Whakakotahitanga | Unity

KEY STAKEHOLDER FINDINGS

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.

Te Whatu Ora
Health New Zealand

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

HĀPAI TE HAUORA
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2024

Part II:
Findings from key stakeholders

"I've fought every step of the way for him. I just think he deserves a life just like everybody else" (whānau voice)

The development of these guidelines sought guidance from whānau to ensure their needs and aspirations guide practice as it is whānau we serve. Furthermore, it is our responsibility to uphold Te Tiriti o Waitangi including the right for Māori to determine their own health and well-being: tino rangatiratanga. It is vital that Māori voices are listened to and acted upon so Māori can achieve their own health goals and aspirations. In addition, health practitioners will utilise the guidelines and thus it was also important to gather their perspectives to increase understanding about what is required to operationalise these guidelines. Thus, comprehensive stakeholder engagement was prioritised to form the basis of guideline development. This paper discusses how stakeholders were engaged and the key themes from their input.

1. Stakeholder Engagement Methods and Analysis

1.1 Team

Stakeholder consultation and subsequent analysis of the data was organised by the Aotearoa (NZ) Guidelines Project Team; Sarah Goldsbury (Ngāti Porou, Te Aitanga-a-Hauiti), and Dr. Andi Crawford (Pākehā), Tania Henderson (Ngāti Ruawaipū, Ngāti Porou), Joanne van Wyk (Pākehā), and in collaboration with Hāpai Te Hauora and Research Leads Maria Ngawati (Ngāpuhi, Ngāti Hine, Ngāti Porou) and Dr Felicity Ware (Ngāpuhi). This team was supported by a Steering Group made up of both tāngata whenua and tāngata tiriti individuals with clinical expertise in Fetal Alcohol Spectrum Disorder (FASD), occupational therapy, speech-language therapy, psychology, medical, training and education, Māori cultural guidance, and lived experience of supporting someone with FASD.

1.2 Engagement Process

Wānanga were advertised through clinical and professional networks, FASDCan and other organisations supporting families impacted by FASD. Stakeholders were invited to attend a kanohi ki te kanohi one-day wānanga held on marae in Tāmaki Makaurau/Auckland, Whangārei, Ōtautahi/Christchurch and Te Papaioea/Palmerston North. Wānanga were opened with tikanga (Māori cultural customs) including karakia (prayer) and whakawhanaungatanga (relationship building). This ensured tikanga was respected and set the context for a culturally safe and inclusive environment to encourage a free flowing of ideas and discussion. A short presentation by the project leads, proceeded large and small group discussions. Open group discussions enabled stakeholders to consider and discuss what the most important factors in having an assessment and making a diagnosis for FASD were, along with barriers to diagnosis.

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

1.3 Demographics

We talked to a wide range of stakeholders to guide the development of the first FASD diagnostic guideline for Aotearoa (NZ). Through wānanga, online hui, individual interview, and surveys we were able to hold space for the voices of people with FASD lived experience, their whānau, clinicians, academics, and other supporting workers (such as Speech-language Therapists, Psychologists, Social Workers, Corrections officers, General Practitioners and Occupational Therapists). See Table 1.

Table 1. Demographic Characteristics

Location and date	Stakeholder background	Number Attended
Tāmaki Makaurau/Auckland Te Mahurehure Marae (2 September 2022)	Whānau, clinicians, academics, education, and corrections.	51
Whangārei Te Puna o Te Mātauranga Marae (9 September 2022)	Whānau, clinicians, academics, education and corrections.	10
Ōtautahi/Christchurch Rehua Marae (30 September 2022)	Lived experience, whānau, clinicians, academics, education and corrections.	53
Te Papaioea/Palmerston North Tuturu Pumau Te Hotu Manawa o Rangitāne o Manawatū Marae (28 October 2022)	Whānau, clinicians, academics, education and corrections.	27
Whānau Online Hui 1 (22 November 2022)	Whānau and Professional.	7
Whānau Online Hui 2 (28 November 2022)	Whānau and Professional.	6
Professional Online Hui (December 2022)	Professional.	6
Pasifika Online hui (11 November 2022)	Professional.	5
Professional Interview (online) (21 November 2022)		1
Survey	Whānau, clinicians, academics, education and corrections.	14
	Total	180

1.4 Data Collection

1.4.1 Wānanga

A slide presentation was provided at the wānanga and online hui to outline the focus of the project and whānau voices from a previous project about FASD. The stakeholders were asked to consider and discuss what the most important factors in having an assessment and making a diagnosis for FASD were. Open-ended 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? During the wānanga, the project team took notes for the larger group discussion, while the small group discussions were recorded and transcribed. Stakeholders from small group discussions were also asked to make notes of key points. These were collected, photographed and then included in the field notes.

