review will need to be considered whether they would be applicable for these guidelines based in Aotearoa.

# Section 1: Whakapapa of knowledge and evidence

This section provides a summary of sources of knowledge that creates a platform for this guideline to be understood. Te Tiriti o Waitangi is central to this guideline and whānau voice gathered through wānanga, interviews and surveys has been prioritised. This diagnostic guideline has been established with the benefit of several local and international frameworks. Specifically, Māori models of health provided a basis for ensuring Māori knowledge and worldview is recognised. A literature review gathered evidence from Aotearoa (NZ) and international research. Existing international FASD guidelines were also compared to understand intersections of agreement. Finally, we reviewed other practice frameworks such as Whānau Ora, Enabling Good lives, Te Mana Ola, Living Standards Framework and United Nations declarations to ensure these guidelines align with what is already agreed as being best practice in Aotearoa (NZ).

## 1.1 Te Tiriti o Waitangi

Te Tiriti o Waitangi is the founding document of Aotearoa (NZ). The prioritisation of Te Tiriti o Waitangi within a health context is emphasised by Te Whatu Ora (Health Ministry) and Te Aka Whai Ora (Māori Health Authority) in the Interim New Zealand Health Plan (2022), Te Pae Tata. The Project Team aspired to ground the guidelines in the articles of Te Tiriti o Waitangi. Instances of this approach includes but is not limited to the following.

- Project leadership was held by tāngata whenua and tāngata tiriti as an expression of kāwanatanga.
- Prioritising whānau voice through a robust consultation process affirming tino rangatiratanga of whānau having authority in determining their health needs and expectations.

- Seeking the voice of populations within our communities that are often suppressed, including the voice of Māori ensuring they are incorporated in the development of the guidelines, as a representation of ōritetanga.
- Incorporating mātauranga Māori models of practice emphasising Te Ao Māori belief systems and wairuatanga.

Resources for further reading about Te Tiriti o Waitangi include:

- <https://www.waitangitribunal.govt.nz/treaty-of-waitangi/meaning-of-the-treaty/>
- [https://thespinoff.co.nz/books/30-01-2024/a-te-tiriti-reading-and-watching-and-listening-guide?utm\\_source=spinoff-share-button&utm\\_medium=email](https://thespinoff.co.nz/books/30-01-2024/a-te-tiriti-reading-and-watching-and-listening-guide?utm_source=spinoff-share-button&utm_medium=email)
- <https://groundwork.org.nz/wp-content/uploads/2023/03/Te-Tiriti-o-Waitangi-information-and-action.pdf>

The Project Team evaluated its adherence to Te Tiriti o Waitangi by employing a nuanced version of the Critical Tiriti Analysis framework prospectively. In summary, the Project Team despite not attaining a state of Mauri Ora is found to have progressed its rating from a state of Mauri Piki to Mauri Oho affirming that the Aotearoa (NZ) Guidelines for Fetal Alcohol Spectrum Disorder (FASD) is grounded in Te Tiriti o Waitangi, which was the aspiration set in 2021.

The next section summarises themes that were collated from hui and wānanga held to ascertain whānau expectations and aspirations alongside perspectives from clinicians and other professionals.

A more detailed thematic analysis can be found in the Key stakeholder Findings Report.

## 1.2 Summary of findings from key stakeholders

Through wānanga, online hui, and surveys we were able to hold space for the voices of people with FASD lived experience, their whānau, clinicians, researchers and other professionals (such as Speech-language Therapists, Psychologists, Social Workers, Corrections Officers, General Practitioners and Occupational Therapists).

Over 120 people attended wānanga held in Tāmaki Makaurau/Auckland, Whangārei, Ōtautahi/Christchurch, and Te Papaioea/Palmerston North. Nineteen people could not attend kano ki te kano (face to face), so online hui were hosted in November and December of 2022. Additionally, 14 people across different communities completed a survey asking similar questions to the wānanga.

*“I’ve fought every step of the way for him. I just think he deserves a life just like everybody else” – (Whānau voice)*

We asked: what were the most important factors in having an assessment and making a diagnosis for FASD? Specific questions that were asked included: how should an assessment be conducted? What is/isn’t working with current guidelines? How can we improve this? What should a diagnosis/assessment give for whānau (purpose)? Is Te Tiriti o Waitangi reflected in current assessment practices? How do we represent Te Tiriti in the guidelines? What ideas do you have to represent both Mātauranga Māori and clinical knowledge in guidelines and in practice? We collected the responses and searched for common themes in the ideas.

Four themes arose from the responses:

The importance of whānau engagement

Recognition of Te Ao Māori through Te Tiriti o Waitangi

Need for clear diagnostic pathways and communication

Development of clinical knowledge and practice.

Note these themes would be applicable to the engagement with whānau, practice, diagnosis and treatment of any disorder, not just FASD.

## Section 1: Whakapapa of knowledge and evidence

### The importance of whānau engagement

Stakeholders highlighted the importance of whānau engagement in the FASD diagnosis process especially the value of whakawhanaungatanga taking time to build relationships with whānau. Whānau said it was important that they were included in decisions and that communication occurred using accessible language. Rangatiratanga (whānau sovereignty) was also considered to be important.

This meant working in partnership with whānau and ensuring whānau were present when planning how to conduct the assessment. Also underscored, was the need for clinicians to listen to whānau expertise. Both whānau and kaimahi (workers) advised that the relationship between health professionals and families should be mana enhancing, respectful, and show aroha.

*“Because as a parent, you should be able to go and advocate for your child and have people bloody well listen to you. But they don't, because you're not a clinician, you know, you're only a silly old mother that is annoying.” (Whānau voice)*

### Recognition of Te Ao Māori through Te Tiriti o Waitangi

We were informed by stakeholders that the guidelines must be centred in Te Tiriti o Waitangi and services must uphold these responsibilities. Many stakeholders reported that current clinical

practice and international guidelines do not uphold these responsibilities. This is reflected in the lack of Māori professionals, lack of culturally appropriate assessment practices, and the system being led by professionals rather than whānau.

*“Just because it's in the guidelines does not always translate into real world practice. I think the key would be how do we enable our workforce to be culturally competent and responsive to meet Te Tiriti o Waitangi obligations.” (Whānau voice)*

Cultural competency in practice, assessments and practitioners was valued by many stakeholders. They brought to light how crucial it is to incorporate mātauranga, te reo and iikanga practices, as was the need for a whānau centred approach. There is recognition that many clinicians may not be able to fulfil the role to include mātauranga, however following a Tiriti o Waitangi framework and ensuring a whānau centred approach will assist in meeting whānau needs and expectations. The merging of clinical and cultural frameworks is complex, and clinicians will need support and supervision. Recommendations for this support are specified in Section 3 of this Guideline.

*“Mātauranga needs to be the lead, clinical knowledge second. It is more important that whānau are listened to and heard than to be schooled in (clinical) language that is not ours.” (Wānanga participant)*

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### Clear diagnostic pathways and communication

Many problems were identified including screening and assessment issues. For example, the process is too complicated, the time it takes to get an assessment is too long, there are no referral pathways (including after diagnosis), and services are difficult to access. Stakeholders also mentioned professionals had very little awareness or understanding of FASD and were underfunded.

*“there's many points in the system where access is difficult...extremely difficult. I mean if you've got a whānau that can't afford five dollars for a prescription we are talking some major barriers to get there.” (Whānau voice)*

Communication was difficult because services used too much academic jargon (words that are usually only used by people within the profession and are not explained) and the way service workers chose to share information didn't consider how different people best absorb that information.

*“I think it's really important that you understand the people that you're communicating with and deliver the information in a number of ways. Because everyone learns and absorbs differently. And I think one size isn't going to fit all.” (Whānau voice)*

### Development of clinical knowledge and practice

Stakeholders often stressed the need for better clinical practice. Making sure assessment practice was appropriate and that care was continued with the same kaimahi was essential. Many suggested creating centres of knowledge, support, practice and advice for practitioners, which would include clinical supervision. They also discussed that clinical practice needed to be holistic, across multiple areas of knowledge and responsive to whānau needs.

*“it's about believing us when we tell you what it's like to walk in our shoes. You know you can't ever understand it until you live it. But we just need people to believe us when we say what it is like”. (Whānau voice)*

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### 1.3 Te Ao Māori frameworks

Mātauranga and Te Ao Māori frameworks are vital if we are to be responsive to whānau Māori and uphold Te Tiriti o Waitangi. This guideline has been fortunate to draw upon already established Te Ao Māori models and frameworks. Three models have been key to the development of these guidelines. The first is Tania Henderson's (2023) Whānau/Whanaungatanga/Whakawhanaungatanga model which outlines key parts to holistic assessment. The model involves four levels:

- **Ko Au/self – Identify, beliefs, strengths, challenges, uniqueness**
- **Whānau – Look within whānau for support**
- **Whanaungatanga – Looking out for support**
- **Whakawhanaungatanga – Identify and establish deeper connections to promote well-being.**

More detail is found in section 2.3 of this main guideline document.

The Hui process and Meihana model (Pitama et al., 2017) supports health professionals to be responsive to whānau Māori by recognising health inequities within the context of Indigenous peoples living on colonised whenua (Section 2.4). The Hui process utilises a hui structure to guide clinical interaction. The Meihana Model further develops Durie's Te Whare Tapa Whā model (Durie 1997) and emphasises the individual/whānau relationship within a holistic assessment of tinana (physical body), hinengaro (psychological/emotional), "ratonga hauora" previously (iwi katoa) (access to quality health services), wairua (connectedness) and taiao (physical environments). The current and

historical influence of colonisation, racism, migration and marginalisation are also included as well as specific Te Ao Māori components of āhua (personalised indicators), tikanga (Māori cultural principles), whānau (relationships, role and responsibilities of the patient within Te Ao Māori including whānau, hapū, iwi and other organisations) and whenua (specific genealogical or spiritual connection between client and/or whānau and land). All these elements are integrated within the formulation, diagnosis and treatment processes. In addition, Te Whare o Oro (McLachlan et al., 2023) (See section 2.5) is a model that utilises mātauranga Māori as the basis for understanding the brain structure and its development and is a very useful framework to describe the neurodevelopmental challenges that exist with a diagnosis of FASD.

Throughout the development of these guidelines, we have heard from whānau Māori who highlighted the importance of meaningful relationships and holistic assessment. The Hui process and Meihana Model provides clinicians with culturally safe practice to work with whānau Māori. Training is available in the Hui process and Meihana Model, however as with all practice this guideline encourages clinicians to engage in regular cultural supervision.

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### 1.4 Existing FASD Diagnostic Guidelines

Up until now most practitioners in Aotearoa (NZ) have utilised the Revised Canadian FASD diagnostic guidelines (Cook et al., 2016) or the Australian Guide to the diagnosis of FASD (Bower & Elliott, 2016). However, there are additional guidelines provided by Scotland (Scottish Intercollegiate Guidelines Network, 2019) and 4-digit code from the United States (Astley, 2013). Appendix 1 of the literature review provides a comparison of key international guidelines and allows us to consider what may be applicable in Aotearoa (NZ).

Furthermore, there was a revision of the Australian Guide to the diagnosis of FASD undertaken at the same time these Aotearoa (NZ) guidelines were being established (Australian Guideline Development Group, 2024). The Australian review conducted a thorough examination of the research literature and applied the GRADE (Grading of Recommendations, Assessment, Development and Evaluation) (Schünemann et al., 2013) framework to decision making. This information was shared to assist the development of clinical criteria and establishment of good practice statements.

For clarity and consistency, the framework proposed by Lotfi et al. (2022) was used for developing and presenting the actionable statements (i.e., recommendations), with some adaptations for these guidelines. Notably, based on the results of the systematic review of lived experiences of the assessment and diagnostic process (Hayes et al., 2023), a novel type of actionable statement was developed.

The following describes the different types of actionable statements.

#### GRADE-based recommendations:

- **Formal Evidence Based.**
- **Developed from systematic review and meta-analysis.**
- **Direct and clear links to the evidence.**
- **Strong recommendations: "The Guidelines Development Group recommends."**
- **Conditional recommendations: "the Guideline Development Group suggests."**

#### Good practice Statements:

- **Aid to clinical decision making.**
- **Not based on synthesised summaries of the evidence.**
- **Do not include formal ratings of certainty of evidence.**

#### Implementation considerations, tools and tips:

- **Supporting information to help practitioners implement recommendations.**

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### 1.5 Research Evidence and Literature

The literature review collates both local and international research to inform evidence-based practice in the diagnosis of FASD. The first section reviews the background of FASD including impact and prevalence and considers historical and contemporary contexts impacting on individuals with FASD, their whānau and those who support them. This includes specific information about our Aotearoa (NZ) experience, both historical and current. We cannot understand FASD unless we also consider the role alcohol plays within Aotearoa (NZ) as well as understanding marginalisation, colonisation and ongoing racism. The literature review considered models of care including Māori models of care, before exploring the experiences of individuals with FASD, and their families/whānau, of the diagnostic/assessment process.

There is a paucity of FASD research in Aotearoa (NZ), thus the international research is reviewed to inform the three areas of care provision: pre-diagnosis, diagnosis, and post diagnostic support and treatment. The Australian review of their Guide to the diagnosis of FASD provided extensive systematic reviews in the areas of 1) Components of the diagnostic criteria (Hayes et al., 2024), 2) Lived experiences of the assessment and diagnostic process (Hayes et al., 2023), 3) Holistic assessment (Reid et al., 2023), and 4) Resource implications and models of care for assessment and diagnosis (Kent et al., 2023). The following summarises the key findings of the literature review.

The literature highlights that FASD is a complex neurodevelopmental disorder that occurs as the result of alcohol crossing the placental barrier. FASD is a life-long condition with wide ranging impacts for both the individual with

FASD and for those who support and care for them. Prevalence rates vary and are higher in special populations (including children in care, international adoptees, special education, and correctional populations), however, FASD is found across socioeconomic groups, ethnicities and education levels. FASD and the development of diagnostic guidelines must be considered within the context of Aotearoa (NZ)'s colonising past. These contexts include the impact of the introduction of alcohol, the government's continued failure to meet its responsibility under Te Tiriti o Waitangi, and the ongoing widespread inequity experienced by Māori across multiple sectors as a result.

There are a number of international guidelines for assessing FASD. This review compares four guidelines:

- FASD 4-Digit Diagnostic Code – University of Washington
- Canadian Diagnostic Guidelines
- Australian Guide to the diagnosis of FASD
- Scottish Clinical Guidelines

Whilst there are some differences, particularly between the 4-digit Diagnostic Code and the other three guidelines around definitions of FASD and the inclusion of an at-risk category; there are also a number of similarities in the four guidelines, including the need for a comprehensive multidisciplinary team to support accurate diagnosis and management pathways.

This review also considers three areas of care delivery. The first area of care – engagement – explores factors involved at the pre diagnosis stage, which include the importance of establishing positive relationships between practitioner and whānau, the need for cross agency collaboration, and the sharing of relevant information. The difficulty in obtaining pre-natal history is also discussed along with the

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need for sensitive enquiry into prenatal alcohol exposure (PAE). Finally, the timing of diagnosis, and the use of biomarkers to confirm PAE are considered.

The literature around obtaining a diagnosis of FASD reveals a number of challenges. These challenges include, a lack of diagnostic capacity, different diagnostic systems, the impact of stigma, along with the impact of colonisation and systemic racism. FASD diagnostic criteria are discussed, including literature around confirmation of PAE, sentinel facial features, growth impairment and neurodevelopmental criteria.

The literature highlights that all four guidelines recommend direct and indirect assessment methods for diagnosing FASD, however further research is recommended to identify the most sensitive and specific tests. The Canadian, Australian and Scottish guidelines also include an "At-Risk for FASD and Neurodevelopmental Disorder" diagnosis. While there is some dispute as to the use of such a label, its inclusion enables pathways to assessment and support to remain available for those not currently meeting the criteria for a diagnosis. Co-morbidities are also noted as an important consideration when assessing for FASD.

A lack of cultural context is evident in three of the guidelines with the exception being the Australian guidelines. Although the need for communicating information in a culturally meaningful way was noted by both the Canadian and the Scottish guidelines. The literature highlights the critical need for practitioners to be aware of differences in cultural conceptions of a diagnosis, as well as cultural responses to them. Therefore, the need for professionals to consider the needs of whānau when delivering information is critical. All four guidelines recommend a coordinated follow up process, including developing a

management plan, referral, management strategies and review dates.

Following a diagnosis, management and referral pathways are critical in supporting positive long-term outcomes. All four guidelines recommend a follow-up plan after assessments have been completed. The research highlights that currently service provision in this area is inadequate, with a lack of information sharing and collaborative approach, and a lack of follow up after the assessment report has been provided. The research suggests that more needs to be done to support families in navigating health and education systems.

Finally, the literature review considers models of care and explored lived experience of the diagnostic pathway. The literature suggests the need for consistent, collaborative, and responsive models of care that are proactive in meeting the needs of individuals and whānau. Appropriate models of care empower families within the process, develop a collaborative relationship between professionals and whānau, and consider historical, cultural, and other contextual factors that impact on whānau abilities to provide support.

Literature from the lived experience of the diagnostic process reveals a wide range of experiences and responses to it. While many report experiencing a range of negative emotions, the literature also highlights that receiving the diagnosis had been helpful in accessing supports and improved understanding of FASD. The research indicates the need for the continued provision of information across the lifespan. Although, this information needs to be tailored to the needs of the whānau and communicated in an appropriate fashion.

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### 1.6 Other Practice Guidelines

The Aotearoa (NZ) FASD guidelines align with the principles of a number of important practice models including:

<p><b>Whānau Ora, Te Puni Kōkiri</b></p>	<p>A culturally grounded holistic approach to improving the well-being of whānau as a group and addressing individuals needs within the context of whānau. The approach places whānau at the centre of decision making to support their needs and aspirations.</p>
<p><b>Te Mana Ola: The Pacific Health Strategy</b></p>	<p>Promoting the valuing of physical, mental and spiritual well-being of Pacific peoples for equitable health outcomes. Empowers Pacific peoples to be in full control of their health and well-being.</p>
<p><b>New Zealand Health Strategy</b></p>	<p>A strategy that honours Te Tiriti o Waaitangi and aspires to achieves healthy futures for all New Zealanders based on the long-term goals of health equity for diverse communities and improving health outcomes for all.</p>
<p><b>Enabling Good Lives.</b></p>	<p>A foundation and framework to guide positive change for people with disabilities that offers greater choice and control over the supports they receive, so that they can plan for the lives they want.</p>
<p><b>Human Rights' models</b></p>	<p>The United Nations Universal Declaration of Human Rights which includes:</p> <ul style="list-style-type: none"> <li>· Right to life and liberty</li> <li>· Freedom of expression and opinion</li> <li>· Right to work and education</li> <li>· Right to health: Everyone has the right to enjoy the highest attainable standard of physical and mental health.</li> </ul>

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<p><b>Human Rights' models</b></p>	<p>The United Nations Declaration on the Rights of Indigenous Peoples which includes:</p> <ul style="list-style-type: none"> <li>· Equality and non-discrimination</li> <li>· Education, information and labour rights</li> <li>· Rights around lands, territories and resources</li> <li>· Rights to cultural, religious, spiritual, linguistic identity, and self determination.</li> </ul>
<p><b>Human Rights' models</b></p>	<p>The United Nations Convention on The Rights of the Child which includes:</p> <ul style="list-style-type: none"> <li>· Right to a number of basic and fundamental rights including life, access to education and healthcare</li> <li>· Government to ensure best interests of the child are taken into account when making decision about the child</li> <li>· Same as adults plus right to protection.</li> </ul>
<p><b>Human Rights' models</b></p>	<p>The United Nations Convention on the Rights of Persons with Disabilities which includes:</p> <ul style="list-style-type: none"> <li>· The right to dignity and independence</li> <li>· The right to have good care and support that fits your needs</li> <li>· The right to be told things in a way that you understand</li> <li>· The right to be told everything you need to know about your care and support.</li> </ul>
<p><b>Living Standards Framework</b></p>	<p>A framework developed by Treasury to prompt thinking when considering policy impacts across different dimensions of well-being. These prompts include distribution, resilience, productivity and sustainability.</p>

## Section 2: Diagnostic Guideline

### 2.1 Overview

Meaningful relationships between practitioners and whānau optimise the effectiveness of assessment and interventions, leading to positive outcomes (Baier et al., 2020; Stagg et al., 2019). Furthermore, the practice of shared decision making between practitioner and professional not only respects autonomy of the individual and whānau but often leads to better clinical decisions (Stiggebout et al., 2012). For tāngata whenua, wairua (spirit) and hononga (connection) form the core of meaningful connections (Wilson et al., 2021, 2022). Values such as reciprocity, trust, and dignity enhance connections and create greater opportunities for shared decision-making. Figure 1 below depicts the interconnectedness of these factors that support connection.



Figure 1. A framework contextualising whānau perspectives of meaningful connection (Wilson et al., 2022, p. 14). Reprinted with permission.

These FASD diagnostic guidelines emphasise the need for relationships and connection to be at the centre of clinical practice to ensure the best possible outcomes for individuals and their whānau. This diagnostic guideline adopts a lifespan approach with the intention of supporting the health system to be more responsive and provide access to diagnostic and assessment services for all individuals seeking diagnosis regardless of age. We have outlined specific considerations for infants and young children as standardised assessment may not be possible. We envisage these guidelines can be applied to all ages using developmentally appropriate tools and clinical judgment.

### Multidisciplinary assessment

A diagnosis of FASD requires clinical assessment from a group of professionals who collaborate and create a shared understanding of the individual's strengths and challenges. A medical doctor is required to rule out other medical conditions. Other professionals in the team may include Psychologists, Speech-language Therapists, Occupational therapists, Physiotherapists, Social Workers and Key workers. A multidisciplinary team approach is best practice with professionals who review the assessment results, taking into account developmental history, environmental and contextual factors. If a medical doctor is not able to participate in the assessment and review process, then a separate medical assessment is required to confirm this diagnosis.

Information may be gathered from a variety of sources, e.g., whānau, schools, employers

and others providing support. Information may be drawn from previous assessments, including relevant information from professionals from other services, locally or out of area. Where possible, care must be taken to ensure assessment results are interpreted with consultation from the professional who collated the data; with an opportunity for those who have provided information to be able to confirm the interpretation that is contained in the report. Ideally, the information will be interpreted together and one document written for the individual, their whānau and professionals.

There may be situations where clinicians do not have the benefit of a multidisciplinary team. In that case, care must be taken in interpreting domains that may be better assessed by other professional groups. For example, the communication domain by Speech-language Therapists and motor domain by Occupational therapists. These situations require careful reflective practice and clinicians are encouraged to form relationships and seek advice and supervision from other professional groups.

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### 2.2 Referral

The aim of the assessment and diagnosis process is to understand a person's FASD status, their needs and how to promote well-being. This may include identifying health and development needs identified by the whānau, increasing understanding of behaviour and establishing strategies to support development. The assessment must address the needs of the individual and whānau within their context and environment.

Before an FASD assessment begins, it is important for the professionals involved and the individual and whānau to be clear about the purpose of an assessment and diagnosis. This will inform how, when and with whom the assessment will occur (e.g., at home, at school, in the clinic, or in justice settings). The assessment context influences how an individual may present and this must be included in interpretation of any assessment results. Feedback of the assessment report in person will support the individual and whānau to understand the outcome of the assessment, with developmentally appropriate explanations as needed. Care must be taken to ensure that the individual and whānau understand what a FASD diagnosis will mean to that person and where to access further support as always, diagnostic decisions should not be influenced by possible provision of service or supports.

The following questions serve as prompts to encourage thoughtful provision of service which acts in the best interests of the individual and whānau:

- Why is an FASD diagnosis required now?
- How does this assessment fit with other assessments that are being conducted?
- How will the individual consent for this assessment?
- Who will be supporting and in the room with the individual being assessed?
- Who is funding the assessment and for what reason?
- Where will the assessment be conducted?
- What assessment tools are appropriate?
- What role will each professional have in the assessment and how the report will be finalised?
- How will information be collated and shared with the individual and whānau?
- Do I have the skills needed to work safely with this whānau? If not, what do I do next?

These questions require practitioners to engage in reflective practice and use both clinical and cultural supervision to support clinicians with navigating these types of challenges. Furthermore, many of these decisions can be made with the whānau e.g., where is the best place for assessments to take place.

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### Informed Consent and Assessment

The Code of Health and Disability Services Consumers' Rights (Health and Disability Commissioner 1996) details three rights specific to informed consent. These are the right to effective communication (Right 5); the right to be fully informed (Right 6); and the right to consent freely given by a competent person (Right 7). It is important that these rights are upheld in all parts of the diagnostic and assessment process, including referral, active assessment, feedback and planning interventions.

Informed assent provides individuals without competence, such as children and individuals deemed to not have cognitive abilities to provide informed consent, 'developmentally appropriate involvement in decision making' (Joffe, 2003). This involves providing information so that individuals will know what will happen and letting them have a say and be listened to regarding their preferences. Informed assent will require consent from the child's parents or legal guardians.

### 2.3 Holistic Assessment:

Developing a holistic profile is an opportunity to bring all the assessment information together, in a strengths-based way to increase understanding of the individual being assessed and their whānau/support system. This approach is future focussed, generating hope and facilitating a collaborative support planning process with individuals and their whānau/support system.

The diagnostic review process allows clinicians to bring together all the assessment findings and discuss and consider how all the exposures and events that an individual may have experienced have potentially impacted their outcomes. Professionals consider and diagnose based on the information available to them at the time. An FASD assessment requires quality diagnostic information in order for the most appropriate diagnostic outcomes to be considered. It is up to the clinician to use judgement as to whether they have enough information and appropriate process to continue. The following whakataukī is an appropriate guide for this process.

Mā te kōrero, ka mōhio (Through discussion, comes awareness)

Mā te mōhio, ka mārama (Through awareness, comes understanding)

Mā te mārama, ka matau (Through understanding, comes knowing)

Mā te matau, ka ora (Through knowing, comes well-being)

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### Ahau/Whānau/Whanaungatanga/ Whakawhanaungatanga (Henderson, 2023)

The following details a model developed by Tania Henderson that prioritises holistic assessment for all individuals and whānau.

*Box 1. Ahau/Whānau/Whanaungatanga/Whakawhanaungatanga (Henderson 2023)*

With assessment and diagnosis, it is important to not just focus on the individual but also the relationship with whānau. This whānau engagement starts prior to the formal assessment and includes all the professionals involved with the whānau. This is more than just information gathering and sharing. This is about supporting the individual who is about to engage in the assessment and their whānau to understand what will happen at each step of the assessment and feedback process. Bringing them onboard as part of the team, ensuring that the FASD assessment process is undertaken 'with' and not 'to' them.

The assessment process will identify strengths and challenges, indicating areas that need to be supported. By investing time and energy in understanding the individual and whānau context, strengths are highlighted and those involved come to understand where many of the challenges arise. This reflective process provides space for whānau agency, considering their next steps alongside the FASD assessment. Strategies and recommendations discussed prior to, during and post assessment can enhance individual and whānau strengths and help them navigate the different support systems available to them.

#### The model involves four levels:

- Ko Au/self – Identify beliefs, strengths, challenges uniqueness.
- Whānau – Look within whānau for support.
- Whanaungatanga – Looking out for support.
- Whakawhanaungatanga – Identify and establish deeper connections to promote well-being.

#### Ko Au/Self

"Everybody has a wairua – we are just all on different currents – wai/rua (two waters), so you need to find the current the tangata whaiora is in and then bring your current alongside" (Ihimaera, 2004, p. 74).

Understand the history and journey of the individual. Everyone is unique and it is important to understand personal strengths and how the person perceives themselves. Building a relationship and making connections with the individual and their whānau through manaakitanga and aroha is paramount. The following questions are prompts to support professionals to build a holistic awareness of the person as an individual and as a whānau member:

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- Inherited characteristics – who does this person remind the whānau of?
- How do they perceive themselves. What do they say? How do they describe themselves? Do they see themselves differently in various settings?
- What are their strengths/interests/talents?
- Are they confident? Do they try new things?
- How are they in group settings?
- Do they engage differently with strangers versus people they are comfortable with?
- When do they lead or follow?
- When thinking about the individual at home, in education/work settings, and in the community; what do they struggle with?
- What is the individual 'at risk' of? e.g., running across the road/impulsiveness/social isolation/depression/substance use.
- How does the individual process their emotions. What triggers them? How long are they upset? What calms them down? How does this impact their relationships with others?
- Who would the individual identify as key people that they are closest to? It doesn't necessarily have to be close whānau members, it could be friends, or a person that lives elsewhere but with whom they remain connected to.
- What are their thinking and learning abilities at school/work (subject specific) and their strengths outside of classroom/work settings (hobbies/picking up new skills, sports, and social skills). What is their memory like? Their ability to process information at speed/pay attention? What is their communication ability/language skills?
- What are their thinking and learning abilities at home e.g., their level of independence. (self-care). How do they do at home with tasks? Can they finish projects/chores by themselves? Do they need prompts and reminders, or step by step support?
- Whānau history e.g., medical issues/learning/mental health.
- Prenatal exposure to substances, development and medical history including hospital stays/head injuries. The prompt to ask about prenatal exposure is intentionally placed at this point and not earlier. It fits best with discussion of birth and developmental history. It also allows an individual and their whānau to share their unique context and areas of strength and challenge, building to a discussion of factors that may have impacted the development of the individual/their whānau member. It can be useful to explore prenatal exposures before pregnancy and then ask about when they found out they were hapū pregnant).
- Finishing with the overall impression of the individual is important. After meeting with them, what do people often say? (reflecting their essence e.g., happy-go-lucky/reserved).

## Section 2: Diagnostic Guideline

Box 1. Ahau/Whānau/Whanaungatanga/Whakawhanaungatanga (Henderson 2023)

### Whānau – Look within for support!

When it comes to FASD, whānau play a crucial role within the individual's life and need to be engaged pre, during and post assessment. Their engagement or inclusivity during all these stages will ensure that the individual living with FASD will be provided with the right support, throughout the process. Even before the assessment starts whānau can be encouraged to begin building support, as whānau will learn more about the role that they play, and how they can support by adapting their behaviour to accommodate their whānau members individual needs. It is also the perfect opportunity to hold conversations around what is needed to support the primary carer/whānau, be this respite, thinking about having a wider whānau hui to build a shared understanding, or who is best placed to support them at multidisciplinary meetings.

The following questions are prompts to support professionals to build a holistic awareness of the individual's place within their whānau and whānau strengths/needs:

- Identify whānau identity. Cultural connections as appropriate (Whānau/Hapū/Iwi) as well as social connections. What activities do they enjoy doing together as a whānau? (e.g., sport/ adventure/gaming/religion etc.).
- Within their whānau setting, how does the individual engage? (leads/follows/well-engaged/ reluctant)
- How does the whānau see the individual? Are they like others their age?
- How do wider whānau see the individual? What do whānau say about them, their strengths/ personality/areas of challenge.
- Where is the individual placed within their whānau (birth order, living with their parents/ whāngai/adopted).
- What were the whānau relationships before, during and after pregnancy?
- Did the whānau move around a lot? What were transitions like?
- Home environment. What is/was their living situation, parenting style?
- Was the individual exposed to trauma? (e.g., accidents, grief/loss, emotional, physical, sexual abuse).
- Has there been any traumatic whānau/community events that may have impacted the individual at any age (e.g. Christchurch earthquake, Cyclone)?
- What has been the experiences of whānau through referral, assessment, diagnosis and follow-up processes.
- Ensure whānau are ready for diagnosis. This includes the birth mother where possible using a non-judgemental sensitive approach.
- Discuss who the key whānau supports are, who may provide ongoing support to the individual and day-to-day carers, and what that support might look like.
- Have the whānau thought about what life might be like in the future and what supports may be required?

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Box 1. Ahau/Whānau/Whanaungatanga/Whakawhanaungatanga (Henderson 2023)

### Whanaungatanga – Looking out for support!

This is a crucial part of this journey, as this is where whānau consider/maintain relationships with those people/organisations who provide support, understanding and guidance during the pre and post stages of the assessment process.

- Who does the individual and whānau identify as key supports?
- How do others, such as teachers/employers, see the individual? What do they say about them, their strengths/personality/areas of challenge? Are they like others their age?
- Outside of the whānau, who is currently providing support – what is their involvement in the referral and assessment process. Are they available for post-diagnostic support? For example: Non-Government Organisations (NGO's), Social Services, Youth Support Services, Education, Health, Corrections, Community groups, Schools/Learning Institutes, and Government agencies.

Are regular multiagency meetings occurring? Are whānau central to support plans in place for the individual? Does the whānau need an advocate to support them in these meetings?

### Whakawhanaungatanga – Deeper Connections

*"Be connected to everything that is connected to Papatūānuku, mother earth" (Rose Pere).*

There are many interpretations of whakawhanaungatanga, including connecting to Papatūānuku/ Mother Earth and drawing upon what she has to offer in time of need. Thinking about what other things can help support in times of need, what things keep people grounded, what things can be done to help deal with trauma, anxiety, and to promote mental well-being. This is critical for those living with FASD and those who are supporting them.

This is a time to stop, it is a time to observe and identify what is out there within the environment that can be drawn upon to establish a place of peace, a place of tau, being calm when all around feels like chaos and uncertainty. For some, it may be going to a favourite place like the beach, river, or bush. For others it may be going to church, library, or spending time with animals.

- What are the activities the individual likes to do?
- What brings the individual back to a place of tau/calmness?
- Where does the individual or whānau go to feel tau/calm?
- How do they connect/reconnect with the world around them?

Whakawhanaungatanga can involve providing platforms/resources to connect with other whānau members supporting loved ones living with FASD across Aotearoa (NZ), as well as building far reaching networks of support, looking beyond Aotearoa (NZ) and connecting with our international FASD partners and learning institutes to further our knowledge around FASD.

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Box 1. Ahau/Whānau/Whanaungatanga/Whakawhanaungatanga (Henderson 2023)

### Summary

Beginning and ending with self is important, as it helps identify personal strengths and challenges. Both whānau and whanaungatanga focus on relationships, and the strength of collectivism as a way of building a support network that is unique to each individual and whānau who are living with FASD. A critical component when creating pathways forward is creating a community for self or whānau where collectivism, mahi tahi, working together as one is key.

The Ahau/Whānau/Whanaungatanga/Whakawhanaungatanga model (Henderson 2023) supports professionals to engage with individuals and whānau in a way that is mana enhancing, providing space for reflection about individual and whānau strengths and needs as part of the FASD assessment process. When considering their unique context, whānau can be autonomous and self-determined about pathways forward, what supports resonate for them now and in the future, and how they would like to engage and with whom. This model gives opportunity to break down some of the barriers that an individual or whānau may be experiencing due to living with FASD. The model also promotes being proactive during all stages pre, during and post diagnosis to build supports for those living with FASD.



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### Co-occurring and differential diagnosis

Holistic assessment also involves considering other co-occurring or differential diagnoses. A systematic review undertaken by Popova et al. (2016) identified that there were 428 co-occurring conditions for individuals with FASD, which spanned 18 of the 22 chapters of the ICD-10. Consequently, co-occurring conditions are common and represent an area of complexity within the FASD diagnostic process.

FASD can co-occur with a wide range of neurodevelopmental and mental health conditions, as different aetiologies can combine to lead to complex presentations and multiple diagnostic outcomes (e.g., someone who presents with strong family history of ASD, ADHD or ID in combination with a heavy level of prenatal alcohol exposure). There can also be a range of co-occurring mental health challenges (e.g., anxiety, depression, suicidal ideation), that may be related to the impacts of PAE, impairments associated with living with FASD and/or due to other etiological factors.

Individuals from the Australian Lived Experience Advisory Group strongly recommended for clinicians to provide appropriate mental health diagnoses, as they shared experiences of where diagnostic overshadowing (i.e., where service providers attributed mental health concerns to FASD rather than a concurrent psychiatric condition) had occurred when trying to seek mental health services for their children or young people.

There also may be situations where a diagnostic formulation approach is more appropriate in the context of other neurodevelopmental or

mental health conditions (e.g., strong family history of ASD, ADHD or ID and low-level prenatal alcohol exposure or not enough information regarding the prenatal alcohol exposure history to determine if it was a relevant risk factor). There can also be a number of environmental or biological factors that can co-occur or provide differential considerations, depending on the level of risk of these factors (e.g., prenatal medications or other drug exposures, extreme environmental neglect, prematurity). Clinicians are tasked with weighing up the probability of all the relevant risk factors in determining what the best explanation/s for an individual's presentation is.

Additionally, genetic syndromes that share some of the clinical features of FASD exist and should be considered as differentials in the diagnostic process. However, there can also be a microarray of results of uncertain or unknown clinical significance and these findings can co-occur with FASD. Consequently, a wide range of conditions and risk factors could either be co-occurring or be differential considerations, and this needs to be determined through an individual case formulation. Understanding an individual's unique profile of clinical features, including all the relevant co-occurring conditions enables treatments and supports to best target an individual's needs.

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## Trauma and prenatal alcohol exposure (PAE)

Given the high prevalence of co-occurring adverse childhood experiences (ACEs) and PAE this area warrants further discussion. In a research context some studies have been able to highlight some of the potential differential and compounding impacts of adverse life exposures and events and prenatal alcohol exposure. An overview of these studies is provided in Figure 2.

However, in practice it can sometimes be very difficult to have access to detailed historical information regarding timing and extent of the prenatal and postnatal factors. It is often the case that clinicians are working with limited information and individuals are presenting with a combination of adverse prenatal and postnatal exposures and events. Each of these exposures may have influenced developmental and behavioural outcomes and it is not possible to quantify the relative contributions of the factors.

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Figure 2. Overview of studies comparing prenatal alcohol exposure (PAE) and adverse childhood experiences (ACEs) outcomes. Reprinted with permission from Australian Guidelines for Assessment and Diagnosis of Fetal Alcohol Spectrum Disorder or Neurodevelopmental Disorder Associated with prenatal Alcohol Exposure (2024).

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# Good Practice Statements

The following Good Practice Statements (GPS) have been prepared to support the assessment process.

Note: All Good Practice Statements in this document were drafted in the “Australian Guidelines for Assessment and Diagnosis of Fetal Alcohol Spectrum Disorder or Neurodevelopmental Disorder Associated with prenatal Alcohol Exposure (Australian Guideline Development Group, 2024)” and applied to the Aotearoa (NZ) guidelines in accordance with available evidence and input from stakeholders and clinicians.

- X *Take a holistic needs-based and whānau-centred approach to the assessment. This can involve considering strengths and challenges, functioning, environment, culture and supports. Gather this information in ways that work best for the individual and their whānau/support network.*
- X *In taking a holistic approach, consider the wide range of complex factors that individuals and families may be experiencing, and the potential influence these factors may have on functioning, well-being, and participation.*
- X *Collaborative goal setting and talking with individuals and their support network can help practitioners take a holistic approach to assessment. This allows for gathering personalised information about individual and whānau strengths, interests, available resources, and future hopes and plans for both the individual and whānau.*
- X *Each person attending for assessment should have a plan tailored to their specific developmental needs. This plan should consider current concerns, developmental age, history, past assessments, and other source documents (e.g., available medical and school records), ability to engage in an assessment, assessment adaptations and adjuncts including interpreters and any other relevant cultural and social factors. Assessment should include hearing and vision tests if these have not been done before.*

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- X *Depending on a person’s presentation, it might be best to plan and recommend assessment across different timepoints to see if their challenges are persistent. These assessments can happen in various places, including primary health care, schools, and private practitioners, not just at specialist services.*
- X *It is useful to gather information from various sources and methods, such as naturalistic observation, assessing function, direct testing, and getting input from different observers (e.g., self-report, parents or other whānau members, teachers, work colleagues, support workers, treating professionals). This is important to overcome limitations of any single method.*
- X *While it can be helpful to do a comprehensive assessment to understand developmental challenges, sometimes it may not be possible or appropriate. Practitioners should decide the neurodevelopmental domains to prioritise based on functioning and how much assessment is necessary to determine whether there are clinically significant impairments and if they meet criteria for diagnosis.*
- X *It is important to understand the overlap of neurodevelopmental domains and influence of environmental factors. Interpreting assessment results requires looking at the whole picture or taking a gestalt approach, including considering how valid measures are for different groups of people and the range of prenatal and postnatal factors that can influence outcomes.*
- X *Consider, offer, and explain one or more relevant diagnostic possibilities, summarising what is most likely, after considering what is less likely or unlikely, given the individual’s presenting concerns and assessment findings.*

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- X *Clinicians are encouraged to be mindful of diagnostic overshadowing and provide all diagnoses relevant in explaining an individual's presentation to facilitate the provision of targeted treatment and support strategies. If whānau require referral to other specialists, clinicians need to provide information about how to access services.*
- X *It is advantageous to assess neurodevelopmental domains concurrently. However, at practitioners' discretion, previous assessments may be used (e.g., in situations where impairment levels are unlikely to have changed, where there have been multiple previous assessments or current assessment is unable to be completed due to current significant behavioural challenges). The decision to retest an individual will depend on the context, referral question and the individual's needs.*
- X *Clinicians are encouraged to be mindful of the impacts of their own clinical training, perspectives and upbringing and how these unconscious biases may influence diagnostic decision making. For example, depending on a clinician's background they may be overestimating what is attributable to trauma and underestimating what is attributable to alcohol or vice versa.*

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### 2.4 Hui Process and Meihana Model

Māori health models support clinicians to deliver a whānau centred approach to assessment and treatment of FASD. Specifically we recommend the utilisation of the Hui Process and Meihana Model to support health professionals "to be responsive to Māori clients/whānau and contribute to the reduction of current health inequities" (Pitama, 2017, p. 8). Perpetuating inequities are driven by inequitable burdens of social determinants of health (such as colonisation, marginalisation and racism). For example, colonisation has severely contributed to health disparities between Māori and Pākehā (Durie, 2000, 2001; King et al., 2018) which have been reported for several decades and resulting in intergenerational maintenance of poorer health outcomes (Pomare & De Boer, 1988; Robson & Harris, 2007; Waitangi Tribunal, 2019). Such differences primarily arise from life course exposure (favouring non-Māori) to affirming conditions in the form of higher incomes, educational achievement, good housing, healthy diets, active lifestyles and better access to quality healthcare (Barnes et al., 2014; Crengle et al., 2005; Curtis et al., 2019; Robson & Harris, 2007).

Within the guideline development process we heard from whānau Māori who were very clear about their expectations including; centring whānau voice, inclusion of Te Ao Māori, use of te reo Māori, centring obligations of Te Tiriti o Waitangi and emphasising whakawhanaungatanga (building relations between whānau and clinician). Thus, embedding FASD diagnostic practice within the Hui process and Meihana Model will aid clinicians to meet the expectations of whānau Māori.

A summary from Pitama et al. (2017) is provided in the box below. This paper "A proposed hauora Māori clinical guide for psychologists: Using the hui process and Meihana model in clinical assessment and formulation" provides a pathway to operationalise the model. It is written for psychologists, but the learning can be applied to many professional groups. In addition, we encourage all clinicians to undertake the Hui Process and Meihana Model training provided by MIHI501 at the University of Otago. Further reading is also suggested within the box below.

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The Hui Process (Lacey et al., 2011) and the Meihana model (Pitama et al., 2014) were developed as part of a Māori health medical curriculum at the University of Otago Christchurch. The goal of these teaching tools is to translate cultural competency principles into an approach that clinicians can use to augment their existing clinical practices, to improve their responsiveness to Māori clients and their whānau.