1.4.2 Online hui, individual interviews and survey

The format for the online hui was similar to the wānanga with a presentation followed by group discussions on the same questions posed at the wānanga. The hui was held in one zoom room and recorded and transcribed. The individual interview also took place online. A short presentation was provided and then the same questions that were presented in the wānanga were posed and discussed. The interview was also recorded and transcribed.

The three surveys were developed using SurveyMonkey software and asked stakeholders open-ended questions similar to those asked at the wānanga. Although adjustments were made for the whānau/caregiver and lived experience questions to ensure a range and depth of experience could be collected. Data from the survey was collected and downloaded from survey monkey software.

1.5 Data Analysis

As all four data streams (wānanga, online hui, interview and survey) provided qualitative data a thematic analysis was conducted to identify common themes. The data analysis process included deep engagement with the data, including repeatedly engaging with the transcripts and photos and where appropriate video recordings to explore emergent themes. Interim findings were shared and explored with the project team. A summary of findings was shared with the Steering Group and Stakeholders who were invited to provide feedback and endorse the summary and the themes identified. These discussions supported the final stage of analyses where the themes were refined to ensure the findings reflected with integrity the messages of whānau and kaimahi from across the data collection points.

A thematic approach to analysis was utilised as it provides a way to identify, analyse and interpret 'patterns of meaning' or themes within the data. It was also suitable for this project as it offers a flexible way to analyse data across multiple data collection sites and methods (Braun & Clarke, 2015).

Four clear themes were identified across all data streams regarding the most important factors in having an assessment and making a diagnosis for FASD. Themes included the importance of whānau engagement, recognition of te ao Māori, development of clinical knowledge and practice, and the need for clear diagnostic pathways and communication.

2. Findings

"Relationships are the most important. If you get that right the rest just flows"
(Professional survey)

2.1 Partnering with whānau

A key theme emerging from the stakeholder engagement process was the importance of partnering with whānau in the FASD diagnosis process. A number of elements to whānau engagement were identified including whanaungatanga, acting with aroha, and in ways that are mana enhancing and empowering for whānau, and taking the time to engage. Also highlighted, was the need to recognise rangatiratanga – whānau sovereignty, and for whānau voice to be heard. A whānau navigator role was also recommended to provide support during and after the assessment process.

2.1.1 Whanaungatanga (Building Relationships)

Whanaungatanga - taking time to build relationships with whānau was seen as fundamental in supporting whānau engagement; "whakawhanaungatanga as the foundation of the guidelines" which "must be maintained or whānau will be lost in the process". Stakeholders also noted the need to be able to communicate in a similar way; to "use and understand their language – this can only be gained through a relationship with the FASD person and their whānau".

There was widespread agreement across the different rōpū on the need to invest time in building relationships with whānau, and professionals needed to be "persistent in trying to engage with whānau – waiting for [right] time and place". While there was also a recognition of limitations such as the "need to make connections but balance with time constraints" suggesting balancing the needs of whānau with practice requirements can be difficult. While whanaungatanga was identified as critical in engaging with whānau a number of stakeholders indicated that it was not present in current practice.

2.1.2 Aroha, Mana Enhancing, Empowering

The need for respect, kindness and aroha was universally highlighted as part of the engagement process. One Pasifika stakeholder commented "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". The need for aroha was succinctly voiced by a whānau member from the whānau online hui (1) who noted "We need someone to ask us if we are ok. It's not hard, you don't have to be an FASD expert to do that." Along with aroha, there was a consistent theme of the engagement with whānau to be mana enhancing and empowering. For example, a whānau member shared "I think it is absolutely crucial that the families are supported in the system they are in and that we are advocating and empowering them with whatever resources are there". While there was a clear need for engagement to be mana enhancing, once again the difficulty under the current system was acknowledged by stakeholders who explained "outcome to be mana enhancing [but] hard with current assessment."