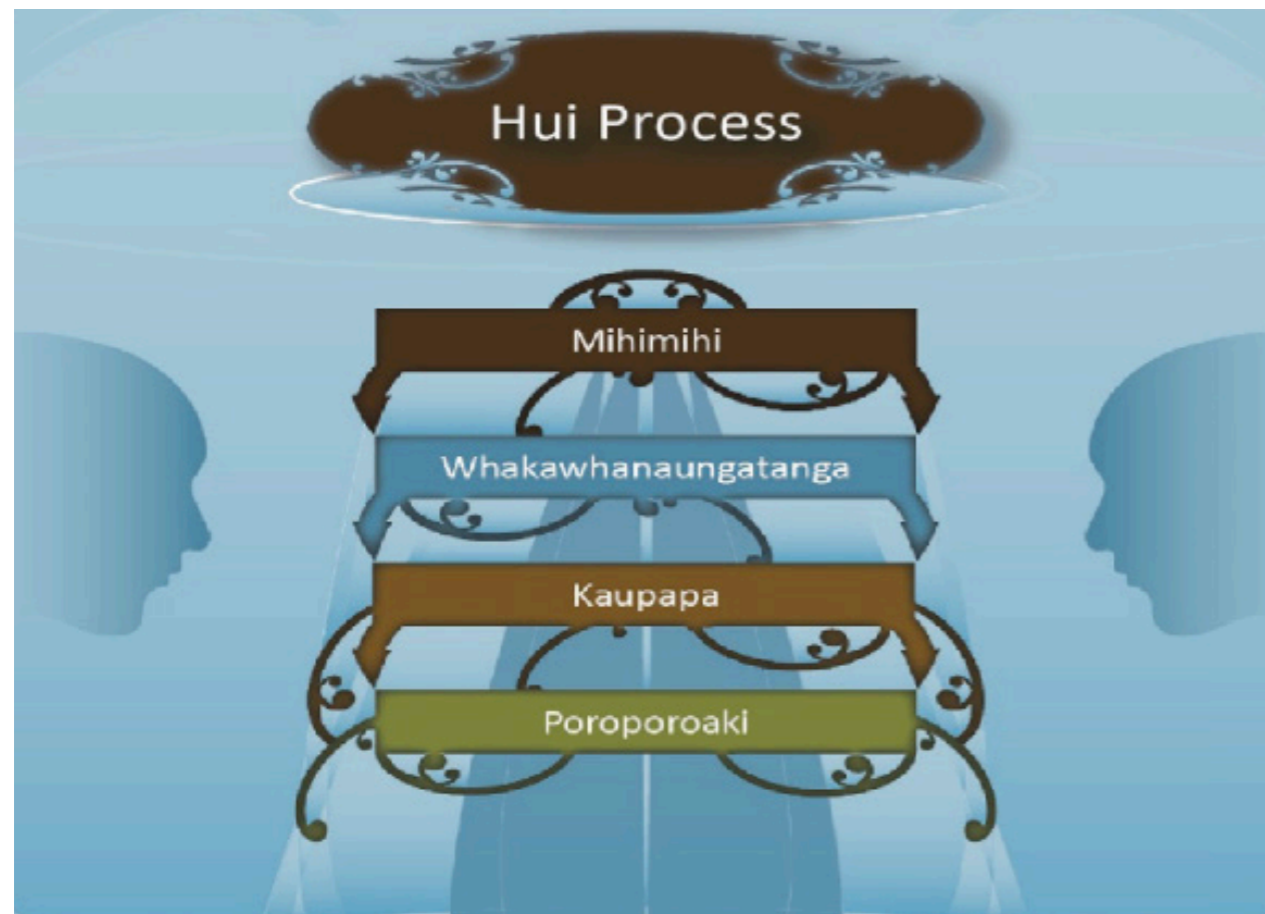


Figure 3. The Hui Process (Pitama et al, 2017) Reprinted with permission

The Hui Process (Figure 3) adapts the structure of the hui to clinical interaction. The Hui Process is comprised of four components, which align with engagement strategies from Te Ao Māori and documents how these apply to clinical interactions. The four components are: mihimihi (initial greeting engagement), whakawhanaungatanga (making a connection/building relationships), kaupapa (attending to the purpose of the encounter) and poroaki/whakamutunga (closing the session).

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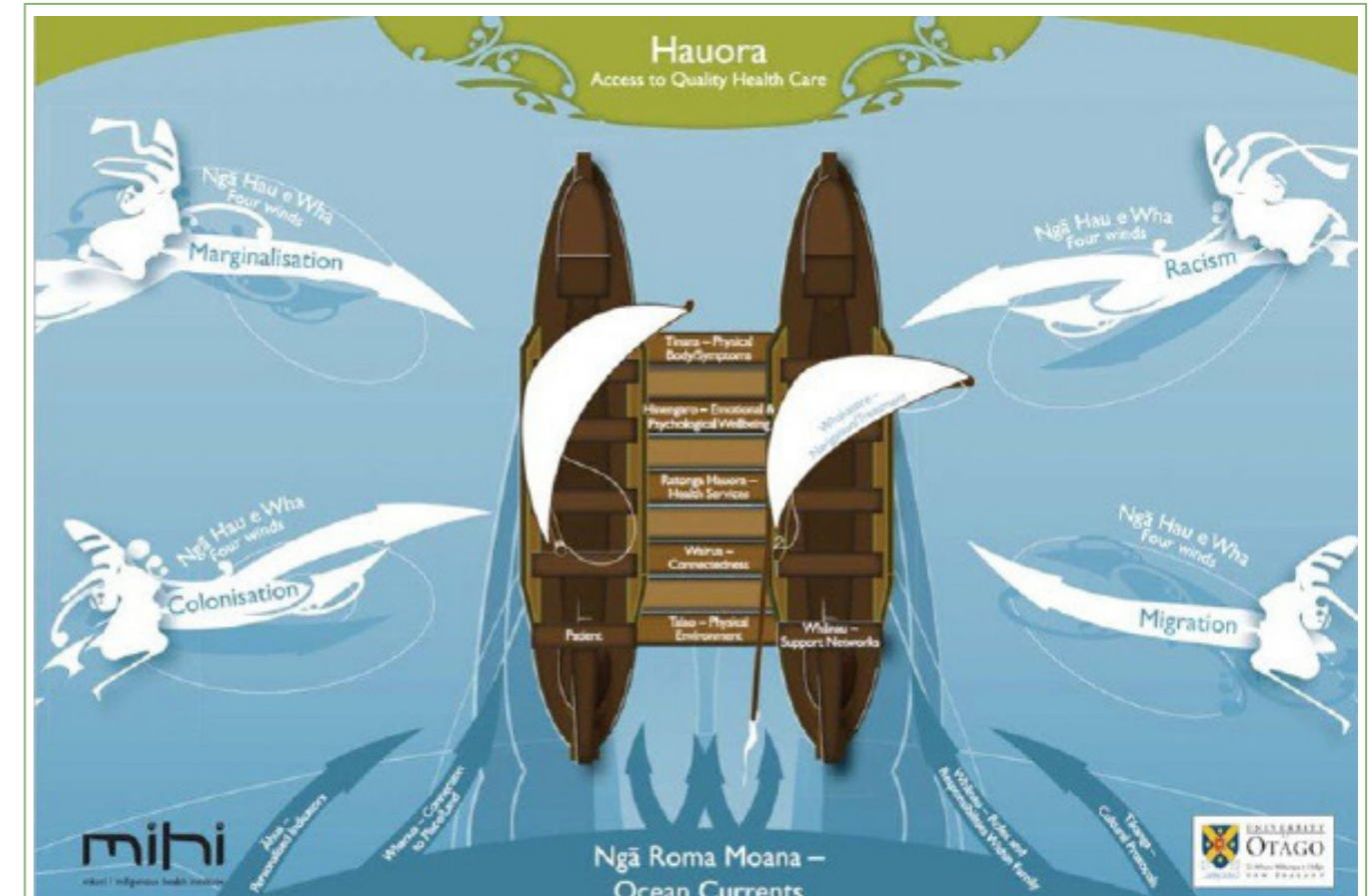


Figure 4. Meihana Model (Pitama et al, 2014). Reprinted with permission.

1. The Waka Hourua (double-hulled canoe) identifies the importance of the client/whānau relationship and its relevance to the presenting issue(s) and future treatment plans. The framework invites and reminds the clinician, to work alongside the client/whānau to explore the dimensions of tinana (physical body), hinengaro (psychological/emotional), "ratonga hauora" (previously iwi katoa) (access to quality health services), wairua (connectedness) and taiao (physical environments) and their relevance to clinical care and decision making with client/whānau.
2. Ngā Hau e Whā (representing the four winds of Tawhirimātea) identifies components that reflect both the historical and current societal influences on Māori as the Indigenous Peoples of Aotearoa (NZ). The four influential and interrelated winds are: colonisation, racism, migration and marginalisation.
3. Ngā Roma Moana (representing the four ocean currents) identifies specific components from Te Ao Māori (Māori world view) that may influence a client/whānau in different contexts. The four components of Ngā Roma Moana are āhua (personalised indicators), tikanga (Māori cultural principles), whānau (relationships, role and responsibilities of the patient within Te Ao Māori including whānau, hapū, iwi and other organisations) and whenua (specific genealogical or spiritual connection between client and/or whānau and land). The influence on these ocean currents varies greatly due to the diversity of individual client/whānau experiences in Te Ao Māori and the effects of colonisation, racism, marginalisation and migration (ngā hau e whā).
4. Whakatere (navigation) draws together the relevant information from the Waka Hourua, Ngā Hau e Whā and Ngā Roma Moana and integrates this information within the formulation, diagnosis and treatment processes. Whakatere also challenges and supports clinicians to acknowledge and mitigate personal and institutional biases within assessment, formulation and treatment.

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*The Hui Process and Meihana Model (Pitama et al., 2017)*

The combined Hui Process and the Meihana Model represent a significant addition to the way in which the psychology training and practice can be responsive to the diverse needs of Māori (Pitama et al., 2007). Further details of the Meihana Model and its components can be found in Pitama et al. (2014).

The Hui Process and Meihana Model have encouraged students/clinicians to identify how specific elements and components inter-relate and assist a tailored approach to working alongside a Māori client/whānau. The training has provided an evidential framework that assists clinicians to articulate how to integrate and demonstrate both cultural and clinical competencies when working with Māori clients/whānau (Pitama 2012).

The centrality of Māori cultural processes for psychologists in teaching, research and clinical assessment and treatment is well established (Bennett, 2016; Cargo, et al., 2016; Waitoki, 2012). The formal and semiformal structure of the Hui Process (Lacey et al., 2011), that occurs in many situations across Māoridom, blends well in a clinical assessment environment with the addition of the Meihana Model (Pitama et al., 2014).

### Useful references.

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 (Online)*, 124(1347).

Mooney, H., Watson, A., Ruwhiu, P., & Hollis-English, A. (2020). *Māori social work and Māori mental health in Aotearoa (NZ) New Zealand*. *Mental Health and Social Work*, 259-279.

Pitama, S., Huria, T., & Lacey, C. (2014). *Improving Māori health through clinical assessment: Waikare o te Waka o Meihana*. *The New Zealand Medical Journal (Online)*, 127(1393).

Pitama, S. G., Bennett, S. T., Waitoki, W., Haitana, T. N., Valentine, H., Pahiina, J., Taylor, J., Tassell-Matamua, N., Rowe, L., Beckert, L., Palmer, S., Huria, T., Lacey, C. & McLachlan, A. (2017). *A proposed hauora Māori clinical guide for psychologists: Using the hui process and Meihana model in clinical assessment and formulation*. 7-19."

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### 2.5 Te Whare o Oro

Te Whare o Oro (McLachlan et al., 2023) is a model that utilises mātauranga Māori as the basis for understanding the brain structure and its development. The framework employs the metaphor of the whare tūpuna (ancestral meeting house) to consider neurodevelopment and the impact of trauma on developmental outcomes of the brain. The model also incorporates Te Whare Tapa Whā, using the structural features, roles and whakapapa kōrero of the whare tūpuna. The model links through metaphor the roro (brain) with the tāhuhu (ridgepole of an ancestral house, spinal column) as representation of the central nervous system. The pou (post, pole or pillar) of the whare tūpuna are seen as the supports that hold up the central nervous system. Finally, the heke (rafters) are used as a metaphor to illustrate the pathways to respond to the impact of trauma that has been identified within the pou. Te Whare o Oro is a very useful framework to describe the neurodevelopmental challenges that exist with a diagnosis of FASD.

<https://teatawhai.maori.nz/te-ro-ro/>



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### 2.6 Pacific Peoples' perspective

Pacific communities within Aotearoa (NZ) are comprised of many nations with the seven largest Pacific groups in Aotearoa (NZ) being Samoan, Tongan, Cook Island, Niuean, Fijian, Tokelauan and Tuvaluan (Statistics NZ, 2018, 2020). Thus, when engaging with Pacific peoples', health professionals need to recognise the unique cultural context and seek guidance and supervision as to the best way to respond to individual and family health needs.

Te Mana Ola: The Pacific Health Strategy (Ministry of Health, 2023) sets the direction for achieving equity and well-being for Pacific peoples living in Aotearoa (NZ). This strategy recognises Pacific people have a holistic view of health and well-being which includes physical, mental and spiritual components and connection to the environment. An individual must also be considered within the whānau and community environment and therefore any diagnostic or assessment process must consider their health needs within these collective systems. The following Soalaupule Ecosystem Framework (Figure 5) demonstrates the collectivism within Pacific communities and the shared decision making that occurs across groups via consensus (Tōfā Mamao Collective, 2023).

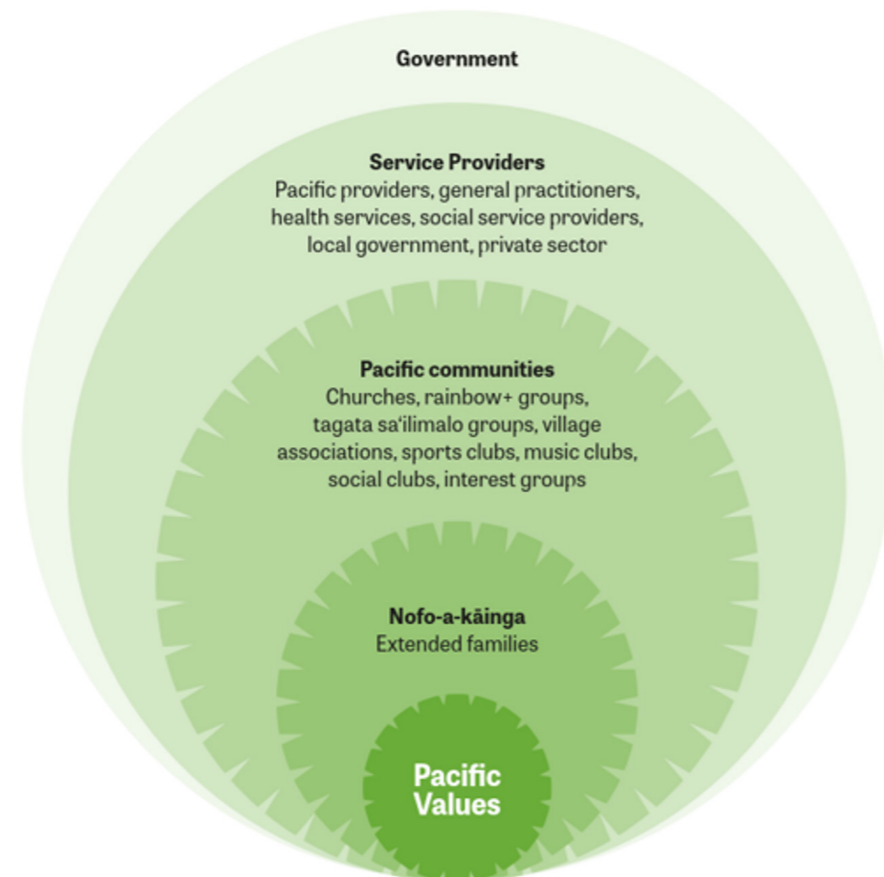


Figure 5. Soalaupule Ecosystem Framework (Tōfā Mamao Collective, 2023)

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Pacific communities in Aotearoa (NZ) experience inequity across health, income, housing and education and the current cost of living crisis is exacerbating these inequities and hardships (Ministry of Health, 2023). Within the assessment process these inequities and system barriers must be identified, and intervention plans need to address these barriers of accessing services and support. There is a paucity of Pacific people in the health workforce and therefore it is the responsibility of clinicians and professionals to connect with Pacific Peoples supports within Te Whatu Ora and the community.

There is no prevalence data for FASD in Aotearoa (NZ) and as such we do not have detail about prevalence in Pacific populations. In general, Pacific people have a much lower level of alcohol consumption when compared to those of non-Pacific ethnicity, although those Pacific people that drink tend to do so at higher levels (Nosa et al., 2021). Furthermore, rates of hazardous drinking for Pacific women/people are increasing within the context of "alcohol, marketing, outlet density, low prices, social inequity and trauma" (Nosa et al., 2021, p. 90). In the New Zealand Alcohol in Pregnancy Study, Pacific women/people were less likely to deem alcohol consumption as safe during pregnancy compared to non-Pacific women (Parackal et al., 2009), however it is possible that the recent increasing trend of alcohol consumption by women may increase risk of pre-natal alcohol exposure before pregnancy recognition.

Fetal Alcohol Spectrum Disorder assessment and diagnostic processes must acknowledge and consider Pacific Peoples values and community context. Values that are highly regarded by Pacific peoples include Tautua (service) which

prioritises showing respect, caring for others and prioritising relationships (Tamasese et al., 2010). Furthermore, Te Mana Ola highlights the importance of Pacific peoples having authority over their own health and well-being. When providing service and support clinicians and other professionals need to recognise power imbalances and empower the family to determine their health and well-being journey.

Pacific peoples have historically had low rates of access and support from health and disability services (Ministry of Health, 2002, 2008). This is due to inequities in service delivery, however high levels of stigma connected to disability within Pacific communities may also be a contributing barrier (Ministry of Health, 2008). Pacific peoples may also be reluctant to access addiction and mental health services as this may be perceived as "a sign of weakness and will bring shame to families" (Nosa et al., 2023, p. 195). Professionals need to increase awareness of potential discrimination and navigate conversations sensitively and ensure families maintain agency over the decisions that are made.

There are differences in western and Pacific peoples worldviews of health and practitioners are encouraged to work beside Pacific families in a negotiated space which acknowledge both knowledge frameworks (Le Va, 2009). Pacific nations are diverse, and time must be taken to understand and acknowledge their unique language and traditions. The Seitapu Framework (Le Va, 2009) shows how clinical theory and practice can sit beside cultural theory and practice. Cultural competencies are across four areas: family (working with the family rather than individual), language (access to staff with language competency), tapu (cultural, spiritual

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and relational markers for working with Pacific people) and organisation (knowledge of the organisations' responsibilities to Pacific Peoples.

For a FASD assessment, consideration must be given as to who and how consent is attained, where the assessment takes place, and who needs to be involved in feedback and support. Furthermore, professionals need to be aware that standardised tests and assessment tools used in the diagnostic process may not reflect cultural norms or have normative samples with Pacific peoples or people who use more than one language. Professionals need to carefully make decisions regarding what tools may be appropriate and results will need to be interpreted with caution. Where possible assessments should be conducted in the language most comfortable for the family and this may differ across family members/generations.

### 2.7 Considerations for other communities experiencing barriers to care.

#### Refugee and Asylum-Seeker

The United Nations High Commissioner for Refugees (UNHCR) has anticipated a 20 per cent increase of refugees needing resettlement in 2024 compared to 2023 (Office for the Coordination of Humanitarian Affairs (OCHA) 2024).<sup>1</sup> There are 130.8 million people forcibly displaced and stateless (United Nations High Commissioner for Refugees (UNHCR), 2024). In 2022 women and girls made up 51% of all displaced peoples (UNHCR, 2022). Aotearoa (NZ) New Zealand is one of around 37 countries that take part in the United Nations High Commissioner for Refugees (UNHCR) regular refugee resettlement programme (Department of Immigration and New Zealand Government, 2024) and will continue to accept 1,500 refugees a year under the Refugee Quota Programme from 2022/23 to 2024/25. Refugees who arrive in Aotearoa (NZ) New Zealand under the Refugee Quota Programme are granted Permanent

<sup>1</sup>International Law defines who is a refugee. The 1951 Refugee Convention defines a refugee as a person who "owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of [their] nationality and is unable or, owing to such fear, is unwilling to avail [themselves] of the protection of that country." (United Nations High Commissioner for Refugees (UNHCR), 2024).

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Residence status in Aotearoa (NZ) New Zealand.

#### Communication

Language and cultural barriers negatively affects healthcare for individuals with limited English proficiency, resulting in significant and costly health disparities (Jones & Boyle, 2011). Legal standards emphasize working with qualified interpreters (Ministry of Business, 2016), and best practice for working with medical interpreters includes tips for before, during, and after an interpreted encounter (Clarke et al., 2019). Best practice for communicating with refugee women and adolescents is to provide a face-to-face accredited female interpreter not known to the whānau or community, allowing culturally safe dialogue about sensitive issues of conception and substance use.

#### Alcohol

Alcohol is the most prevalent substance used worldwide. Refugees by definition have experienced trauma. Witnessing or experiencing traumatic events generates risk for developing mental, neurological and substance use problems. Substance use behaviours among refugees are context specific, related to a range of pre- and post-displacement influences. Unhealthy alcohol and other drug use is a prevalent yet often neglected problem affecting many refugee communities (Kane & Greene, 2018). A systematic review of qualitative research on substance use among refugees completed in 2021 resulted in four main findings: refugees have considerable susceptibility to substance use and substance use disorders (SUDs); the harmful consequences of substance use are negatively complicated by the persistent social insecurities of refugees post-settlement in host countries;

barriers to treatment and health facilities for refugees remain high; there is a strong need to improve access to treatment, interventions and prevention approaches (Saleh et al., 2022).

A community-based cross-sectional study was employed in to examine alcohol consumption and its determinants among pregnant women in Amhara Ethiopia (a country where many refugees originate) in 2022 (Abetew et al., 2022). A total of 555 pregnant women participated in this study of whom 45.6% consumed alcohol. Determinants for alcohol consumption were high wealth, pre-pregnancy consumption, poor social supports and unplanned pregnancy (Abetew et al., 2022). In some situations there are strong social controls against women's alcohol use and men's drinking to intoxication (Ezard et al., 2012). However changing social controls among displaced and refugee families may reflect disruption of dominant social controls when surviving protracted displacement (Ezard, 2014) increasing the likelihood of substance use and risk for alcohol alcohol-exposed pregnancies (Ezard 2014).

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### Pregnancy

Sexual and gender-based violence (SGBV) is a common trauma for refugee and asylum-seeking women and girls. Mass displacement and the breakdown of social protections increases the risk of SGBV, Intimate partner violence (IPV) and early child marriage for refugee women and girls (World Health Organisation (WHO), United Nations Population Fund (UNFPA) et al., 2020). Findings from Southeast Asia showed a very high prevalence of IPV among refugee women reaching as high as 80% among Afghan refugees in Iran (Delkhosh et al., 2019) and 72% among Rohingya refugees in Bangladesh (Islam et al., 2022). Nearly 50% of Congolese women refugees in Rwanda experienced IPV (Sipsma, et al., 2015).

### Screening for Alcohol Use and Pregnancy

Questions need to be trauma and culturally informed. Being mindful of the prevalence of SGBV and child forced marriage (CFM) among refugee and asylum-seeking women and girls is essential when framing questions about pregnancy. Current and past pregnancies and marriage may not have begun by choice. Stigma and dominant social controls against alcohol use should not prevent consideration of an alcohol exposed pregnancy (Pagano, 2014). Vulnerabilities and stressors of pre- and post-settlement life can influence new or ongoing, covert or overt, alcohol consumption. Information revealed about conception, gestation, birth and substance use changes over time as individuals develop trust of their health practitioners. Asking woman and girls about their alcohol use and pregnancies is problematic if the interpreter is

male and or if the interpreter is known to the community of origin.

Screening and talking about alcohol use in pregnancy with refugee and asylum-seeking women and girls can be completed sensitively with a cultural- and trauma-informed approach. Questions about alcohol use should be included as routine healthcare when working with Refugee and Asylum-seeking woman and girls on every occasion of clinical engagement post-settlement, irrespective of the health professional's knowledge and/or unconscious bias about countries of origin, genders, sexualities, faiths and beliefs of the person seeking healthcare. Questions about alcohol use routinely embedded with comprehensive psychosocial and preventive screening questions, diminishes stigma and allows admission of alcohol use and other sensitive or stigmatising problems over the time of a trusted therapeutic relationship. Comprehensive screening at every health engagement allows onward referral of women, girls and their children to services designed to meet identified health needs and risks arising from or associated with past or ongoing alcohol use (Kane & Greene, 2018; Rijnders, et al., 1998; Saleh et al., 2022).

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### Developmental delay

Children born to migrant parents have higher rates of language difficulties, intellectual disability and autism (Abdullahi et al., 2020, Allport et al., 2023; Mutch et al., 2012). Mothers from Low to Middle income countries (LMICs) are likely to have been disadvantaged early in their lives and may continue to face social disadvantages in accessing primary health care with fewer supports, as well as language and knowledge barriers post-settlement. Knowledge barriers and beliefs about developmental delay can result in families not engaging in recommended post-settlement medical systems or therapies (Abdullahi et al., 2020; Allport et al., 2023; Mace et al., 2014; MacMillan et al., 2015; Mutch et al., 2012; Zwi et al., 2015; Zwi et al., 2018). Mothers and or bad spirits can be blamed as reasons for a child's developmental difficulties. Beliefs about developmental delay place stigma and shame upon the whānau, most often the birthmother and rarely on consanguinity which is common in certain groups of refugees. Blame and shame of mothers and their children with developmental disabilities places each at risk of human rights abuses including neglect, physical violence and exit trafficking.

Health literacy about developmental delay and brain domains of function can be built through interpreting resources, practical images, and therapies using analogies, google image, visual aids and practical occasions of observation. Increasing the health literacy of refugee parents about their child with developmental disabilities requires, language and cultural interpretation over time and within a trusted therapeutic relationship. Patience and time as

well as maintaining a trauma-informed lens will facilitate working with families about their child's developmental difficulties, build their efficacy and capacities for self-advocacy and success.

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### Rainbow communities

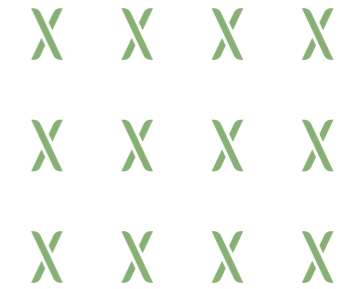
In this guideline we have used the terms “LGBTQIA+”, and “MVPFAFF+”. We acknowledge that not everyone will identify with these terms and that there are many different cultural understandings and terms for sexuality and gender diversity. LGBTQIA+ is an evolving English acronym that covers a wide range of diverse sexualities and gender identities and expressions, and intersex variations. This includes lesbian, gay, bisexual, transgender, takatāpui, queer, questioning, intersex and asexual identities. It is used in a similar way to ‘rainbow’. In Aotearoa (NZ), MVPFAFF+ is an umbrella term that refers to the diverse gender and sexuality expression and roles across Pacific cultures including mahu, vakasalewa, palopa, fa’afafine, akavai’ne, fakaleiti (leiti), fakafifine, and more (Inside Out, 2021). As each person’s identity, needs and experiences are unique it is important that practitioners be respectful of diversity, and ensure their practice and services are inclusive, and responsive to the needs of this community. This includes:

- Recognising that each individual is the expert of their own gender and/or sexual identity and that their unique journey needs to be acknowledged (respect self-determination).
- Recognising the impact of minority stress, which impacts different people differently but may include negative effects on social, spiritual, psychological and physical health and affirm the inherent worth of each person as deserving respect and inclusion.

- Use of language, including names and pronouns, can be an important part of young people exploring identity. Use the names and pronouns requested by the individual (he/him, she/her, they/them etc) and be sensitive that use of these may be situational depending on who is present.
- Listening and reflecting back the language each person uses about themselves, including gender identity terms, preferred names (even if not legally changed) and correct pronouns.
- Ensure all information contains the appropriate name and terminology or their choice.
- Displaying material, such as health promotion posters, that are inclusive of gender and sexual diversity.
- Provide gender neutral toilet options.
- Adapted from: Guidelines for Gender Affirming Healthcare for Gender Diverse and Transgender Children, Young People and Adults in Aotearoa (NZ) New Zealand. (Oliphant et al., 2018).

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The need to consider Rainbow communities when developing guidelines is important as evidence indicates that transgender and gender-diverse individuals, on average, have higher rates of autism and other neurodevelopmental diagnoses (Hisle-Gorman et al., 2019; Warriar et al., 2020). There is no research pertaining to the prevalence of people who identify as LGBTQIA+ and MVPFAFF+ within FASD populations. However, it is important to note that there are increased rates of attention deficit hyperactivity disorder (15 times higher than general population) and Autism Spectrum Disorder (2 times higher than general population) among children diagnosed with FASD (Lange et al., 2018), suggesting practitioners need to ensure their practice is inclusive and respectful. This is especially important as both the Rainbow community and people with FASD experience a considerable number of barriers to accessing healthcare services (Bagley, 2019; Charles et al., 2015). Importantly LGBTQIA+ Australia (2023) point to a cycle of invisibility where without explicit policy and practice LGBTQIA+ people may hide or modify their identity in health care/service settings, becoming invisible. This in turn can mean service providers fail to consider their needs and act appropriately.



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### Resources

Information and support can be found from a number of organisations and groups that work with the rainbow community and their whānau.

#### X **Gender Minorities Aotearoa (NZ)**

<https://genderminorities.com/>

An Aotearoa (NZ) transgender advocacy organisation run by and for transgender people (including binary, non-binary, intersex, and irawhiti takatāpui).

#### X **LGBTIQ+ Health Australia**

<https://www.lgbtiqhealth.org.au/hub>

An Australian organisation that provides health-related programs, services and research focused on lesbian, gay, bisexual, transgender, intersex and queer people and other sexuality, gender and bodily diverse (LGBTIQ+) people and communities.

#### X **InsideOut**

<https://insideout.org.nz/>

A national charity providing education, resources, consultation and support for rainbow and takatāpui communities.

#### X **Intersex Aotearoa (NZ) (ITANZ)**

<https://www.intersexaotearoa.org/>

Intersex Aotearoa (NZ) is an intersex-led non-profit organisation that provides affirmation, advocacy and referral for intersex people and their whānau.

#### X **Patha: Professional Association for Transgender Health Aotearoa (NZ)**

<https://patha.nz/>

PATHA is an interdisciplinary professional organisation working to promote the health, well-being, and rights of transgender people. With professionals who have experience working for transgender health in clinical, academic, community, legal and other settings.

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#### X **Rainbow Rights in Aotearoa (NZ)**

<https://rainbowrights.nz/>

A New Zealand website that provides information about the legal rights of rainbow young people in Aotearoa (NZ).

#### X **Rainbow Youth**

<https://ry.org.nz/>

A national organisation based in Tāmaki Makaurau/ Auckland providing peer support, information and resources for rainbow young people.

#### X **Takatāpui: A Resource Hub**

<https://takatapui.nz/>

An Aotearoa (NZ) resource hub for takatāpui people, their whānau and communities.

#### X **Te Ngākau Kahukura**

<https://www.tengakaukahukura.nz/>

A partnership between rainbow communities and Ara Taiohi who work across a range of kaupapa and sectors to build understanding, embed rainbow-competent practice and grow the capacity of people who are making change.

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### 2.8 Assessment Principles

These principles and diagnostic criteria have been developed on the premise that shared decision making and collaboration between the clinicians and the whānau is present throughout the whole assessment process. Note these principles were developed with the Australian Guideline Development Group and reviewed by clinicians and whānau in Aotearoa (NZ). The following Assessment Principles are provided to help support clinicians in applying the diagnostic criteria in their practice:

- For individuals already with a diagnosis of FASD under previous criteria, re-assessment is not required, unless clinically indicated.
- Prenatal alcohol exposure can result in a wide range of whole-body outcomes from subtle to severe. In making a diagnosis of FASD we are aiming to identify individuals who are experiencing pervasive, persistent, and clinically significant impairments that impact daily functioning, where it is determined that PAE has significantly contributed to these outcomes.
- Assessment should include input from health professionals across multiple disciplines. In applying this principle, clinicians should be mindful of the overarching principles of value-based health care and person-centred care. Both of these approaches respectfully place the individual, their carer(s) and support people, at the centre of care through fostering trust and mutual respect and by providing education and support so that they can actively engage in making decisions about tailoring care to their needs.
- There is no formally agreed definition of

impairment within, or between, health disciplines. As such, differences in functional performance and/or physical features evidenced by indices such as percentile ranks, should not be used in isolation. Clinical judgement informed by the relevant available information is essential to determine the best explanation for an individual's neurodevelopmental or physical differences, and in turn, whether their presentation meets criteria for a diagnosis of FASD.

- Clinicians are encouraged to adopt a 'developmentally informed approach'; whereby different assessment approaches are applied across developmental stages to provide the most appropriate assessment, given an individual's presentation.
- Assessment and diagnosis of FASD can and should take place across the lifespan. Individual attributes that may manifest as barriers to equitable inclusion may only become evident with age. Review should occur periodically when clinically indicated, but in the context of the supports being put in place and the potential impacts of major life transitions on functioning.
- In providing a diagnosis of FASD clinicians are making the determination that an individual is impacted by a life-long condition. This means that impairments are not transient or only due to changes in current circumstances or enduring environmental adversity. However, clinicians also need to take into consideration how an individual's presentation may change over time due to life experiences and opportunities, intervention and other formal supports or the lack thereof, as well as differing expectations across life stages and contexts.

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- Practitioners are encouraged to seek relevant discipline-specific clinical supervision, preferably from practitioners with specific FASD expertise to support them in undertaking assessment and diagnosis in their specific settings, whilst also being mindful of professional and ethical guidelines.

### 2.9 Diagnostic Criteria

The "Australian Guidelines for Assessment and Diagnosis of Fetal Alcohol Spectrum Disorder or Neurodevelopmental Disorder Associated with prenatal Alcohol Exposure" (Australian Guideline Development Group, 2024) clinical criteria and systematic review has been applied to these Aotearoa (NZ) guidelines in accordance with available evidence and input from stakeholders and clinicians. Permission has been granted to use and adapt the Australian diagnostic documentation in the Aotearoa (NZ) guidelines with the view to promote international collaboration and consistency.

Diagnostic criteria aim to inform clinicians of the symptoms usually required to ensure accurate diagnosis of a health condition, while also allowing a degree of flexibility to accommodate natural variances in presentation and clinical decision making (World Health Organization, 2004). As such, the following diagnostic criteria do not form strict rules for diagnosis, but rather evidence-based guidance to inform the clinical assessment, diagnostic reasoning, and case formulation when working with people suspected of conditions related to prenatal alcohol exposure.

Please note an extensive amount of additional information is provided in the sections following the diagnostic criteria to support implementation.

#### Terminology

Clinicians are encouraged to use shared decision-making with individuals attending for assessment and their families, carers, or significant others, to determine what their preference is for the terminology to be used in describing the individual's diagnosis and with whom that diagnosis is shared.

There are also a range of differences in terminologies applied both within and between disciplines and across different clinical settings regarding a variety of aspects of the assessment process. For example, the terminology of 'clinically significant impairments' has been used in the diagnostic criteria, however clinicians may prefer to use wording of 'severe impairments.' The terminology of standardised tests has been used, but clinicians may prefer to use wording such as standardised measures or tools or validated tests, measures or tools when appropriate. The diagnostic criteria and guidelines are not meant to be prescriptive, but to provide guidance and support for clinicians in their practice.

# Fetal Alcohol Spectrum Disorder (FASD)

All criteria (A-E) must be present, and all relevant specifiers applied for diagnosis.

## A. Evidence of prenatal alcohol exposure (confirmed by point 1 or 2)

- Evidence consistent with heavy or very heavy prenatal alcohol exposure (PAE) at any time during gestation, including prior to pregnancy recognition. Practitioners could consider moderate PAE depending on the strength of concurrent evidence. See the additional information section for further details. Confirmation of PAE may be obtained from any of the following sources: self-report of alcohol use in pregnancy, and/or collateral reports from individuals who directly observed the prenatal alcohol use, and/or information obtained from medical or other records.
- In the absence of a confirmed history of PAE, the presence of the three sentinel facial features (i.e., short palpebral fissures, thin upper lip, and smooth philtrum) may be considered sufficient to meet Criterion A, following the exclusion of other causes.

## B. Presence of pervasive neurodevelopmental impairments.

This is evidenced by clinically significant impairments in three or more neurodevelopmental domains (general intellectual abilities, communication, motor, literacy or numeracy skills, memory, attention, executive functioning, emotional and/or behavioural regulation, adaptive/social functioning).

Clinically significant impairment is defined through points 1 and 2:

- Reports indicative of clinically significant developmental and/or behavioural problems as described by the individual undergoing the assessment and/or multiple informants across different settings; and
- Direct evidence of clinically significant impairment. The preference is for these impairments to be evidenced through developmentally appropriate standardised tests. In situations where standardised tests are not appropriate or cannot be performed (e.g., due to the individual's level of functioning); historical record review, diagnostic interview, clinical observation, and clinical reasoning may be used to assess the significance of the impairments.

Note: In infants or young children, three facial features, microcephaly and global developmental delay may be considered sufficient for diagnosis of FASD, following rigorous consideration of other causes.

## C. The neurodevelopmental impairments necessitate significant supports across multiple areas of functioning as appropriate for an individual's developmental stage and cultural context to support equity across the lifespan.

## D. The onset of neurodevelopmental impairments is evident during development.

Note:

- Different intellectual, behavioural, and functional capabilities emerge variably as individuals grow and mature and that some delays in development may represent age or developmentally appropriate diversity rather than impairments.
- Neurodevelopmental impairments may not become apparent or not fully manifest until demands of life and context exceed developmental capabilities. As such, repeat assessments may be required to meet Criterion D.

## E. The symptoms are not better attributed to another condition or exposure.

Diagnosis requires consideration of other conditions or exposures, which could better explain the person's presentation. However, some conditions and exposures can co-exist with FASD. This includes consideration of other neurodevelopmental risk factors such as, but not limited to:

- Predisposing/familial (e.g., family history of learning disorders, cognitive impairments, mental ill-health, intergenerational trauma).
- Genetic conditions (e.g., Fragile X, copy number variants including microdeletion or duplication syndromes, or chromosomal anomalies that are known to be associated with neurodevelopmental impairment).
- Prenatal (e.g., exposure to other teratogens, including prescription medications [e.g., sodium valproate] and/or other drugs [e.g., nicotine, cannabis, amphetamines, opioids], pregnancy complications, congenital infections, premature birth, other environmental factors [e.g., nutrition stress during the pregnancy]).
- Postnatal (e.g., hypoxic ischaemic encephalopathy, adverse childhood, adolescent, or adult experiences, acquired or traumatic brain injury, central nervous system infections, or cranial malformation).
- Other neurological conditions (e.g., delirium, dementia, seizure disorders [e.g., genetic seizure syndromes, epilepsy encephalopathies], metabolic [e.g., mucopolysaccharidoses] or other neurocognitive conditions).
- Current medications or substances (i.e., the direct physiological effects associated with the use of medications or substances by the individual being assessed).

### Specify if:

- 1, 2 or 3 or no sentinel facial features (include the specific measurements for palpebral fissure length (e.g., 10th [1.28 SD], 5th [1.65 SD],  $\leq$  3rd percentile [ $\leq$  2 SD]).
- Head circumference restriction at birth and/or postnatally (e.g., at the 10th [1.28 SD], 5th [1.65 SD],  $\leq$  3rd percentile [ $\leq$  2 SD]; include the specific measurements for head circumference at birth and postnatally).
- Physical size restriction at birth and/or postnatally (weight and/or length/height at the 10th [1.28 SD], 5th [1.65 SD],  $\leq$  3rd percentile [ $\leq$  2 SD]; include specific measurements at birth and postnatally).

Note: The physical features provide clinically meaningful information and are an important part of the assessment. Presence of physical features can provide increasing levels of certainty for clinicians regarding the causative specificity of PAE. These features are not provided as specifiers to diminish their importance but are included here as not all individuals present with physical features. This approach allows clinicians to document each of the physical features along a continuum, informing both current and future clinical care and research.

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### Associated features:

Record all associated features including structural brain abnormalities, neurological conditions (e.g., seizures of unknown origin, cerebral palsy, hearing, or vision impairments), congenital anomalies (e.g., cardiac, renal, or other organ defects, ptosis, strabismus), musculoskeletal conditions, (e.g., flexion contractures), other health problems (e.g., sleep disorders, eating/feeding or toileting concerns), sensory processing challenges, social cognition impairments, social communication/pragmatics, motor speech or speech-sound impairments.

### Co-occurring conditions:

FASD can co-occur with a wide range of conditions. This includes but is not limited to other neurodevelopmental conditions (e.g., ADHD, ASD, developmental language disorder, specific learning disorder), mental health conditions (e.g., anxiety, depression, trauma and other stressor-related conditions, substance use conditions). Assessment should include consideration of all relevant co-occurring conditions to enable appropriate conceptualisation of an individual's treatment and support needs. Where an individual is found to meet criteria for multiple diagnoses, care should be taken to consider the possible overlap of symptoms and consider whether multiple diagnoses provide additional explanatory power to assist in understanding the individual's needs.

### At risk of FASD:

In situations where PAE is confirmed and concerns are identified, but an assessment process cannot be completed, or available assessment is insufficient to determine if pervasive and clinically significant impairments exist, individuals may be considered 'at risk of FASD' with follow-up and reassessment recommended as clinically indicated.

Practitioners should specify why the 'at risk' designation has been used. This designation should not be used where diagnosis is not possible due to lack of resources.

## 2.10 Additional information

### Structure of the diagnostic criteria

A novel structure was developed to account for the findings from the evidence review. Whereby clinical features with sufficient evidence were included as part of the diagnostic criteria and other features without sufficient evidence were included in the 'associated with' section. This supports the consideration of associated features in the assessment process to inform recommendations and supports.

## Criterion A: Evidence of prenatal alcohol exposure (PAE)

Whilst evidence of prenatal alcohol exposure is a key part of diagnosing FASD care must be taken to ensure this is gathered in a sensitive and supportive way. Thus, it is often not the first question asked and is generally discussed within the bounds of a trusting relationship between clinicians and families.

PAE is a key factor in differentiating FASD from other conditions. Clinicians need to have reliable PAE evidence at sufficient levels that are known to have the potential for adverse outcomes on the components of the diagnostic criteria.

Criterion A has been specifically worded to align with the findings from the evidence review, whereby heavy and above PAE was more consistently found to be associated with adverse

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diagnostic outcomes. The available evidence was uncertain regarding the potential impacts on diagnostic outcomes at a moderate PAE level. However, there are some key limitations that need to be considered when using this evidence in practice at an individual level:

- There were less outcomes available assessing moderate PAE exposure, which limited the ability to understand the potential for impacts at this level of exposure.
- The review was unable to control for, or compare, different timings or patterns of exposure (e.g., chronic exposure, exposure only prior to pregnancy recognition, first trimester only exposure, or binge exposure). This was due to the variability in definitions, reporting of information, and the number of studies available assessing the same outcomes. It is possible that a lower level of exposure at a critical period of gestation could result in adverse outcomes and clinicians need to have flexibility and use clinical judgement to take this into consideration.
- Whilst adjusted outcomes were used where possible, the review was often unable to control for, or compare, different individual prenatal parental and child factors, which may exacerbate or ameliorate impacts of PAE (e.g., prenatal nutrition, metabolic rates, genetic differences, biochemical and inflammatory responses to alcohol).
- Whilst adjusted outcomes were used where possible, the review was often unable to control for or compare different individual postnatal parental and child factors, which may exacerbate or ameliorate impacts of PAE (e.g., postnatal environments and events, postnatal nutrition).

As per the assessment principles section, the PAE criterion A1 should not be rigidly applied in isolation. Clinicians need to take into consideration the timing, duration (i.e., the

number of weeks during the pregnancy that the exposure occurred) and the pattern of the exposure (i.e., less frequent but larger quantities of alcohol, versus more frequent exposure at lower levels or varying patterns between pre-recognition of pregnancy and post-recognition of pregnancy). A binge exposure pattern may fall into moderate, heavy, or very heavy exposure categories, depending on how many drinks were consumed during one or more binge occasions per week. Rather, the available evidence should be used to inform clinical decision making as part of an individual's case formulation.

In practice, exact information regarding the number of drinks per week may not be available. For example, the biological parents may not be available to interview, or the biological parents may not be able to recall that level of specific detail. However, other information is commonly available that is consistent with a heavy level of exposure. For example, self-reported information, witness reports or available records that documented episodes of intoxication during the pregnancy period. In such instances, after considering the reliability of the information at hand, clinicians may exercise informed clinical reasoning about the PAE risk based on the best available information. Clinicians are encouraged to engage in case discussion to support clinical decision making.

Overall, clinicians should use their clinical judgement to determine, based on the best available PAE history, the likely level of risk of the exposure and in the context of the individual's presentation, the likelihood that PAE has played a significant role in an individual's presentation. Clinicians are encouraged to remember that whilst PAE is a risk for neurodevelopmental impairments, risks are not predetermined.

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### Considerations from the evidence review

To support assessment and diagnosis across a wide range of clinical contexts, including outside of specialist settings, feedback from the Clinical Advisory Group indicated that practitioners would benefit from further guidance regarding assessment of PAE.

An extensive evidence review was undertaken. To allow appropriate comparison across the diagnostic outcomes available evidence was quantified according to the grams of ethanol per week of alcohol exposure and grouped into different levels of exposure (Table 1).

These levels are comparable to Aotearoa (NZ) alcohol guidelines which states to reduce the risk to your health women should consume no more than two standard drinks per day (and no more than 10 per week) and men should consume no more than three standard drinks per day (and no more than 15 per week) (Ministry of Health, 2022).



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**Table 1.**

Definitions of PAE levels per week used in the evidence review.

*Note. these definitions are not intended as rigid cut offs in practice but rather provided as information to inform clinical decision making.*

PAE level	Total number of standard drinks per week	Grams (g) of ethanol (pure alcohol) per week
Light	Up to 2 drinks	1 – 20 g
Moderate	>2 and up to 10 drinks	21 – 100 g
Heavy	>10 and up to 20 drinks	101 – 200 g
Very Heavy	>20 drinks	>200 g
Any	Exposure dichotomised as ‘yes’ or ‘no’	
Confirmed/unquantifiable	Exposure confirmed but enough detail available to quantify the specific level, but generally reported as heavy or very heavy PAE.	