2.1.3 Rangatiratanga (Whānau Sovereignty)

Acknowledging and respecting rangatiratanga (whānau sovereignty) was also raised as important for whānau engagement and the diagnostic process "Tino rangatiratanga is about for whānau-by-whānau approach." Themes of rangatiratanga were reinforced by stakeholders highlighting the need for working in partnership with whānau and ensuring whānau voice in the assessment process. Stakeholders suggested "inviting whānau to co-lead" as a way to enhance building partnerships with whānau.

The importance of partnership was also mentioned by a kaimahi who noted it was important to "see whānau as partners in the assessment process. Listen to what whānau need and who they want to include. But to do this will take time". While the importance of acknowledging rangatiratanga and listening to whānau voice were highlighted by stakeholders, as already discussed, many stakeholders shared that this was not happening in practice. Stakeholders stressed the importance of holistic understanding "Don't create another box. Get to know their story." and highlighted the need to consider a "child and young person's view, voice, emotions after feedback." Unfortunately, many whānau across the different rōpū shared experiences of not being listened to. For example, whānau commented: "I have to repeat [my] story over and over again. I find it really traumatising to have to, and it is the whole thing of I have to do it because nobody will believe me otherwise." Not being believed was a concerning issue that was repeatedly raised across the different rōpū. The importance of professionals engaging with whānau and listening to, and believing, their experiences is highlighted by a whānau member who shared:

> *"Nobody can know what it is like to walk in our shoes because you ... you know just like I don't know what it's like to walk in your shoes, because I don't , but 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."*

Notably the kaimahi from the professional interview raised an ethical issue around consent for assessment when ordered by a judge explaining:

> *"It takes away that person's right to choose whether they go through an assessment process. A young person can't turn up to a YJ [youth justice] assessment without there being a repercussion. So all of a sudden, there's an ethical issue there about who gets to say no."*

Ethical issues around ownership of the assessment report were also raised by a whānau member who commented:

> *"We only ever got to see the report in the barrister's office and the courtrooms, and we weren't allowed to take a copy of it with us because, even though it was about our mokopuna it didn't belong to us, it belonged to the court."*

2.1.4 Whānau Navigator

Stakeholders shared they would like better coordination and a navigator to help facilitate improved whānau engagement and understanding of the assessment process. This would include a "simple way for whānau to find someone to navigate the system, gather information, walk alongside family during and afterwards, ideally an outside of service 'safe' person" as well as "co-ordinated hubs and a connected process [with a] centralised service person". There was recognition that other services have models that could be applied to the FASD process: "you've got other systems where they've got those kind of navigators, or they've got the coordinators, or they've got somebody who is whānau, they can actually kind of bring a lot of information in already". There was a consistent theme of the need for ongoing support "The journey is long and the need for support continues well after that feedback appointment."

2.2 Recognition of te ao Māori

Stakeholders underscored that the guidelines must be centred in te ao Māori. Stakeholders shared the need for the "exploration of te ao Māori practice that helps the pathway forward" along with "strength-based te ao Māori conceptualisation of FASD." As part of having a te ao Māori focus stakeholders, once again, highlighted the need for "whakawhanaungatanga, along with 'kotahitanga/unity,' aroha, and safety." In order to ensure te ao Māori is represented in the guidelines a stakeholder noted the need for "wide consultation with Māori, as to what is important for Māori to have included in the guidelines." Key features of including te ao Māori within the guidelines included upholding responsibilities of Te Tiriti o Waitangi and including mātauranga within the guidelines.

2.2.1 Te Tiriti o Waitangi

There was widespread agreement across both tāngata whenua and tāngata tiriti in the different rōpū, that centring te ao Māori in the guidelines meant upholding responsibilities of Te Tiriti o Waitangi and embedding them within the guidelines. For example, the guidelines need to "embed NZ cultural context/te Tiriti o Waitangi into guidelines" and Te Tiriti o Waitangi should be the "central foundations from which the guidelines spring."