*Note. PAE = prenatal alcohol exposure. 1 standard drink = 10g ethanol. “Light” exposure level was determined based on clinical situations where people report having consumed no more than 1 to 2 standard drinks (SD) per week. The distinction between “moderate” and “heavy” exposure was based on the NHMRC Alcohol Guidelines (2020) determination of risky drinking (i.e., no more than 10 standard drinks per week). A pragmatic distinction was made to separate out the two higher levels of PAE to provide the opportunity to differentiate between “heavy” and “very heavy” exposure. Exposure may be one or more occasions during a week. A binge exposure pattern is included and may fall into moderate, heavy, or very heavy exposure categories depending on how many drinks were consumed on the one or more binge occasions per week. PAE = prenatal alcohol exposure.*

The evidence review indicated that associations between PAE and diagnostic outcomes were more consistently observed across multiple neurodevelopmental domains at heavy and very heavy PAE levels. Significant effects were less often observed at a moderate and light levels.

It is not possible based on the available evidence from this review to exclude the possibility that light prenatal alcohol exposure may be associated with subtle levels of neurodevelopmental impairment. As noted elsewhere in this document, a wide range of other outcomes that may be associated with this pattern of exposure have not been examined. Hence, it is not the role of these guidelines to provide public health messages regarding prenatal alcohol exposure.

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# Good Practice Statements: Prenatal Alcohol Exposure Assessment

The following good practice statements (GPS) have been prepared to support collection of prenatal alcohol exposure information.

- X Asking about prenatal alcohol exposure can be sensitive. Therefore, conversations need to occur within a respectful and trusting relationships.
- X Sensitively and respectfully include discussions about alcohol use and potential risks as part of routine antenatal and postnatal care.
- X Ask about alcohol use as part of routine pregnancy history taking, alongside other prenatal exposures and events (e.g., medications, tobacco, illicit drugs, infections, diet, exercise, stress, and pregnancy complications).
- X Separate the assessment of prenatal alcohol exposure into pre-pregnancy recognition (i.e., before a woman or person knew they were pregnant) and post-pregnancy recognition (i.e., after a woman or person found out they were pregnant).
- X To support accurate assessment of risk, assess PAE both before and after pregnancy recognition. Standardised screening tools, such as the AUDIT-C can be used.

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- X Consider that some individuals may not be aware of what constitutes a standard drink of alcohol (i.e., 10g of ethanol). Explain the definition of a standard drink prior to using the AUDIT-C tool. The use of a standard drinks guide, such as that included in the Manatū Hauora guidelines, can facilitate communication of what constitutes a standard drink. Clinicians can also gather the information and then convert that information into standard drinks for the individual.
- X Be mindful that there are many factors that may have influenced alcohol use during the pregnancy period and collect information in a supportive, compassionate, and non-judgemental manner.
- X Recognise that individuals might face ongoing challenges with alcohol or other complex issues and provide appropriate support and referrals.
- X Contact biological parents directly, if possible and appropriate to assess PAE. Otherwise, carefully review other sources of information (e.g., reliable observer reports, medical or legal records). Note that a history of alcohol use without evidence of consumption during the index pregnancy is not sufficient to confirm exposure.
- X Consider that self-reports of PAE may be influenced by a range of factors. For example, the context in which information was collected (e.g., child protection settings) and the timing (e.g., during pregnancy and reported in antenatal records or later in the child's life). Practitioners may want to contact biological parents to check previously collected information.
- X Sometimes there may be inconsistencies about PAE in available information. In instances when information was collected directly from the pregnant woman/person during an assessment, this information should be prioritised over other sources. Practitioners can document any inconsistencies and indicate that re-assessment could be considered should additional information arise.

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*Note: All Implementation considerations within this document were drafted in the “Australian Guidelines for Assessment and Diagnosis of Fetal Alcohol Spectrum Disorder or Neurodevelopmental Disorder Associated with prenatal Alcohol Exposure (Australian Guideline Development Group, 2024)” and applied to the Aotearoa (NZ) guidelines in accordance with available evidence and input from stakeholders and clinicians.*

### Implementation considerations: transfer of information from the pregnancy record to the child’s record

To support early identification of prenatal factors that can influence developmental outcomes critical information that could affect longer term health outcomes for children can be transferred from the pregnancy record to the child’s health record. This information should be kept to the minimum required to support the well-being of the child and no personal or identifying information of the parents should be included.

### Implementation considerations: bias in the assessment process

Prenatal alcohol exposure can adversely impact people across all groups in our society. Stakeholders noted that it is important for people to be aware that prenatal alcohol exposure is “everyone’s business and everyone’s responsibility.”

Clinicians need to be mindful of bias in the referral and assessment process and careful to not make assumptions about the likelihood of prenatal alcohol exposure or FASD based on an individual’s demographic features.

### Implementation considerations: accurately assessing risk

It is important to note level of risk can be underestimated based on how prenatal alcohol exposure information is collected. Clinicians should:

- Ask questions in a non-judgemental manner, which may support individuals to feel safe to provide accurate information about alcohol use.
- Provide information about standard drink sizes and ask people what size container they usually drink from.
- Ask questions about both pre-recognition and post-recognition. As people may only consider the period after they found out they were pregnant and not take into consideration alcohol use that occurred before awareness of their pregnancy.

### Implementation considerations: AUDIT-C pre- and post-pregnancy recognition

The AUDIT-C is a tool structured to collect information pre- and post-pregnancy recognition. This has been mapped to the levels of prenatal alcohol exposure used in the evidence review for the guidelines and can support clinical decision making regarding the assessment of the level of risk.

### Implementation considerations: child protection settings

Challenges with gathering prenatal history for children in out-of-home care was discussed as a major barrier to the assessment. To support collection of accurate prenatal alcohol exposure information and identification of FASD the following implementation considerations are provided:

- Information about prenatal alcohol exposure should be documented alongside other relevant prenatal factors (e.g., other drug exposure, domestic violence, whānau medical history).
- As part of training and practice resources for child protection staff, include information on the accurate collection and documentation of prenatal alcohol exposure and local referral pathways.

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- There can be many reasons why prenatal alcohol exposure occurs, including that the exposure occurred before a woman/person knew they were pregnant, pre-existing alcohol use disorder or drinking to cope with domestic violence or other traumatic circumstances. Pregnant women/people need to feel safe to discuss concerns regarding prenatal alcohol exposure and to seek help for themselves and their children without the fear of their children being removed.
- Information about plans for assessment, diagnostic outcomes, and support planning should be incorporated into a child’s health management plan and this information be provided to foster carers.

### Implementation considerations: justice settings

Challenges with collecting prenatal history were also noted for individuals involved with the justice system, including collecting this information through court-ordered assessments within restricted timeframes.

Notably, the United Nations Convention on the Rights of the Child (UNCROc) General Comment No. 24 states: “Children with developmental delays or neurodevelopmental disorders or disabilities (for example, autism spectrum disorder, fetal alcohol spectrum disorders, or acquired brain injuries) should not be in the child justice system at all, even if they have reached the minimum age of criminal responsibility. If not automatically excluded, such children should be individually assessed.” Whilst the UNCROc comment concerns children, this should also be considered in the adult justice context.

To support collection of accurate prenatal alcohol exposure information and identification of FASD the following implementation considerations are provided:

- FASD should be considered in the early phases of contact with the police and justice systems to permit timely access to support and to prevent further escalation of behavioural challenges.
- Where appropriate, collect and document information about prenatal alcohol exposure alongside other relevant prenatal (e.g., other illicit substance exposure, domestic violence, whānau medical history) and postnatal factors and use this to inform referrals to local assessment providers.
- Provide information about accurate collection and documentation of prenatal alcohol exposure and local referral pathways to all professionals in legal and justice contexts as part of staff training and practice manuals.
- Where consent/assent is provided, information regarding FASD should be documented on an individual’s police and justice records to help inform approaches to support.
- Consider non-custodial therapeutic diversionary options where possible, including appropriate place-based culturally responsive programs for individuals with FASD.

It is also important to acknowledge that irrespective of age, and disability type, people with disabilities are proportionally over-represented in the criminal justice system as offenders and victims, and often reach this status and experience greater negative consequences due to inherent structural biases within those systems and the underpinning frameworks (Lambie, 2020).

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### Criterion B: Presence of pervasive neurodevelopmental impairments

The evidence review indicated that there is potential for adverse outcomes across all neurodevelopmental areas included in the diagnostic criteria, but this was dependent on the level of PAE (i.e., increasing risk was associated with increasing levels of exposure).

To provide evidence of the pervasive nature of the impairments, there needs to be clinical evidence that an individual's daily functioning is being negatively impacted in three or more neurodevelopmental domains. The Guidelines Development Group have retained the three or more domains on the premise that the impact of prenatal alcohol exposure needs to be demonstrated across multiple areas of functioning. It is recognised that further research is needed to empirically validate this.

As per Criterion E, clinicians need to consider all other possible conditions or factors that could explain the neurodevelopmental impairments. Clinicians need to be cognisant that having three or more neurodevelopmental domains with clinically significant impairments is not specific to FASD and can apply to a wide range of other neurodevelopmental conditions. Thus, while the neurodevelopmental domains included can be impacted by PAE, they are not discriminatory for PAE. As discussed earlier in this document PAE is a risk for neurodevelopmental impairments, it is not predetermined. Clinicians may also need to consider a higher threshold for pervasive impairments in the presence of

multiple comorbidities. Clinicians need to also consider that a range of psychiatric conditions can cause (often transient) neurodevelopmental impairments.

#### Considerations from the systematic review of diagnostic criteria components

There was a large body of evidence investigating associations between prenatal alcohol exposure and neurodevelopmental outcomes. However, there was limited evidence available that reported this information according to specific percentile ranges or standard deviations on standardised tests. Further, for clinical cut offs to be meaningful, evidence needs to be available to show that there are differences in important life outcomes between people above or below a cut off. Therefore, information regarding the interpretation of test scores and how these scores are used to inform clinical decision making regarding clinical significance of impairments is based on:

*"consensual expert guidance or 'best practices' that clinicians can consider incorporating into their work.. The integrative analysis of a neuropsychological test profile rests solely with the judgement of individual clinicians and their appreciation for and expertise in synthesizing information from multiple medical, historical, cultural, behavioural and other sources to arrive at clinical formulations, impressions and diagnoses"* (Guilmette et al., 2020, p. 442).

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### Determining the clinical significance of neurodevelopmental impairments in practice

Clinicians are required to use all the information collected as part of the assessment to decide if clinically significant impairments are present in each of the neurodevelopmental domains that were assessed. Single test scores should not be used to establish impairments in multiple neurodevelopmental domains.

As described in the assessment principles section, there are no formally agreed definitions of 'impairment'. Test scores should not be used in isolation to define impairments.

Percentiles are a simple metric for conveying test information. However, as has been described previously (e.g., Crawford et al., 2009) there are numerous challenges that clinicians should be aware of. Appendix A provides a brief overview of some key considerations. Given the complexity in interpreting test scores, it is important that practitioners follow established conventions for instruments used in the assessment, when reporting an individual's performance. More generally, practitioners may benefit from considerations suggested by Guilmette et al. (2020) when determining impairment (see Appendix A for an overview).

Guilmette et al. (2020) proposed the following (Table 2) for characterising levels of performance on tests that have normally distributed scores. Test scores in the exceptionally low score range and the below average score range could be considered as being significantly below the normative level. While useful, clinicians are reminded to consider the characterisation of performance on the tests they use in line with established best practices for each test.

All tests, irrespective of their rigour in development and exactness in application, produce scores that contain both the individual's true ability + test error. To accommodate this, most tests provide confidence intervals for subtest, index and full-scale scores. Some also provide confidence intervals for percentiles. Where confidence intervals are available or can be calculated, clinicians should use confidence intervals of scores together with the suggestions on the previous page to support interpretation.

It is important to note that most normative studies of standardised measurement tools do not include Aotearoa (NZ's) culturally diverse population. Therefore, these recommendations should be used with great caution with individuals from different cultures to the population the tests were normed on. Reporting should include suitability of the tools used and discuss potential limitations including impact on test performance. Assessment information should also be triangulated with other clinical sources such as interviews and direct observation.

As noted at the start of this section, test scores or the score labels do not equal impairment, "scores cannot be impaired; only a function can be impaired" (Guilmette et al., 2020, p. 442). The test score labels are intended to be descriptive, providing information about the position of scores relative to a normative or clinical comparative sample.

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**Table 2.**

Recommended test score labels based on standard scores and percentiles for tests with normal distributions taken from Guilmette et. al (2020) and adapted to correspond with guidance from NZSign (2021)

Standard score	Percentile	Score label
>130	>98	Extremely High
120–129	91–97	Very High
110–119	75–90	High Average
90–109	25–74	Average
80–89	9–24	Low average
70–79	2–8	Very Low
<70	<2	Extremely Low

*Note: these scores do not necessarily hold for tests that have non-normal score distributions and these categories may vary by a few or several standard scores (or percentiles) depending on the nature of a measure's distribution of scores.*

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### Assessing neurodevelopmental domains in practice

An overview of the neurodevelopmental domains and specific considerations for assessment are provided in Table 3. FASD is a complex and multifaceted condition that is best assessed and diagnosed via an interprofessional framework. As such, clinicians are encouraged to engage in a collaborative approach to formulating individual cases (e.g., through case conferencing), to bring their relevant scope of practice to the assessment process, and to access clinical supervision to support application of the diagnostic criteria within their skill set and clinical context. Different clinicians in a multidisciplinary setting should not simply contribute their assessment findings without consideration of all the domains, in consultation with their team.

Ideally, specific disciplines will assess certain domains (e.g., speech pathology assessing communication, occupational therapy assessing motor skills). However, there may be settings where all disciplines are not available. In these situations, clinicians can work within scope of practice, qualifications, training, and experience to provide assessment across different domains. This would require relevant upskilling, consultation, and supervision to support clinicians in working to the full scope of their practice. Practitioners are reminded this does not mean they can use a single sub-test they are able to administer to measure a whole domain (e.g., using verbal fluency as a sole measure of communication). Further, assessment of all domains is not always required to consider a diagnosis of FASD.

As noted in Criterion B, standardised assessment approaches are preferred. However, it is acknowledged that there may be some circumstances where this is not appropriate. Some examples include (note – non limiting list): individuals

who are extremely low functioning, where forcing them through a standardised tests would not likely produce valid results and may negatively impact their well-being; situations where clinicians in consultation with the individual or their whānau decide that the use of standardised tests are not culturally appropriate; or when assessment of a domain or use of a tool is not appropriate given the persons history such as academic testing of a child who has not engaged in the education context for many years.

Specific examples of measurement tools are not provided, as clinicians should apply their discipline specific knowledge and clinical judgement to determine the most appropriate approaches for the individual attending for assessment, the clinical context and the limits of their own professional expertise. Feedback gathered during the Australian review process indicated that the list of example measurement tools included in the 2016 Guide was sometimes being applied rigidly, which could negatively impact on providing person-centred and culturally responsive assessments. Similarly, concerns have been raised in Aotearoa (NZ) regarding rigid application of measures and diagnostic practices.

Note that descriptions and assessment considerations for the neurodevelopmental domains are provided based on discipline specific guidance from clinicians across Australia and Aotearoa. For example, the previously named 'academic achievement' domain is now 'literacy and/or numeracy' to be target more specifically the impairments considered in this domain (i.e., to clarify that this is not related to general behaviour/ functioning in educational settings).

FASD is a complex and multifaceted condition that is best assessed and diagnosed via an interprofessional framework. As such clinicians are

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encouraged to engage in a collaborative approach to formulating individual cases (e.g. through case conferencing), to bring their relevant scope of practice to the assessment process, and to access clinical supervision to support application of the diagnostic criteria within their skill set and clinical context.

There are many contexts where information may be gathered from a variety of professionals who are located in different services or locations. In this situation care must be taken to ensure assessment results are interpreted with consultation from the professional who collated the data. Furthermore, those who have gathered information need to be able to confirm the interpretation that is contained in the report.

### Assessment of infants and young children

Consistent with the principles underpinning these guidelines and good clinical practice, clinicians should consider the appropriateness of all assessment components to the individual infant or young child and their whānau. As per the diagnostic criteria, infants, or young children with all three facial features, microcephaly, and global developmental delay (as per DSM-5-TR) may be diagnosed with FASD following rigorous consideration of other causes.

Internationally, diagnostic criteria differ regarding whether microcephaly alone meets criteria for brain impairment. Astley (2013) documented that the combined presence of the three facial features and microcephaly was predictive of later significant impairments. However, concerns have been raised regarding the application of such an approach in Aotearoa (NZ) in the absence of documented heavy-to-moderate PAE, given (1) the lack of local tools and norms for facial features assessment, (2) inter-rater reliability issues in assessing facial

features reported in clinical practice, (3) the lack of concordance between microcephaly and functional neurodevelopmental outcomes, and (4) the current lack of research in this area. Given these considerations and that diagnosis is not required to access early intervention in Aotearoa (NZ), a cautious approach is currently recommended at this time.

### Consideration of other comorbid neurodevelopmental conditions

Diagnoses of co-occurring conditions (e.g., ADHD, ASD, anxiety, depression) have not been included in the neurodevelopmental domain table (Table 3). Feedback from Clinical Advisory Group indicated that the inclusion of these as part of the domain table may lead to a 'tick box' approach to diagnosis. Pre-existing diagnoses can provide helpful information regarding current functioning and should be considered when reviewing the available evidence. Clinicians are encouraged to consider an individual's functioning in each of the neurodevelopmental domains based on all the available information and decide if they believe there are clinically significant impairments. Further, as per the co-occurring conditions section listed below the diagnostic criteria, clinicians should provide diagnoses of all relevant co-occurring conditions to support comprehensive understanding of an individual's presentation. If an individual is using medication that may impact functioning, then this must be considered in the formulation and analysis of results and included in the report.

See the co-occurring and differential diagnosis section of this document for further information.

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### Neurodevelopmental domains: evidence for inclusion

Inclusion of domains was based on review of the best available evidence (Hayes et al., 2024). For inclusion as a domain, the available evidence had to demonstrate an association between prenatal alcohol exposure and the neurodevelopmental area. Areas that were not included in the neurodevelopmental domains following review of the evidence were: social cognition, social communication/pragmatics, motor speech impairments, speech-sound impairments, voice disorders, sensory processing, neurological conditions, and seizures. Whilst these areas can still be assessed to inform support needs, they are not included as part of the diagnostic criteria as further research is needed.

Wherever possible adjusted outcomes were used that incorporated consideration of confounding variables. However, the available neurodevelopmental evidence did not often include adjusted outcomes. As such the available evidence often did not exclude the impact of other factors that may also influence neurodevelopmental outcomes. To provide additional examination of the evidence a summary of the studies that included regression analyses was also undertaken (Hayes et al., 2024). Overall, the pattern of results was consistent, whereby after controlling for confounding variables results remained significant at higher levels of PAE.

Extensive discussion occurred across Aotearoa (NZ) and Australia regarding the conceptualisation and complex interplay of the neurodevelopmental domains. This included that some domains can be considered as primary impairments (e.g., intellectual abilities, memory, attention) and some domains that can be considered as more secondary impairments (e.g., academic, adaptive, social).

Detailed information is provided in Table 3 to support clinicians in considering the complex interplay between neurodevelopmental domains in the formulation process.

Creating higher order groupings of the domains was considered and discussed. However, it was decided that this would be introducing another arbitrary element to the diagnostic criteria, which would not currently be evidence based and may lead to the exclusion of certain presentations from this type of grouping system. It was determined at this stage that it is better for clinicians to undertake these conceptualisations at the individual case formulation level. Future research could explore different higher order groups of neurodevelopmental domains and how these work in practice.

Additionally, the conceptualisation of each of the domains individually was reviewed and updated based on available evidence and discipline specific best practice recommendations. A notable change is the previously termed 'affect regulation domain,' which is now 'emotional and/or behavioural regulation.' The evidence available was self and informant reports, of which the most commonly available measure was the ASEBA Child Behaviour Checklist and Teacher Report Form. Thus, the available evidence was focused on symptomatology not presence of psychiatric conditions. Additionally, the possibility of splitting the adaptive and social domain was discussed, however it was determined that further research was also required to inform decision making in this area.

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**Table 3.**

Overview of neurodevelopmental domain definitions and specific assessment considerations

**Domain:**  
**General intellectual abilities (Cognition)**

**Definition:**

Clinicians should apply generally accepted models of intelligence which is often defined to include the capacity for abstraction, to solve problems, acquire new skills. As there are multiple models and definitions in current usage, clinicians are recommended to consider the implications of the model they select and maintain their knowledge of this area.

**Specific assessment considerations:**

- Impairment in this domain may be established through identifying deficits in an underlying general factor of intelligence ('g' e.g., full-scale intellectual quotient) or one or more major subdomains that load on this factor according to established models of intelligence. Examples include, Verbal Comprehension, Visual Spatial Index (visual perception), Fluid Reasoning, Working Memory, and Processing Speed constructs as defined in the Wechsler paradigm or broad and narrow constructs as defined by the Cattell-Horn-Carroll Model.
- If available records indicate a person's presentation is consistent with significant impairments in intellectual abilities this could be indicative of neurodevelopmental impairments across multiple domains. We encourage clinicians to take into consideration an individual's level of functioning when planning the assessment approach.
- Assessment may be limited to nonverbal measures where appropriate.
- Clinicians should consider the impact of any language impairments on measures which include verbal instructions or responses.
- Clinicians are advised that while discrepancy analysis forms a critical part of interpreting test scores in co-normed test batteries, discrepancy analysis and scores are not sufficient in and of themselves to demonstrate impairment.
- Working memory could be included in either this domain or the attention or executive functioning domains depending on whether the scores are considered to be most strongly associated with performance on tests of general intellectual functioning or with the individual's attention and executive functioning performance.

**Domain:**  
**Communication(Language skills)**

**Definition:**

Communication is the means by which we receive and convey ideas, thoughts, feelings etc. to other people. Communication is highly sensitive and varies according to the context in which it takes place (e.g., setting, who the communication partner(s) is, power dynamics, topic, motivations, emotions and many other variables). Culture and communication are intrinsically linked. Language skills refers to the words, syntax, morphology, and pragmatics we understand and use to communicate in oral and written forms.

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This domain focuses on language as a developmental process with which prenatal alcohol exposure can interfere. Although language skill development is sensitive to a range of factors (including other exposures, absence of modelling, hearing difficulties etc.) it can also be disrupted idiopathically. Currently there is no clear phenotype for disordered language skills in the presence of prenatal exposures across the lifespan. Therefore, the domain should be assessed in keeping with best practice recommendations, and with careful attention to this within the specific bicultural setting on Aotearoa (NZ). More information is provided in Appendix B which assessors must consider before choosing assessment methods for this domain and deciding on how the information gained might be analysed and reported, including considering what information may not be available due to the paucity of appropriate tools designed specifically for the New Zealand context.