While including Te Tiriti o Waitangi in the process was viewed as critical, there was broad agreement across the different rōpū that Te Tiriti was not reflected in current assessment practice, and the reliance on international guidelines were problematic "given that assessment [practices] are adopted from another country they cannot reflect Te Tiriti." Issues of a lack of equality were raised by stakeholders, for example, "Ōritetanga [equality, equal opportunity] Māori promised the rights of British citizens – yet we cannot get FASD assessment." One kaimahi in response to whether Te Tiriti was present in assessment practice commented:

> *"On the whole, I'd say No! I think individual clinicians try really hard to practice in culturally appropriate ways with Te Tiriti o Waitangi (health) principles in mind, often in larger 'systems' that actually create barriers to doing so (e.g., inadequate resourcing, therefore time constraints on service delivery; totally inappropriate assessment spaces)."*

A number of challenges were raised with the current assessment process. Stakeholders advised that "the guidelines aren't culturally responsive" and assessment tools are not fit for purpose "because some of our questionnaires, [...] they're very 'us' centric aren't they. They are very kind of ethnocentric."

Overall, the rōpū sent a clear message for the need for Te Tiriti o Waitangi to be central in the guidelines and that this was not currently the case. Although caution was raised by one respondent from the professional survey who stated:

> *"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."*

This highlights the need for ongoing training and support for professionals to ensure they are able to practice in culturally responsive ways. One professional survey respondent noted "A sensitive practitioner can easily reflect the Te Tiriti Waitangi, by inclusion and joint participation and decision making."

2.2.2 Mātauranga

The importance of including mātauranga in the guidelines and assessment process was highlighted across the rōpū including "incorporating Māori models of health". Another stakeholder explained the importance of mātauranga for helping whānau understand FASD and its impact stating, "mātauranga Māori helps us to understand ourselves, it makes sense of things that may not make sense. Mātauranga needs to be the lead, clinical knowledge second". Stakeholders suggested that mātauranga could be included in the process by the use of models such as Te Whare Tapa Whā (Durie, 1984) and Meihana model (Pitama et al. 2014), "The "Hui" process and Meihana models could be applied easily to FASD assessments". While "the use of the Māori metaphor he awa whiria (braided rivers) to combine the strengths of the two worldviews into a workable whole" and the use of "atua pūrākau" (explanations/narratives about key deities) were also suggested.

Stakeholders also shared that they would like access to experts in mātauranga to guide them on appropriate application of this knowledge. Stakeholders shared "it's actually important to recognise that there are Māori experts in particular areas and that they are really important to be consulted with. The rōpū also raised the need to "gain mātauranga Māori from a range of whānau, kaumatua etc, to understand what hauora hinengaro looks like and what supporting that looks like for Māori."

Please note that within the themes of recognition of te ao Māori and mātauranga a considerable number of rōpū expressed the need for clinicians to practice in culturally safe and competent ways. These views have been analysed within the development of clinical knowledge and practice section further below.

2.3 Accessibility – Pathways and Communication

Accessibility was another clear theme that emerged from stakeholder consultation. Within this theme the need for clear diagnostic pathways and clear communication were raised. However, a number of challenges were identified including lack of pathways to diagnosis, long wait lists and a lack of post-diagnosis pathways to support. Stakeholders highlighted the need to explain the process and provide practical information in easy-to-understand language. Stakeholders also identified barriers to accessibility including the cost to access assessment services and a lack of knowledge and awareness of FASD by professionals.

2.3.1 Clear diagnostic pathways

The need for clear pathways to diagnosis, both pre-diagnosis and post-diagnosis, was raised across the different rōpū. For instance, "we need to have easier pathways to diagnosis", and "access pathways to FASD specialists." The need to have a referral pathway was also highlighted by a whānau member who noted:

> *"My pre-diagnosis request would be that if anyone health or education says behaviour issues or behaviour problems, that there is a process that immediately asked,'What have you done to work out whether there's neurodiversity including FASD?'."*

Whānau suggested "partnering with the service [which is a paediatric assessment of children involved with the Ministry for children Oranga Tamariki] is an obvious place to start for pathways". Finally, the need for pathways to diagnosis for adults was also raised by a whānau commenting "In terms of getting any kind of cognitive or neurodevelopmental assessment in adulthood, it was really difficult". Whilst professionals also noted the need for ongoing assessment as well as flexibility within assessment practice.