There is currently limited evidence that other communication disorders (e.g., motor-speech, speech sound, and voice disorders etc.) are associated with or attributable to prenatal alcohol exposure. Therefore, such other communication disorders will not contribute to a FASD diagnosis but are important to the overall clinical profile and treatment of a client and should be characterised and documented in reports, with recommendations made as appropriate.

**Specific assessment considerations:**

The points below mirror the guidance provided in the Australian FASD Diagnostic Guidelines and will be relevant to some children, young people and adults whose communication will be assessed in New Zealand as part of a FASD or related assessment. However, please note the information given in Appendix B relating to current concern expressed by some in the New Zealand context about the suitability of language assessment and diagnostic frameworks that have not included Indigenous knowledge or perspectives and have been derived by researchers and clinicians who rely on Western and medical models and terminology relating to language, communication and impairments. Given that there are ongoing discussions relating to developing Aotearoa (NZ) specific approaches to the assessment and diagnoses of conditions relating to language and communication that take a bicultural perspective, it will be necessary to bear those considerations in mind currently and update these guidelines over time.

- Criteria should be considered met if the individual's language is found to be disordered. Please note that the term 'disordered' is not always an acceptable term to all the populations who may be participating in assessment and advice and care will be required to ensure appropriate framing and terminology is used. It will be essential that careful consideration is given to other possible explanations that may explain or contribute to the way the person is communicating and results of any testing must be triangulated e.g., hearing difficulties, lack of exposure to the language forms targeted by the testing, suitability of the tests for the person being assessed. A Dynamic Assessment approach is likely to be useful to ensure assessment findings are consistent and valid.
- Assessment should be according to principles of best practice that has been adopted in many countries as highlighted by Bishop et al. (2016; 2017) , but bearing in mind the points expressed above about the potential limitations and possible unsuitability of such an approach for some individuals being

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assessed.

- Specifically, it should consider that disordered language is heterogenous, and a thorough assessment should examine the principal dimensions of language:
  - Phonology (where indicated and considered linguistic in origin, though phonology should not solely contribute to meeting the criteria)
  - Syntax/Morphosyntax
  - Word finding and semantic knowledge
  - Pragmatic language
  - Discourse/narrative
- Verbal learning/memory (if best attributable to communication skills than memory abilities)
- Functional language skills must also be considered as part of the assessment (e.g., how the person performs in everyday meaningful tasks).
- Evaluate the prognostic indicators for poor outcomes resulting from disordered language.
- Terminology should not distinguish between 'expressive' and 'receptive' subtypes as these are not categories that are considered stable over time.
- Impairment in pragmatic language skills is a type of language disorder (see Statement 11, Bishop et al., 2017) and should be considered within the Communication domain.
- If an individual meets criterion for FASD and disordered language is identified, the appropriate diagnosis is 'Language Disorder associated with FASD/PAE' (as per Statement 6; Bishop et al., 2017).
- domains depending on whether the scores are considered to be most strongly associated with performance on tests of general intellectual functioning or with the individual's attention and executive functioning performance.

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### Domain: Motor skills

#### Definition:

Motor skills include general motor abilities and areas of fine motor, gross motor, graphomotor (handwriting) skills and/or visual motor integration.

#### Specific assessment considerations:

- Assessment of more than one aspect of motor skills is recommended to provide an understanding of strengths and challenges in this domain.
- Gross motor impairment may not be detected without a comprehensive assessment of gross motor skills.

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- Assessment could commence with understanding of what is the area of functional motor concern. A dynamic performance analysis can be undertaken to understand where the breakdown in performance is occurring and to help select the most appropriate standardised test or further functional assessments required.
- Assessment should consider performance on standardised tests as well as within a functional context (e.g., handwriting within the classroom, gross motor skills moving around a playground). Information from whānau is important to understand the wide range of motor strengths and difficulties an individual can have.
- There is a need to establish that an impairment in visual motor integration is due to a motor issue and not a visual spatial deficit.
- Graphomotor tasks require learned skills and need to be assessed in relation to opportunity and only after access to relevant intervention.
- Other causes of motor challenges, such as dysfunction of the vestibular system, executive function, musculoskeletal system, or peripheral nervous system should be considered.

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### Domain: Memory

#### Definition:

Memory includes ability to encode, store and retrieve information. It has traditionally been conceptualised as including declarative (explicit) and procedural memory. Explicit memory may be further subdivided by modality (verbal, visual) or the type of information including episodic memory (personal events and experiences) and semantic memory (knowledge of factual information; Mujawar et al., 2021).

Memory may be assessed through performance on free recall, cued recall (immediate, delayed) and recognition tasks.

The available evidence for the impact of PAE did not include procedural/implicit memory tasks or separate the impact of PAE on different stages of memory (encoding, storage, retrieval). However, the foundation of a sound memory assessment requires that these be assessed to provide a comprehensive understanding of an individual's memory challenges, to identify memory disorders, and to inform targeted supports.

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### Specific assessment considerations:

- Consider the interplay between attention, language skills, intelligence, executive functioning and memory; and based on test performance what the best explanation is.
- The memory domain does not include working memory, which is generally considered under the general intellectual abilities and/or executive functioning domains.
- Consideration should be given to memory abilities across settings (including but not limited to home, education, work, and community), to accurately represent any deficits and their functional impacts.
- It may be appropriate for clinicians to also assess prospective memory (i.e., remembering to perform a specific action in the future, at a particular time or in response to a specific event) to assist in understanding an individual's day-to-day functional memory problems.
- In considering prospective memory, clinicians should consider the multi-dimensional nature of this ability including any impact of the individual's executive abilities (Ji et al., 2021).

### Domain: Attention

#### Definition:

There are many models of attention, however a commonly used framework is to conceptualise attention as having the following components:

- Selective (i.e., focusing on a particular stimulus);
- Sustained attention (i.e., attending for longer periods of time with resistance to distractions);
- Distractibility (i.e., susceptibility to distractions).

Attention refers to both auditory and visual modalities. The available evidence for the impact of PAE did not demonstrate differences between auditory and visual attention. Therefore, it is advisable to assess attention using the method most appropriate to the individual.

### Specific assessment considerations:

- Depending on the individual's presentation during the assessment of attention and their performance on language skills, memory, and executive function assessment; more basic attentional processes (i.e., visual scanning, immediate attention span) could be considered as part of the attention domain while more complex attention processes (e.g., inhibition, dividing, shifting/switching) could be considered as contributing to other domains (executive functioning, communication, memory, literacy/numeracy) as appropriate.
- As with all domains it is important that hearing and vision is ascertained to be in the typical range before assigning this domain.
- Challenges with visual scanning could have an oculomotor control origin and this could be further explored if clinically indicated.
- Consider the potential impact of prescribed medications (e.g., stimulants), level of engagement/rapport, and whether formal testing was conducted in a quiet room without distractions.

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### Domain: Executive Functioning (EF)

#### Definition:

There is no universally accepted definition of executive functioning and similarly no universally accepted models of executive functioning.

Executive functions are traditionally defined as higher-order cognitive functions including initiation, inhibition, mental flexibility, novel problem solving, planning, emotion regulation, and self-awareness, all of which are needed for adaptive goal-directed life functioning (Sira & Matee, 2014).

Among the many conceptualisations of EF that clinicians may find helpful for characterising the individual and differentiating functions within domains is the distinction between hot (i.e., reward or affective-related, high emotional arousal during decision-making) versus cold (i.e., purely cognitive) domains of EFs. There are many abilities that fall under the cold EF umbrella; however, core skills are better assessed by formal tests and include (and are not limited to): response inhibition (e.g., inhibitory control), cognitive flexibility, updating (i.e., self-monitoring, working memory), shifting (i.e., switching flexibly between tasks or mental states), planning and problem-solving. Hot EFs, can include processing of information related to reward, emotion, and motivation, and can be better assessed via clinical history, questionnaires, or direct observation (Salehinejad et al., 2021).

### Specific assessment considerations:

- Capabilities and deficiencies in EF are best captured through a combination of formal tests, domain specific questionnaires and semi-structured interviews.
- Consideration should be given to performance of EF across settings (including but not limited to home, school, work, and social engagement), to accurately represent any deficits and their functional impact.
- Individuals with severe EdF may have limited insight and awareness into their cognitive and/or functional difficulties and may not be able to accurately represent their level of functioning. In such instances, convergent information from a reliable informant should be sought (e.g., via informant questionnaires).
- For older children, adolescents, and adults EFs are generally considered as multi-factorial, including different inter-related and inter-dependent skills that act within an integrated top-down control system.
- For young children some research has indicated that EFs could be considered as a unitary concept that only differentiates as children age. There is discrepancy in available research regarding specific ages at which differentiated EF skills have been found to emerge (e.g., can vary from 6 to 12 years depending on study methodologies). Clinical judgement is required to determine if multi-component assessment of EF skills is beneficial based on an individual's presentation.
- Depending on assessment results, emotion driven (reward, arousal, affective based) EFs may be considered under the behavioural regulation domain.
- if clinically indicated.
- Consider the potential impact of prescribed medications (e.g., stimulants), level of engagement/rapport, and whether formal testing was conducted in a quiet room without distractions.

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### **Domain:** **Emotional and/or behavioural regulation**

#### **Definition:**

Could include significant difficulties with any of the following:

- mood (internalising symptoms such as depression or anxiety, negative affect)
- emotional regulation (e.g., irritability, low frustration tolerance, mood lability, suicide threats, where this is not the direct impact of another aetiology).
- behavioural regulation (externalising behaviours could include rule-breaking behaviour [e.g., confabulation, taking things that belong to others], oppositional/ non-compliant, behavioural outbursts, and reactive aggressive).

#### **Specific assessment considerations:**

- The frequency, intensity, severity, and duration of the behaviour must be disproportionate and/or inappropriate for the context and developmental age of the individual.
- The behaviour must be persistent over time and across contexts, though may present differently due to the nature of specific contexts; and the behaviour does not only occur in response to specific life circumstances. Where required, re-assessment can be recommended to be able to determine whether these behaviours are persistent in nature.
- Consider the individual's available historical information and what may be the best explanation for the current presentation (e.g., whānau history, postnatal exposures, and adverse childhood experiences). Parental substance use may be associated with an increased genetic and environmental risk for emotional and behavioural regulation problems.
- Consider whether the individual has had access to evidence-based treatments and how well they have responded.
- Involvement with the criminal justice system should not be used as evidence of significant impairment in this domain as a variety of criminogenic factors could lead to involvement with justice that are not related to an individual's impairments.
- Emotional/behavioural regulation impairments should only be considered diagnostically when there is sound evidence to suggest they are due to the direct effects of PAE or secondary effects of the disabilities that have arisen from PAE.

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### **Domain:** **Literacy and/or Numeracy**

#### **Definition:**

Literacy (reading, writing, and spelling) and/or mathematics skills).

#### **Specific assessment considerations:**

- This domain should only be considered towards a FASD diagnosis when individuals have had access to appropriate levels of education and evidence-based interventions in the learning environment that target academic skills and for which the person has not responded in such a way as to indicate effective remediation.
- Consideration must also be given to an individual's educational placement (e.g., mainstream, educational support class, special school) and opportunities (e.g., remote location, multi-lingual setting, new immigrant) and the type and level of supports provided.
- It is possible that impairments in literacy and/or numeracy could be a direct consequence of PAE or a functional consequence of the combined impacts of impairments in other neurodevelopmental domains (e.g., intellectual abilities, communication, attention, memory, executive function). As such, clinicians must carefully consider whether literacy and/or numeracy deficits independently contribute to the person's neurodevelopmental profile when formulating against the diagnostic criteria.
  - For example, if significant attention impairments are identified it is recommended, they are treated before retesting to determine if impairments in literacy and/or numeracy are also present.

### **Domain:** **Adaptive/social functioning**

#### **Definition:**

Collection of skills that people learn to enable them to function in their daily lives in accordance with cultural and societal expectations of their functioning. This can include concepts of money and time, activities of daily living (personal care), occupational skills, safety, health care, travel/transportation, schedules/ routines, interpersonal skills (e.g., quality of peer relations and challenges in social interactions), social responsibility, gullibility, naivety, suggestibility, or social problem solving.

#### **Specific assessment considerations:**

- Consider any formal and informal supports the person may be receiving and how this may influence ratings of their adaptive/social functioning.
- Consider different expectations and skills required at different developmental stages.
- Consider level of exposure to different adaptive and social opportunities and differences that can exist across different communities (e.g., urban vs rural and remote settings).
- Consider direct functional assessments of adaptive and social skills, as well as informant rating scales.
- Consider the functional impacts of language skills and pragmatic language skills on social functioning communication and social problem-solving abilities.

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# Good Practice Statements: Neurodevelopmental Assessment

The following good practice statements (GPS) have been prepared to support the assessment process.

- X** Comprehensive assessment across neurodevelopmental domains with a view to explaining identified developmental and behavioural challenges is beneficial. However, there are times and situations where this may not be feasible, achievable and/or appropriate. In such instances it is appropriate for the clinician to determine the depth and breadth of assessment needed for determining if clinically significant impairments exist and if they are sufficient to meet diagnosis.
- X** It is important to take into consideration the overlap (i.e., shared variance) between neurodevelopmental domains and often complex, multifaceted interactions between environment and neurodevelopment. Interpretation of assessment results requires a gestalt/holistic approach. This includes understanding the validity of measures applied to different groups of people, how different neurodevelopmental domains interact and fit together, and considering the wide range of factors that influence neurodevelopmental outcomes (e.g., other prenatal and postnatal exposures and events) to provide the best possible understanding of an individual's presentation.
- X** Convergence of information across different assessment methods is important to overcome limitations of any single method. Different methods can include naturalistic observational, functional assessment, direct testing, collecting information from different informants (e.g., self-report, parents or other whānau members, teachers, work colleagues, support workers, treating professionals).

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- X** It is advantageous to assess neurodevelopmental domains concurrently. However, at clinicians' discretion, previous assessments may be used as deemed clinically appropriate (e.g., in situations where impairment levels are unlikely to have changed and current assessment is unable to be completed due to current significant behavioural challenges). The decision to retest an individual at any time interval will depend on the context, referral question and the individual's needs.
- X** In considering re-assessment, practitioners are reminded to be mindful of the complexities involved in reliably re-testing individuals; particularly, the influence on test performance that comes from direct practice effects, individual task paradigm familiarity, and the individual's positive or negative habituation to the testing paradigm and environment. Practitioners are also reminded of the complexities in empirically characterising reliable changes in an individual's performance on specific tasks across time. The decision to retest an individual should always be based on clinical reasoning.
- X** There may be situations where previous assessment results and diagnostic outcomes can be used to inform clinical decision making regarding whether an individual is experiencing clinically significant impairments in specific neurodevelopmental domains. This needs to be based on the existence of impairments in the relevant domains from available assessment information and consideration of the person as a whole. Critically, this also needs to consider better explanations for an individual's presentation (e.g., whānau history, lack of educational access, severe environmental neglect).
- X** Assessment will naturally vary based on the availability of resources. Where services are not available to meet the needs of an individual's assessment in a single service setting, engagement with other services through a shared-care approach is suggested to support accessibility of assessment and diagnostic services.

Importantly, please refer to assessment guidance in Section 2.3 Whānau/Whanaungatanga/Whakawhanungatanga and Hui Process and Meihana Model to ensure a holistic process and responsive practice for whānau Māori.

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### Criterion C: The neurodevelopmental impairments necessitate significant supports

It is important to demonstrate the connection between the neurodevelopmental impairments, the impacts on functioning and the need for supports. Initially, this criterion (Criterion C) was framed from the perspective of DSM-5-TR conditions, whereby impairments needing to result in clinically significant distress. However, based on feedback from the Advisory Groups, it was recommended for this criterion to be consistent with a social model of disability. Therefore, this criterion is framed from a support perspective, as if appropriate supports are provided this should facilitate a person's day-to-day functioning and ameliorate distress. As per other neurodevelopmental diagnoses, clinicians are required to use their clinical judgement to determine if a significant level of support is required, given the individual's level of impairments. Care should be taken to ensure that this determination is based on the level of impairment and not due to other contextual factors (e.g., whānau, school or community factors that influence functioning).

### Criterion D: Onset of neurodevelopmental impairments in development

It is important that this criterion does not impact on adults accessing assessment and diagnosis. This criterion should not be interpreted to mean

that specific assessment results are required from the early developmental period for diagnosis of adults. Rather, that the overall pattern of available evidence indicates that impairments were present in the developmental period and, that impairments are not a decline in abilities or due to life circumstances or events. Information from previous assessments can be used as support for Criterion D, if they are available.

### Specifiers: Sentinel facial features

The review of current diagnostic criteria indicated that nearly all current diagnostic criteria only permit diagnosis without confirmed PAE in the presence of three sentinel facial features. The two diagnostic criteria that included two facial features (i.e., Revised IOM and CDC) stated that criteria had been changed to two facial features to improve the sensitivity of diagnosis, however there was no evidence included to support this change. There were also no studies identified through the evidence review that provided support for a change from three facial features to two facial features. Future research is required to further understand the potential diagnostic utility of such a change. The inclusion of facial features as a 'specifier' aims to support documentation of facial features along the full continuum, enabling monitoring and future evaluation.

#### Palpebral Fissures

Short palpebral fissures are still defined at  $\leq$  3rd percentile (i.e.,  $\leq$  2 SD). There was limited evidence available and comparison across different percentile cut offs was not possible. Current implementation factors were considered, where

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the University of Washington facial analysis software, applies  $\leq$  3rd percentile definition of short palpebral fissures. Thus, changing this definition without appropriate tools to support practice could create significant barriers for clinicians. Importantly, as discussed in the assessment principles section, clinical cut-offs are arbitrary, physical features occur on a continuum. The inclusion of facial features as specifiers aims to enable clinicians to document the continuum of the facial features and utilise this information in diagnostic decision making.

Due to the small number of studies and lack of reporting of the normative charts used in the available research, the evidence review was not able to examine the impacts of different palpebral fissure reference values on diagnostic outcomes. There was also limited research available that had investigated comparisons between the available palpebral fissure normative charts. In a retrospective comparison of U.S FASD clinical data, Hemingway et al. (2019) observed that switching to the Clarren charts at 6 years resulted in an artificial decrease in short palpebral fissures. In the only Australian study to examine this, Tsang et al. (2017) found that the Strömmland et al. (1999) norms were the best fit from the norms available for a sample of Aboriginal children from one Australian community. Currently there are no studies from Aotearoa (NZ). Based on this limited information available the Strömmland, charts are recommended for use across the lifespan. However, concerns were raised across Australia and Aotearoa (NZ) regarding the lack of local norms for assessing palpebral fissure length.

#### Lip and Philtrum

The University of Washington lip/philtrum guides were the most commonly used in the available evidence and are recommended for continued use. Clinicians are required to use clinical judgement to decide which lip/philtrum guide is the most applicable for use based on the individual's physical features (i.e., Guide 1 Caucasian or combination of ethnicities with features most similar to Caucasian or Guide 2 African American or combination of ethnicities with features more similar to African Americans). As per the palpebral fissures section we lack locally developed lip/philtrum guides and the appropriateness of these tools for the Aotearoa (NZ) context is an important consideration for future research.

#### Assessment of facial features for individuals from culturally diverse backgrounds

Concerns were raised regarding the lack of local norms and lip/philtrum guides for the assessment of people from diverse ethnic backgrounds in Australia and Aotearoa (NZ). Clinicians are encouraged to use shared decision making with individuals and families attending for assessment to provide information about the limitations of the current norms and tools available in Aotearoa (NZ), so that people can make informed decisions about their assessment process. The wording of Criterion A.2 that facial features "may be considered sufficient" is to reflect that inclusion of facial features in Criterion A is not a requirement for diagnosis if not deemed appropriate, following consultation with individuals and families.

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### Specifiers: Head circumference and physical size restrictions

Based on review of the best available evidence, physical size ≤ 10th percentile (i.e., weight, height/length, and head circumference) are included in the diagnostic criteria. However, as noted in the diagnostic criteria it is recommended practitioners report the specific measures, which would also include reporting 5th percentile and 3rd percentile ranges to enable reporting of the full continuum of these features. Also as described in the assessment principles section measurement error, interpretation of norm charts in the context of ethnicity and assessments over time (where available) should be used to ensure this is not applied as a rigid clinical cut-off.

### Other associated conditions

There was insufficient evidence for the associated features listed on page 43 to be included in the main diagnostic criteria. Information should be collected regarding the presence of these features/conditions as they can provide vital information to inform individualised referrals, treatment, and ongoing supports. Future research is required to better understand potential associations of these features/conditions with PAE.

### Reasoning regarding structural brain abnormalities

Based on a review of the best available evidence, prenatal alcohol exposure is associated with a range of structural brain abnormalities. However, research documenting these abnormalities is predominately based on advanced quantitative MRI findings. Available data from routine clinical MRI (i.e., qualitative radiological MRI) does not currently provide diagnostic utility. Therefore, at this stage, abnormal clinical MRI results are recommended to be recorded as other associated medical conditions. This still supports recording and consideration of available results in the assessment process but does not include these results as part of the neurodevelopmental domains, based on the available evidence.

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### Reasoning regarding other neurological conditions

A review of the best available evidence indicated there was insufficient evidence to understand the association between prenatal alcohol exposure and other neurological conditions. Therefore, at this stage other neurological conditions are recommended to be recorded as other associated medical conditions. Some of the Clinical Advisory Group members also highlighted that the genetic basis of seizures is an emerging area of research and would require review for future reviews of the diagnostic criteria. This still supports recording and consideration of neurological conditions in the assessment process but does not include these conditions as part of the neurodevelopmental domains, based on the available evidence.

### At risk of FASD

Feedback gathered has indicated that the 'at risk' designation has been a helpful option for clinicians to have available. Specifically, it was discussed how this option can support access to early intervention and encourage review when children are older to determine if a diagnosis is appropriate. In Aotearoa (NZ), access to early intervention does not require a diagnosis, but rather presence of developmental delay. Therefore, an 'at-risk' designation in these cases should not impact access to early intervention. Rather, it would allow for more time and careful consideration to be applied in consideration of whether a lifelong diagnosis would be appropriate.



Notably, concerns were also raised that the 'at risk' designation can be inappropriately used and that this can lead to inequities for individuals and families. For example, across different settings where resources and clinical capacity can differ. Clinicians are encouraged to use shared-care approaches with other clinicians/providers to support additional assessment and diagnostic pathways in low resource settings and access clinical supervision as required.

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# Good Practice Statements: Medical Assessment

As described in the assessment principles section, it is critical a comprehensive medical examination and detailed history is completed as part of the assessment process. Specific good practice statements are provided below for the key areas of facial, other dysmorphic features and physical health conditions, physical size (including head circumference) and genetic testing.

The following good practice statements (GPS) were developed based on the available literature and with input from clinicians to support assessment of facial and other dysmorphic features, physical health conditions and assessment of physical size, including head circumference:

- X Practitioners should consider the appropriateness of all parts of the medical assessment for the individual and their whānau and ideally collaborate with individuals and families to make decisions about what the assessment will involve.
- X Use the University of Washington (UW) Lip-Philtrum Guide. This is the Lip-Philtrum Guide currently used in clinical practice in Aotearoa (NZ) . Guide 1 is recommended for use with individuals who present with a less full lip/philtrum and Guide 2 is recommended for use with individuals who present with a fuller lip/philtrum.
- X Use the Strömmland et al. (1999) palpebral fissure norms. This normative sample spans from birth to adulthood and are recommended for use.
- X Use the University of Washington facial analysis software to measure palpebral fissure length and/or take and assess measurements by hand using a small, clear plastic ruler if you are not able to use the facial analysis software.
- X Examine and document the presence of additional dysmorphic features of the face and the body. This includes history of major birth defects of the cardiac, renal, neurological, visual, auditory, and skeletal systems.

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- X Consider other syndromes/genetic conditions as part of the differential diagnosis. Dysmorphic features can occur in many other syndromes/genetic conditions. Look for signs suggestive of syndromic diagnosis. If there is any uncertainty regarding differential diagnosis, refer for review by a clinical geneticist.
- X Following informed consent and assent, a chromosome microarray (CMA) and DNA test for fragile X syndrome (FXS) can be requested. CMA and FXS testing can be performed using blood or buccal swabs according to local health service guidelines. Refer to your local genetic health service if any concerns are identified as a result of CMA/FXS testing.
- X Medical professionals can request a range of further tests as clinically indicated to help support understanding of current functioning (e.g., thyroid functioning, vitamin B12, iron studies and imaging).
- X Physical size can vary across the population due to a wide range of demographic, maternal, placental, and fetal factors. Identifying and differentiating what is a typical physical size should be based on a combination of medical assessment and consideration of relevant individual risk factors. Over-reliance on growth charts alone, without consideration of wider contextual information may pathologize typical variation or miss children in need of support.
- X Assess birth weight, length and head circumference of full-term infants using the WHO (2006) growth standards. This information can be collected from the birth record or baby's personal health records (e.g., red, blue, or yellow books).
- X Assess birth weight, length and head circumference corrected for gestational age of preterm infants. Gestational age correction is completed until the baby is 24 months of age.
- X Consider differential diagnoses for individuals who are outside of the norms for height, weight and/or head circumference, and investigate appropriately.

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*Note: All Implementation considerations within this document were drafted in the "Australian Guidelines for Assessment and Diagnosis of Fetal Alcohol Spectrum Disorder or Neurodevelopmental Disorder Associated with prenatal Alcohol Exposure (Australian Guideline Development Group, 2024)" and applied to the Aotearoa (NZ) guidelines in accordance with available evidence and input from stakeholders and clinicians.*

### Implementation considerations: accessing the UW lip/philtrum guide

More information about the University of Washington Lip-Philtrum Guides is available from the FAS DPN website, including instructions regarding how to order electronic versions: <https://depts.washington.edu/fasdpn/htmls/lip-philtrum-guides.htm>

### Implementation considerations: accessing the UW facial analysis software

More information about the University of Washington Lip-Philtrum Guides is available from the FAS DPN website, including instructions regarding how to order a copy of the software, how to take and analyse the photos. <https://depts.washington.edu/fasdpn/htmls/face-software.htm>

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### 2.11 Feedback and Post diagnosis support

#### Feedback and disclosure of diagnosis

Individuals and whānau have unique strengths and challenges which need to be considered in how assessment and diagnostic feedback is delivered and post diagnostic supports established. There needs to be a balance between providing a realistic understanding of the challenges, but also a strength-based focus to maintain a sense of hope (Baskin et al., 2016). Professionals should aim to support the individual and whānau understand factors that increase the risk of the individual experiencing challenges, what factors are maintaining the current difficulties, and the influence of contextual and systemic factors. Acknowledging these factors and working to whānau strengths is key to supporting their agency, recognising and moving past stigma, and striving for equity for their whānau member (Le Va, 2009; Pitama et al., 2017).

Assessment feedback is best delivered face to face as individuals and whānau need time to consider the information and space to ask questions. Use of teleconferencing facilities should be considered when geographical location is a barrier. Including wider whānau, key support people, and community providers can be helpful to increase a shared understanding of the support needs for the individual and whānau.

Providing visual aids during an FASD assessment feedback helps the individual and whānau to focus their attention, process the meaning of what is being shown and discussed, and allows them to refer back to it as needed. Whānau have reported feeling overwhelmed by too much information at an emotional time. Professionals must communicate findings in plain language, where possible highlighting how assessment findings correlate with the information provided by whānau and key people. Supporting the whānau to understand their whānau members strengths and challenges based on the assessment information, and what this may look like in the home/education/work and community context (e.g., based on the individuals' skills with statements such as..., he/she would do well with tasks that...). This is providing feedback with aroha and manaakitanga, taking care to support whānau understanding and bringing the report to life, helping them to see how it applies to their unique context (Hayes et al., 2022).

A post-feedback check in is an important part of the diagnostic process as it provides time to follow-up with relevant resources and to address further questions and reaffirm a shared understanding of what the assessment and diagnosis represents (Ola et al., 2020). Providing a tailored resource with relevant contact details supports the individual and whānau to connect to post diagnostic support, where possible including established FASD networks that can facilitate contact with others with similar experiences

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# Good Practice Statements: Feedback and Support Planning

The following good practice statements (GPS) were developed to guide the formulation, feedback and support planning process:

- X Bring together information from the assessment to create an individualised holistic profile. This should summarise the key developmental factors. It is best if practitioners from different disciplines review this information.
- X Consider all possible causes or conditions, including prenatal and postnatal factors, that might be influencing developmental outcomes.
- X Consider, offer, and explain one or more diagnostic possibilities, summarising what is most likely, after considering what is less likely or unlikely, given the individual's presenting concerns and assessment findings.
- X Practitioners should be aware of diagnostic overshadowing (i.e., where an individual's mental health concerns are attributed to the primary diagnosis rather than to a concurrent psychiatric condition) and provide diagnoses relevant in explaining an individual's presentation to facilitate targeted treatments and supports.
- X Practitioners should consider how their own background, training and unconscious biases might influence their diagnostic decisions. For example, they may be overestimating what is attributable to trauma and underestimating what is attributable to alcohol or vice versa.

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- X Actively include the individual attending for assessment and their whānau in involve individuals and whānau in diagnostic decisions. Individuals and whānau have the right to decide if diagnoses are appropriate for them, given their personal, social, and cultural context and beliefs. Sometimes, challenges can arise balancing the rights of the child and the rights of the parent/caregiver, but actively engaging and supporting all parties throughout the assessment can help to overcome these challenges.
- X Individuals attending for assessment should be provided with developmentally appropriate feedback regarding the assessment and diagnostic outcomes. This feedback can be delivered with whānau and key support people present. Done well, the feedback is tailored to the individual's needs, highlighting their strengths and areas of challenge, with time dedicated to discussing what the individual and whānau see as the area/s of most need requiring immediate support.
- X Recognise that observed challenges might have multiple explanations and communicate this to individuals and families to enable effective supports.
- X Actively include individuals, whānau and key support people in the support planning process. Professionals should support the individual and whānau to identify the areas most important to them, where they would like support, and in what form that support needs to be provided given their personal, social, cultural context and beliefs (providing relevant strategies, and linking them with service providers that are available in their community or nationwide).

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### Post-diagnosis support

**Support for the individual and their whānau should follow an FASD assessment and diagnosis. The following model promotes holistic well-being and can be used across cultures (Henderson, 2023; outlined in Box 1 (p34))**

### Ko Au/Self

Assessment findings can provide useful strategy's that align with the individual's strengths and challenges. These strategies need to be framed holistically and provide a roadmap to help promote learning and manage emotional/ behavioural challenges. A person living with FASD can benefit and be empowered with the understanding of how their brain and body works if it is communicated in a way that makes sense to them (see brain domains visual resource). As mentioned above, communication needs to be tailored to the individual's style of learning. Visual resources such as a social story developed about their strengths and challenges can be a useful way to help the individual and their whānau understand how best to support them, adapting their environment to maximise success. Understanding that repetitive movement activities such as colouring in, bouncing a ball, and walking, can help an individual to calm when triggered, to support their brain to learn, and cope with challenging situations ('bottom-up' brain processing, by Bruce Perry).

The assessment may recommend specific interventions to support development. This may include referrals to health, education and disability services. Within a health setting, they may see a medical practitioner if a trial

of medication is suggested (GP, Paediatrician, Psychiatrist). Other professionals such as Speech-Language Therapists, Occupational Therapists, Psychologists, Physiotherapists, Mental Health Clinicians, Special Education Advisors, Resource Teachers of Learning and Behaviour, Adult and Community educators may be involved as needed. Transition to employment support may be provided by schools or MSD-funded services, however, where accessible Whaikaha NASCs may also provide supports such as behaviour management, respite, advocacy and transition to employment, as determined by a needs assessment.

### Whānau

As outlined in Box 1 (p. 34) whānau play a crucial role within the individual's life. Support involves providing whānau with FASD informed education to help them adapt the environment and their response to their whānau member's needs. Professionals can facilitate discussion of what supports are in place and what is needed to support the primary carer/whānau, including considering who else in their whānau can provide support and in what way. Cultural and social connections are a key part of holistic support.

### Whanaungatanga

Individuals and whānau may need support at a community level. Professionals with an understanding of what is available locally can provide key information and contacts across health, disability, education, employment, social development and justice services. A holistic assessment will identify these wider needs and

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provide a pathway for access. For whānau Māori, the Meihana Model identifies historical and current societal influences such as colonisation, racism, migration and marginalisation as well as specific components from Te Ao Māori that may support well-being.

Often a multi-disciplinary approach with health, education, social development and justice, provides effective support following diagnosis. Whānau identified that navigating these systems is exhausting and confusing especially for families who experience extra stressors such as mental health, addiction, housing needs and financial stress. Connecting individuals and whānau with a navigator/co-ordinator to advocate and guide the family has been identified as a priority (Flannigan et al., 2021). In some areas in New Zealand there is an identified FASD co-ordinator. If this is not available then the professionals involved need to engage with key people and/or agencies providing support, to identify local community or iwi organisations who may be able to provide navigational services such as Whānau Ora (indigenous health initiative in Aotearoa (NZ), driven by Māori cultural values to empower communities and whānau to determine their own holistic health and wellbeing)). The goal is for whānau to be supported to identify the priorities that are important to them, highlighting their immediate and longer-term needs.

Whānau have identified the need for schools/ educational institutes/employers to be FASD informed. The Ministry of Education is responsible for the training and professional development of their staff. Professionals undertaking the FASD assessment and those supporting the whānau can provide wider feedback so key support people working alongside the individual

with FASD can understand the learning and behavioural implications of a FASD diagnosis. If their individual profile suggests that they need specific accommodation in certain settings e.g., court, then these needs must be clearly identified and supports put in place to ensure equity and access to a just process.

### Whakawhanaungatanga

The assessment should also identify what deeper connections will help the individual and whānau to establish a sense of tau/calmness especially when experiences of trauma, anxiety and other mental health difficulties are also present. Whakawhanaungatanga is found in many forms be it connecting to nature or building deeper support networks. Identifying what an individual and their whānau enjoys will help provide a roadmap for connection.



# Resources

Information about FASD can be found on a number of websites and other sources. Please note that terminology about FASD may differ from websites. Also, information on resources, services and support from international websites may not be available or relevant in Aotearoa (NZ)/NZ settings. Information was current as of 15th December 2023.

## Aotearoa (NZ), Frameworks and Resources

### **FASD-CAN | <https://www.fasd-can.org.nz/>**

An Aotearoa (NZ) website that provides FASD information, education, support, advocacy and connection. The website has information and resources for parents, carers and whānau, adults living with FASD, and professionals supporting those with FASD. For members of FASD-CAN a very useful caregiver toolkit is provided. See [https://www.fasd-can.org.nz/the\\_handbook\\_caregiver\\_toolkit](https://www.fasd-can.org.nz/the_handbook_caregiver_toolkit)

### **Fetal Alcohol Network New Zealand (FANNZ) | <https://www.ahw.org.nz/Issues-Resources/Fetal-Alcohol-Spectrum-Disorder>**

An Aotearoa (NZ) website that comes under the umbrella of Alcohol Healthwatch. FANNZ's focus is on FASD prevention and intervention, along with advocating for change through up-to-date evidence-based information.

### **Ministry of Health (Manatū Hauora) | <https://www.health.govt.nz/your-health/conditions-and-treatments/disabilities/fetal-alcohol-spectrum-disorder-fasd>**

Provides information on FASD, with a focus on prevention. Has links to external websites such as FASDCan.

### **TKI (Te Kete Ipurangi) Inclusive | <https://inclusive.tki.org.nz/guides/>**

A Ministry of Education website that offers information and resources to support the learning and well-being of students including those with FASD across all levels of the curriculum.

### **Oranga Tamariki | <https://practice.orangatamariki.govt.nz/our-work/disability/practice-when-working-with-disabled-people/fetal-alcohol-spectrum-disorder-fasd-and-neurodiversity/>**

A website resource for Oranga Tamariki practitioners for guidance on their work with tamariki and their whānau and has a section that focuses specially on FASD.

### **Te Whare o Oro | (McLachlan et al., 2023) | <https://teatawhai.maori.nz/te-roro/>**

A mātauranga Māori framework for understanding brain structure and development through the metaphor of the whare tūpuna (ancestral meeting house).

### **Whānau pack – Tools for families and parents with Teenagers | <https://www.northlanddhb.org.nz/assets/Your-Health/NDHB-Whanau-Pack-ED2-v2.pdf>**

Developed by Dave Hookway-Kopa for Northland DHB this pack provides parents with tools to communicate with their teenager with a focus on alcohol use and impact.

## International Websites, Frameworks and Resources

### **FASD Hub | Australia <https://www.fasdhub.org.au/>**

An Australian website that provides general evidence-based information and resources to health professionals, parents and carers, researchers, policy makers and the general public.

### **National Organisation for Fetal Alcohol Spectrum Disorders Australia (NOFASD Australia) | <http://www.nofasd.org.au>**

An Australian website that provides information and training to increase knowledge and awareness about FASD. Has information and resources for parents, carers and families, along with Adults with FASD. Also has information for service providers.

### **CanFASD – Canada FASD Research Network <https://canfasd.ca/>**

A Canadian research network that translates research knowledge into community policy and action. Has information and resources for parents, carers and families, along with Adults with FASD. Also has information for professionals supporting those with FASD.

### **KnowFASD | <https://knowfasd.ca/>**

A Canadian interactive website that allows a person to consider the neurobehavioural impacts that may appear through the lifespan of individuals with FASD. KnowFASD was developed by CANFASD.

### **National Organisation for Foetal Alcohol Syndrome – UK | <http://www.nofas-uk.org/>**

A UK website that provides support to people with FASD, their families and communities; campaigns to raise public awareness; and promotes relevant policies and practices. Has information and resources for parents, carers and families, along with adults with FASD. Also has information for professionals supporting those with FASD.

### **Me & My FASD | <https://fasd.me/>**

A UK website for young people with FASD, created by medical professionals, teachers, parents alongside an advisory team of adults and young people with FASD. Has interactive content and downloadable resources for people living with FASD and their parents and caregivers.

### **FASCETS | <https://fascets.org/>**

A website that offers education and training to parents/carers, educators and professionals on the Neurobehavioural Model. The model was developed by Diane Malbin and reframes behavioural symptoms of FASD in a manner consistent with research.

### **Edmonton Fetal Alcohol Network | <https://edmontonfetalalcoholnetwork.org/>**

A website offering useful resources for FASD prevention, assessment, intervention and supports. A useful handbook 'Strategies not Solutions' can be found at [https://edmontonfetalalcoholnetwork.org/wp-content/uploads/2019/02/strategies\\_not\\_solutions\\_handbook.pdf](https://edmontonfetalalcoholnetwork.org/wp-content/uploads/2019/02/strategies_not_solutions_handbook.pdf)

### **The Neurosequential Model in Education | (Perry, 2019) | <https://www.neurosequential.com/nme>**

A model that utilises brain mini-maps (arranged to reflect brain organisation) to rate students across different brain domains to highlight strengths and challenges.

# Section 3: Recommendations & Next Steps

The scope of this project was to develop a Guideline for the Diagnosis of FASD. However, a successful implementation of these diagnostic guidelines will require extra resourcing to provide practical resources, training and supervision. Clinicians will have varying knowledge and understanding of FASD, cultural safety, neurodevelopment and trauma. If clinicians have not completed training or education in FASD then ongoing supervision is required if these guidelines are to be utilised. The following have been identified as essential initiatives to ensure diagnosis is clinically and culturally safe.

- Establish diagnostic resources. This would include but is not limited to; assessment templates, summary handouts e.g., (good practice statements, referral/informed consent questions) and whānau feedback resources.
- Offer general FASD education to increase understanding before beginning specific diagnostic training.
- Training clinicians in Aotearoa (NZ) FASD Diagnostic Guidelines. Offer a series of workshops adapted for different contexts e.g., health, justice, education, adult mental health and disability services, alongside post workshop clinical and cultural supervision.
- Review of the Guidelines to incorporate implementation learnings and new research evidence.

Other limitations included the scope of consultation. This guideline development project sought to prioritise whānau voice to ensure meaningful and safe assessment and diagnosis of FASD. We have centred whānau as tāngata whenua represented in Te Tiriti o Waitangi. However, the next step would be to seek endorsement from hapū and iwi to guide how this work would best serve their communities and how they could be involved in supporting whānau with diagnosis.

It is imperative that effort is focused on providing resources and ongoing support of individuals and whānau living with FASD. The recommendations found in Table 4 are in response to concerns and discussion points raised at wānanga across 2022 and 2023. These recommendations give direction for future service development and research.

**Table 4:**

Recommendations for future service development and research.

Discussion Points	Recommendation
Lack of clear diagnostic pathways	Stakeholders were clear that there is a lack of clear diagnostic pathways and inequity of access occurs between regions. To solve this the Ministries of Health, Education, Justice and Corrections, need a commitment to increasing capacity and access to assessment diagnostic services.
Critical Tiriti Analysis findings and Stakeholder engagement themes highlighted the need for cultural safety, especially considering the workforce using the guidelines will be largely non-Māori.	<p>Establish a workforce development plan to fund and support tāngata Māori clinicians and professionals to provide this guidance.</p> <p>Fund training and cultural supervision for clinicians applying the guidelines.</p> <p>Create a centre of excellence which incorporates:</p> <ul style="list-style-type: none"> <li>· Provision of clinical and cultural supervision to support clinicians’ cultural safety including training, supervision.</li> <li>· Ongoing research and development.</li> <li>· Clinicians need to have personal responsibility and form relationships within their own Māori health services or in their community.</li> </ul>
Other Critical Tiriti Analysis Findings include.	<p>For a state of Mauri Ora to occur the Ministry of Health would:</p> <ul style="list-style-type: none"> <li>· Fully honour its responsibilities to reduce the inequitable harm from alcohol for Māori.</li> <li>· Reset the levers that it has in its control, influencing other Ministries to do the same.</li> <li>· Advocate for restrictions in the sale and/or at the very least advertising and education about the impact of exposure prenatally to the unborn child.</li> <li>· Commit to providing training and cultural supervision to all practitioners who will utilise the guideline to ensure the competency both clinically and culturally of all practitioners.</li> <li>· Commit to funding those with an FASD Diagnosis at the same levels as those with other diagnosis.</li> <li>· Commit to engaging in a consultation process with iwi and hapū regarding FASD.</li> <li>· Commit to reviewing the guideline every three years.</li> </ul>
Guidelines need to be in te reo Māori.	Fund translation of guidelines into te reo Māori. Te reo Māori is an official language and ensuring a translation will serve the population in Aotearoa (NZ) where Te reo Māori is their first language.
Justice sector considerations	This diagnostic guideline is written from a health perspective and there is extra implication for the justice sector. For example, in the justice sector there are specific reasons an assessment is important e.g., fitness to stand trial, sentencing considerations. Diagnostic and assessment considerations that are specifically related to the justice sector needs to be considered by those with Forensic expertise and funded by justice rather than health agencies.

### Section 3: Recommendations & Next Steps

Table 4:

Recommendations for future service development and research.

Social development sector considerations	Diagnosis and assessment in the social development sector will require specific consideration especially in the areas of consent for the assessment and feedback and reporting. These considerations will require expertise from those working in the social development and care and protection system.
Education sector considerations	Currently FASD assessment occurs mostly in the health sector via public or private organisations. However, there may be opportunity for assessments to occur via collaboration between health and education. The education sector needs to consider how individuals with complex neurodevelopmental challenges such as FASD are identified, understood and supported through their education journey.
Lack of assessment pathways for adults.	Most FASD assessments in the public systems are in child and youth services. Access to adult FASD assessments is important to ensure the individual's needs are understood and supported appropriately.
Lack of post diagnosis support	Stakeholders were very clear that there is an overwhelming need for post-diagnosis support. Detailed guidelines for this support were outside the remit of developing diagnostic guidelines therefore a further project to establish post-diagnosis support is important for individual well-being, whānau and education, support.
Communication and reports given to whānau are often difficult to understand.	While some resources have been developed within the distinct context of Aotearoa (NZ) e.g., Te Whare o Oro, there is a need for more whānau friendly resources. This includes resources to help explain FASD to children, young people and adults who live with FASD. Clinicians also reiterated that developing resources suitable to the context of Aotearoa (NZ) would be useful for communicating assessment results.
Co-ordinated services across agencies and sectors	Individuals and whānau are connected to many agencies and services. Co-ordination of this support is key and whānau stated that having one person as a co-ordinator/navigator/advocate would make a large impact to their whole whānau well-being.

### Section 3: Recommendations & Next Steps

Table 4:

Recommendations for future service development and research.

Increasing knowledge and practice	<p>Fund and co-ordinate community based FASD informed training across sectors and agencies.</p> <p>Include FASD informed practice in professional training programs such as:</p> <ul style="list-style-type: none"> <li>· Teacher Education</li> <li>· Psychology</li> <li>· Medical training</li> <li>· Speech-language therapy</li> <li>· Occupational therapy</li> <li>· Physiotherapy</li> <li>· Social work</li> <li>· Counselling</li> <li>· Law</li> <li>· Police</li> </ul> <p>Professional groups need to take responsibility for FASD informed training and guidance.</p>
Reduce the impact of stigma	Stigma can be a barrier for diagnosis and support both for the whānau and the individual living with FASD and also for professionals who may be reluctant or biased to diagnose or not. Further work is required to reduce the impact of stigma by considering the language that is used and how training is delivered in teaching programmes and the community.
Lack of data/information from Aotearoa (NZ)	Establish a national data base to understand the needs of those living with FASD in Aotearoa (NZ).
These guidelines require implementation and evaluation.	Pilot and review implementation of the guidelines. This would ideally happen across agencies and within both public and private sectors.
Norms for sentinel facial features to not reflect the distinct context of Aotearoa (NZ).	Establish norms which are applicable to Aotearoa (NZ).

# Section 4: Evaluation

These Guidelines have used a Critical Tiriti Analysis (Came et al., 2023) and the Grading of Recommendations, Assessment, Development and Evaluation system (GRADE; Schünemann et al., 2013) as evaluative tools.

## 4.1 Critical Tiriti Analysis

Haami Harmer (Ngāti Kahungunu) completed a Critical Tiriti Analysis (CTA) in December 2022 and December 2023. The intent of this analysis was to offer commentary on the aspiration of the Project Team to, “ground the development of Aotearoa (NZ) New Zealand diagnostic guidelines for Fetal Alcohol Spectrum Disorder (FASD) within Te Tiriti o Waitangi.” The following is a summary of those assessments. Further detail can be found in The Critical Tiriti Analysis Report.

According to the CTA framework, the assessment of the project in December 2022 rating was FAIR – score two (2) whereas in December 2023 the rating increased to EXCELLENT – score four (4).

### Combined CTA and Mauri rating

	Dec 2022	Dec 2023
Article One – Kāwanatanga	3	4
Article Two – Rangatiratanga	2	3
Article Three – Ōritetanga	2	2
Wairuatanga	2	3
Māori Final Word	2	4
<b>Combined Score of</b>	<b>11</b>	<b>16</b>

In December 2022 we applied the combined score of 11 to the Mauri Scale proposing that the guidelines attained a state of Mauri piki (between 8 – 12).



In December 2023 we applied the same methodology where the combined score of 16 to the Mauri Scale was attained elevating the state of Mauri to Mauri oho (between 13 – 17).

The increase to a state of Mauri Oho, reflects the notion that the Aotearoa (NZ) diagnostic guidelines for Fetal Alcohol Spectrum Disorder (FASD) are grounded within Te Tiriti o Waitangi. Therefore, the project team has attained the aspiration they set in 2021.

Due to the limitations of funding, scope, time and personnel the attainment of a state of Mauri Ora was always beyond the capacity of the project team to achieve. For a state of Mauri Ora to occur the Ministry would have to influence other Ministries and advocate for restrictions in the sale and/or at the very least advertising and education about the impact of exposure prenatally to the unborn child. As a society we need to acknowledge that FASD is preventable and impacts the lives of whāiora, the whānau and the community throughout their life span.

## 4.2 GRADE evaluation for clinical criteria

The Australian FASD Diagnostic Guidelines Review used the Grading of Recommendations, Assessment, Development and Evaluation (GRADE; Schünemann et al., 2013). The GRADE system developed to rate quality of evidence and strength of recommendations. In Australia, GRADE is used in the development of Guidelines that seek National Health and Medical Council (NHMRC) approval. Recommendations derived using the GRADE system are based on assessing the quality of the evidence which includes; study limitations, inconsistency of results, indirectness of evidence, imprecision, reporting bias (Guyatt et al., 2008).

Evidence to Decision Framework criteria forms the basis of recommendations and includes the following considerations:

- Priority of the problem
- Benefits and harms
- Certainty of evidence
- Values and preferences
- Resources
- Equity
- Acceptability
- Feasibility

The section below details GRADE based diagnostic recommendations based on evidence to decision frameworks and other considerations. Where there was not enough certainty of evidence good practice statements were developed by the Australian Guidelines Development Group and reviewed by the New Zealand Clinical Advisory Group and Steering Group.

Section 4: Evaluation

4.2.1 Connections between the evidence and the diagnostic recommendations

The Assessment Principles and Diagnostic criteria section outlines the associated evidence to decision frameworks that have informed the development of the diagnostic criteria. Table 5 provides a summary of GRADE-based recommendations for the diagnostic criteria. Further detail about how the GRADE approach has been applied can be found in the Supplementary Files detailing GRADE Ratings and meta-analyses in the Australian Technical Report (Hayes et al., 2024) and Appendix B: Summarised versions of the evidence to decision frameworks (Australian Guideline Development Group, 2024).

**Table 5.**

Summary of GRADE-based recommendations for the diagnostic criteria (Australian Guideline Development Group, 2024).

**GRADE-based recommendations**

The Australian Guidelines Development Group suggests that birthweight corrected for gestational age according to the appropriate age- and sex-specific charts is included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Low to Moderate Certainty).

The Australian Guidelines Development Group suggests that birth length corrected for gestational age according to the appropriate age- and sex-specific charts is included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).

The Australian Guidelines Development Group suggests that postnatal weight according to the appropriate age- and sex-specific charts is included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).

The Australian Guidelines Development Group suggests that postnatal height according to the appropriate age- and sex-specific charts is included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).

Section 4: Evaluation

**GRADE-based recommendations**

The Australian Guidelines Development Group suggests that philtrum smoothness, vermilion thinness, and palpebral fissure length are included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).

The Australian Guidelines Development Group recommends against including minor dysmorphic features in the diagnostic criteria for FASD/ND-PAE (Strong Recommendation, Very Low to Low Certainty).

The Australian Guidelines Development Group suggests that head circumference corrected for gestational age according to the appropriate age- and sex-specific charts is included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).

The Australian Guidelines Development Group recommends against including structural brain abnormalities as observed on clinical imaging in the diagnostic criteria for FASD/ND/PAE (Strong Recommendation, Very Low Certainty).

The Australian Guidelines Development Group recommends against including neurological conditions of hearing and vision impairments, seizures, and cerebral palsy in the diagnostic criteria for FASD/ND/PAE (Strong Recommendation, Very Low Certainty).

The Guidelines Development Group suggests that neurodevelopmental outcomes of communication, motor skills, general intellectual abilities, attention, memory, executive function, emotional and/or behavioural regulation, literacy and/or numeracy, and adaptive/social functioning are included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).





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

2024

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# Glossary

<b>Ahau</b>	I, me.
<b>Āhua</b>	Personalised indicators (From Te Whare Tapa Whā model (Durie, 1997).
<b>Aotearoa (NZ)</b>	Māori name for New Zealand.
<b>Aroha</b>	Compassion, love, empathy.
<b>Hapū</b>	Kinship group, clan, tribe, subtribe.
<b>Hauora</b>	Health, healthy, fit, well.
<b>Hononga</b>	Union, connection, relationship, bond.
<b>Hinengaro</b>	Psychological/emotional (From Te Whare Tapa Whā model (Durie 1997), mind, thought, intellect, consciousness, awareness.
<b>Hui</b>	Meeting.
<b>Iwi</b>	Extended kinship group, tribe, nation, people, nationality, race.
<b>Iwi katoa</b>	Access to quality health service (From Meihana Model, (Pitama et al., 2017).
<b>Kaimahi</b>	Worker, employee.
<b>Kanohi ki te kanohi</b>	Face to face, in person.
<b>Kaupapa</b>	Matter for discussion, plan, purpose.
<b>Kāwanatanga</b>	Government, dominion, rule, authority.
<b>Ko au</b>	Self.
<b>Koha</b>	Gift, present, offering, donation, contribution.
<b>Kupu Reo</b>	Māori word.
<b>Kotahitanga</b>	Unity, togetherness, solidarity, collective action.
<b>LGBTQIA+</b>	Acronym used to cover a wide range of diverse sexualities and gender identities and expression, and intersex variations.
<b>Mahi</b>	Work, job, employment.
<b>Mahi tahi</b>	Work together as one.

<b>Mana</b>	Essence, presence, status, authority.
<b>Manaaki</b>	To support, take care of, give hospitality to, protect, look out for.
<b>Manaakitanga</b>	Hospitality, kindness, generosity, support - the process of showing respect, generosity and care for others.
<b>Māori</b>	"Māori, Indigenous New Zealand, Indigenous Person of Aotearoa (NZ)/New Zealand – a new use of the word resulting from Pākehā contact in order to distinguish between people of Māori descent and the colonisers" (Te Aka Māori Dictionary, 2023). "Can refer to a wide range of people of varying ethnic compositions and cultural identity" (Greaves et al., 2015, p. 541) and encompasses diverse Māori realities (Durie, 1995).
<b>Mātauranga Māori</b>	The body of knowledge originating from Māori ancestors, including the Māori world view and perspectives. Māori creativity and cultural practices.
<b>Mauri</b>	life principle, life force, vital essence, special nature.
<b>Mihimihi</b>	To greet, greeting, speech of greeting.
<b>MVPFAFF+</b>	An acronym that refers to the diverse gender and sexuality expression and roles across Pacific cultures.
<b>Ōritetanga</b>	Equality, equal opportunity.
<b>Ōtatahi</b>	Christchurch.
<b>Pacific Peoples</b>	An overarching term used to describe people whose ancestral heritage originates from a number of Pacific Island nations in both Polynesia and Melanesia (Bisley, 2008, cited in Ataera-Minster et al., 2018). "Pacific peoples may also be recent migrants, long settled in New Zealand, or New Zealand born" (Ministry of Education, 2022, Pacific and Pasifika terminology, para. 3).
<b>Pacifica</b>	A generic term used to represent many Pacific Island cultures: Samoan, Tongan, Cook Islands Māori, Fijian, Niuean, Tokelauan, and Tuvaluan (Singh & Zhang, 2018).
<b>Pasifika</b>	Refers to Aotearoa (NZ) as home, but continue to have family and cultural connections to Pacific Island Nations.
<b>Pākehā</b>	English. Foreign. Introduced from or originating in a foreign country. New Zealander of European descent "New Zealander of European descent – probably originally applied to English speaking Europeans living in Aotearoa (NZ)/New Zealand." (Te Aka Māori Dictionary, 2023). New Zealand Europeans. Māori term for the descendants of the early white settlers (Sibley et al., 2011).
<b>Papatūānuku</b>	Earth, Earth mother and partner of Ranginui - all living things originate from them.

<b>Pono</b>	Be true, valid, honest, genuine, sincere.
<b>Poroaki</b>	To take leave, farewell.
<b>Rōpū</b>	Group.
<b>Taiao</b>	World, Earth, natural world, environment, nature, country.
<b>Takatāpui</b>	"A traditional Māori word that traditionally means 'intimate friend of the same sex'. It has since been embraced to encompass all tāngata Māori who identify with diverse genders, sexualities or variations of sex characteristics. Takatāpui denotes a spiritual and cultural connection to the past. It is best understood within its cultural context and may mean something different to each person" (Inside Out, 2021, p.10).
<b>Tāngata tiriti</b>	Translated means 'tiriti (treaty) people' and is defined as "all people who came to Aotearoa (NZ)/New Zealand under the authority of Te Tiriti o Waitangi" (Treaty Resource Centre, 2007, p. 8).
<b>Tāngata whaiora</b>	A person seeking health (Luckman et al., 2022).
<b>Tāngata whenua</b>	Local people, hosts, Indigenous people – people born of the land. Used to describe the Indigenous peoples of Aotearoa (NZ)/New Zealand. A direct translation of the term 'tāngata whenua' is 'people of the land' (Hond et al., 2019; Te Momo, 2021). The relationship between Māori and land is understood as Māori 'belonging' to the land, rather than 'owning' it (Kingi, 2008).
<b>Tāmaki Makaurau</b>	Auckland.
<b>Tautua (Gagana Samoa)</b>	A servant, to serve, to be of service.
<b>Tāwhirimātea</b>	God of the weather (Te Ara 2024).
<b>Te Ao Māori</b>	The Māori world or Māori world view.
<b>Te Papaioea</b>	Palmerston North.
<b>Te reo Māori</b>	Māori language.
<b>Tikanga</b>	Correct procedure, custom, habit, lore, practice, protocol.
<b>Tika</b>	To be correct, true, upright, just, fair, accurate, appropriate, lawful, proper, valid.
<b>Tinana</b>	Physical body (From Te Whare Tapa Whā model (Durie 1997)).
<b>Tino rangatiratanga</b>	Self-determination, sovereignty, autonomy, authority.

<b>Te Tiriti o Waitangi</b>	An agreement between tāngata whenua and British Crown signed in 1840. "a treaty outlining the relationship between Māori and the British Crown that affirmed the rights of Māori" (Wilson et al., 2021, p. 3540), signed in 1840 by representatives of the English crown and iwi.
<b>Wairua</b>	Spirituality/beliefs.
<b>Wairuatanga</b>	Spirituality.
<b>Waka hourua</b>	Double canoe.
<b>Wānanga</b>	Discussion.
<b>Whakakotahitanga</b>	Unity, unification, to be united.
<b>Whakamutunga</b>	End, concluding, final.
<b>Whakapapa</b>	Genealogy, lineage, descent.
<b>Whakataukī</b>	Proverb, significant saying.
<b>Whanaungatanga</b>	Relationship, kinship, sense of family connection.
<b>Whakamana</b>	To be mana enhancing. To give authority to, give effect to, give prestige, empower.
<b>Whakatere</b>	Navigation, to steer, navigate.
<b>Whakawhanaungatanga</b>	Relationship building.
<b>Whānau</b>	Family, family group.
<b>Whenua</b>	Land, country.

Unless otherwise stated meanings of Māori words are taken from Te Aka Māori Dictionary (2024)

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# Appendix A: Neurodevelopmental assessment considerations

## Summary of challenges with use of percentiles for clinicians to consider in their practice.

Percentiles are a simple metric for conveying test information. However, as described by Crawford, Garthwaite and Slick (2009), there are several challenges clinicians should be aware of:

1. There are different definitions of a percentile. These include the percentage of:

- scores that fall below the point at which a given scores lies in a specified distribution.
- scores that fall at or below the point at which a given score lies in a specified distribution.
- half the scores that fall at or below the point at which a given score lies in a specified distribution.

2. The difference between percentiles obtained with these definitions can be marginal or considerable, which in turn impacts interpretation of the individual's score in an assessment. Contributors to this include:

- size of the normative sample
- whether the range of scores in the normative sample is narrow or wide
- the nature of the test or measure (having few items or many items)

3. Percentile ranks are essentially point estimates, which depending on the normative sample may carry a small to large level of fallibility. As with all point estimates, the level of uncertainty/certainty should be clarified by using confidence intervals (interval estimates such as 95% or 90%), that quantify the uncertainty.

4. The performance rating of an individual suspected of a condition of interest (such as FASD) under the normative data constructed from a sample of people without the condition of interest, can be vastly different to the performance rating when compared to normative data constructed from people with the condition of interest. Unfortunately, normative data sets for FASD samples are not currently available, and so calculating the probability of clinical group association is not possible. Therefore, clinicians cannot be certain that a given percentile on any assessment measure defines the presence or absence of FASD.

## Summary of considerations suggested by Guilmette et al. (2020) that clinicians may benefit from considering with determining impairment.

- Normal intra-individual variability and frequency of low scores in normal populations. Important to note that having low scores is common in healthy individuals and the more scores that are derived the higher likelihood that low scores will occur.
- The convergence of shared versus unique variance among tests. Assessment tools have unique and shared variance. That is, they will have contributing elements that represent overlapping and discrete functions. It is important that clinicians understand these features of the tools they are using and take into consideration the impact of unique and shared variance when interpreting scores from the tools they are using.
- The characteristics of the normative/comparison standard (e.g., demographically stratified versus general population versus clinical group norms).
- Performance and symptom validity.
- Test engagement and rapport.
- Cultural factors and diverse backgrounds (e.g., primary and additional languages, literacy skills, level and quality of education, familiarity, and comfort with testing situation, testing biases, communication style).
- Emotional and medical conditions, medications, current substance use, physical and cognitive factors.
- High scores or the lack of low scores, do not preclude the determination of functional limitations or 'impairment.' Conversely, low scores do not necessarily indicate functional impairment; consideration of context is required to make such determinants.
- The functional relevance of the finding in the context of the referral.
- Environmental and tasks demands as well as supports that ameliorate or mitigate the neurocognitive or neurobehavioural capacity and how these changes singularly and together over time.

# Appendix B: Communication assessment considerations

## Thank you to Sally Kedge and Tracy Karanui-Golf for providing the following guidance.

Anyone undertaking assessment of the communication domain must thoroughly consider the unique cultural and linguistic context of Aotearoa (NZ) and understand the historical and contextual factors that mean that carrying out language and communication assessment and drawing conclusions about a person's profile of communication skills here may include considerations and practices that are different from what may occur in other countries.

In recent years, many Western countries have adopted terminology relating to language assessment and diagnostic frameworks that have been derived from research and practice from predominantly English-speaking-only contexts where Western medical models of diagnosis and intervention have dominated. Many of these contexts operate different funding processes and criteria for access to support for speech, language and communication compared with the New Zealand context.

Consideration of Indigenous perspectives and frameworks of knowledge were not included in the development of the current dominant models utilised in language and communication research and in some clinical practices relevant to the diagnosis of FASD and related conditions. Although the assessment practices, research, diagnostic models and related terminology being utilised in many parts of the world may have relevance in the Aotearoa (NZ) context, there has not yet been sufficient consideration of how these may be culturally relevant and safe to use within the bicultural context of New Zealand and alongside Indigenous methodologies and conceptual frameworks, particularly when Māori whānau are participating in assessment and diagnostic processes.

Western conceptualizations of language, cognition, and educational processes often contrast the normative with the disordered. Te Ao Māori frameworks instead consider function against domains of well-being. Well-being can be within the person (hinengarō, wairua, ngākau) or external (taiao, whānau). Characteristics of personality and behaviour can be associated with characters of atua, whakapapa or whānau rather than a deficit or disorder of specific domains.

These issues have not been ignored in New Zealand and the speech-language therapy community and the New Zealand Speech-language Therapists' Association, including Māori members have been exploring how best

to proceed, but there is yet to be clear consensus on what assessment processes and diagnostic frameworks and terminology may be most appropriate for Aotearoa (NZ). Te Tiriti considerations require Māori to decide what will be right for Māori whānau and it is essential for methodologies and conceptual frameworks to serve all the relevant populations well. The methods used for assessment of communication, the analysis, framing and reporting of the resulting information must be carried out in ways that are acceptable and useful to Māori whānau and practitioners.

Non-Māori practitioners who may not have sufficient understanding of the relevant cultural considerations and may not have the relevant knowledge of te reo Māori, Māori tikanga or Mātauranga Māori knowledge need to seek specialised cultural support and guidance before embarking on assessment of a person who has Māori whakapapa. Language (reo) is considered a taonga (treasure) in Māori culture, emphasizing its significance and value. Therefore, when addressing issues related to communication skills, it's crucial for clinicians to approach the pathologization of these skills with great care. They must strive to integrate Western scientific methodologies with frameworks that hold meaning for Māori whānau.

Clinicians should avoid marginalizing Māori families by not carrying out assessments of language and communication due to concerns about deficit-based diagnoses. Such actions only serve to further marginalize these families. Moving forward, clinicians should endeavour to utilize Western scientific approaches alongside Indigenous knowledge systems. This approach can help whānau better understand their communication profiles, rather than focusing solely on frameworks that pathologise their language and communication characteristics. If the person has whakapapa Māori, particular care is essential for considering risk factors that might have relevance for how the person communicates and their linguistic profile and the way their language and communication profile is described to them and in any reports.

Cultural and linguistic consideration about assessment methods, analysis and diagnostic processes and reporting are also relevant for other cultural and linguistically diverse groups in New Zealand, as the tools, resources and current practitioner base is dominated by English-only speaking, Pākehā practitioners.

All practitioners need to carefully consider the unique cultural and linguistic factors relevant to each individual in terms of how they plan, carry out, analyse, and

describe their findings, being mindful about what they may not have been able to explore or verify, and ensuring this is reported carefully too.

Before commencing any assessment of language and communication using tests, explore the person's own views about their language and communication history and experiences. This will include exploring what languages/dialects are relevant to them - what do they say about the languages they and the people who have looked after them use? There might be a range of contexts that will need to be explored to understand their linguistic history relating to the languages they might speak/understand/write/read. This may have varied at different points in their lives e.g., at home/early years/during schooling/in the community. Also, what do the important adults in their lives say about the languages this person might have been exposed to? Bear in mind that sometimes the person who is the key current informant may not know about the person's early life linguistic experiences. It is essential to determine whether they have had only monolingual experiences, bilingual or multilingual experiences before deciding how any assessment of their language and communication profile may need to be carried out using the appropriate materials, tools, speakers of those languages/interpreters etc that relate to their bespoke profile. You will need to consider the impact of the different languages on how the person currently communicates and whether any scores you derive or language samples or communication behaviours observed accurately reflects the person's skills. Consider carefully how you will report the limitations of the process used and information gathered. It may be inappropriate to use standardised tests designed for a monolingual population because they will not accurately provide information about the person's language functioning, and the reporting of standardised scores on a monolingual English language test carried out with a bi- or multi-lingual person is problematic.

Bear in mind that talking about bilingual/multilingual status can be a sensitive and complex topic and is often inaccurately reported on referral forms or in official records and sometimes by the person themselves as the level of confidence or feelings they have about different languages may vary for a range of reasons. The specific dialect or relevant register of a language needs to be explored.

Communication also needs to be considered from a cultural lens. How the assessment is conducted (e.g., how the assessor talks and communicates, in which language,

how the assessor identifies and presents culturally and whether that is similar or different to the person being assessed, where the assessment takes place and what languages and linguistic registers have power and influence in those places, what cultural relevance or experience the person may have of the materials used in the assessment) will all influence how the person may communicate during assessment and what information is then gathered about their linguistic skills. It is essential that the person gathering information about communication is aware of the influence of the multiple complex variables that may have on the way the person communicates. Inaccurate conclusions about their communication profile can easily be reached without a highly sensitive and careful approach.

The assessor should ascertain the person's own views about what they find easy and/or challenging in a range of talking contexts. The person can explore with the assessor who is easy to talk with and why, how they get on when they need to communicate in a range of situations, such as with unknown individuals, older people, younger people, in groups, informal situations as well as situations where there are complex challenges for communication e.g., contexts where listening for a long period to understand linguistically complex information is required or when the person may need to use language for demanding functions such as negotiation, detailed explanation, reasoning, discussing hypothetical situations or abstract, metaphorical language.

The assessor must note what appears to support the person to communicate more easily and what seems to make communication more difficult for the individual. The person themselves may be able to explain the strategies they know help that they might use themselves or they've noticed others using. They may also be able to explain what they know makes communication much more difficult for them. A co-authored communication passport might be a useful resource to develop where the person being assessed and the Speech-Language Therapist or professional undertaking assessment of the Communication Domain develops a one page or short resource that captures the key information about the person's communication and what helps or hinders them in different situations, providing guidance for others about how to support effective communication. The person's own words about their communication profile and the strategies they want included can be used.

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