> *"Whānau think the assessment needs to be updated as things are changing, or the assessment is out of date but this isn't always the case. It is a snapshot in time – need to adapt approaches to make recommendations more appropriate for age and stage."*

Currently there is a lack of pathways to obtaining assessment and diagnostic services. This view was evident across multiple stakeholder sites, suggesting this is a key area of concern. For example, a kaimahi explained "When I told [my] colleagues, I'm coming to this today they said 'Oh FASD is just a nightmare here' because access to diagnostic services is so poor." Similarly, the Pasifika group also noted the difficulty of accessing a diagnosis, noting:

> *"The public health system for FASD diagnosis in [DHB] is long and complicated. There is only one psychologist in the disability clinic and the waitlist is long. In [DHB], most FASD assessments are provided by the private sector where the assessment is funded by Oranga Tamariki."*

Long waiting lists was also raised by a number of the rōpū. For example, stakeholders noted that "if you could find a gate," there was "2-3yr wait list for services". Similarly, whānau advised that the "people waiting for [a] diagnosis is quite huge." As a stakeholder stated "it takes too long, then getting supports is an even slower train to arrive." Another whānau member noted "we need more clinicians." Whānau repeatedly raised the difficulty of accessing assessment services. Finally, one stakeholder also pointed out the "lack of support while waiting" suggesting access to diagnosis and assessment services is a critical area of need.

The need for pathways to post-diagnosis support was raised several times. For example, a kaimahi commented "don't stop at diagnosis" noting that there needs to be "access to right fit supports."

> *"You know, people come in and they pour out all their trauma to you. And you go, I'm sorry, I can only see you twice. And then I'm writing a report and I don't know where to send you for the rest of the rebuilding after that".*

Indeed, a number of rōpū commented on the lack of post-diagnosis support "currently whānau read [assessment report] and go what's next? And there is no what next."Whānau advised "post-diagnosis, I would say what needs to happen, again, is more funding into community-based health organisations that can provide the service on the ground and make it obvious where people can go". The value of having post-diagnosis support was highlighted by a whānau member from the whānau online hui (2) who explained "I just happened to stumble across people who become real supports. I think creating spaces for people to kind of connect at that and know where to go."

Throughout the different rōpū it was clear that there were considerable challenges accessing diagnostic and assessment services in both the private and public sectors. For example, stakeholders highlighted that both sectors "needed funding to allow assessment to occur" and noted it is currently a "struggle to deliver services with no dedicated funding." Finally, whānau commented:

> *"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."*

> *Some kaimahi felt a sense of hopelessness in being able to respond to whānau effectively for instance professionals are "controlled by the ones that hold the purse strings and constrained by them".*

2.3.2 Communication

Along with clear diagnostic pathways, communication was a key theme that came up repeatedly across the different rōpū. Stakeholders highlighted that professionals need to clearly communicate the assessment process, in ways that meet the needs of whānau. This includes how and when they deliver information, making sure they use language that is easy to understand, and that they make time for whānau to process and go over the information they have shared.

The need to clearly explain the assessment process was highlighted across the different rōpū. Both whānau and kaimahi noted the need for "good communication so families know what to expect". Others identified the importance of clearly communicating the assessment results. For example, assessment reports need to be "jargon free" and not use "clinical language." While other stakeholders suggested that there needs to be "more communication – more like a chat." Stakeholders also noted the need for language to be responsive to whānau for example "language needs to be relevant to the person and whānau with FASD" acknowledging that it is not just parents and caregivers that professionals are communicating with. Stakeholders said the information also needed to be useful "whānau centric/friendly language is needed, i.e., what does this information mean for my day-to-day life with our FASD person." This view was reinforced by other stakeholders who noted, "it is more important that whānau are listened to and heard than to be schooled in(clinical) language that is not ours." Finally, a whānau member commenting on the assessment report stated:

> *"It's very complex, full of jargon. Even for someone like me, I've got a blinken PhD, I couldn't understand the blinken jargon and we read it about 10 times. And handing it on to others that are the same whether it's educators or whoever. [...] yes, by all means do a complex report, but also do a simple report, a simple summary in plain English would be really helpful with just key points."*

Overall, the need for clear, consistent, easily understood information was a strong theme across the different rōpū. Stakeholders also raised the need for the assessment to provide information of practical use, including providing information on resources and services. Stakeholders advised "professionals need to be upfront with what is available as families often don't know what to ask for in a needs assessment." Also raised by the different rōpū was that information should improve their understanding of their child. For example, one whānau member commented:

> "I only wanted that diagnosis because with that diagnosis I would then know how to deal with it. I knew there was no supports out there, but it was knowing how to deal with what was going on and adapting my parenting to his needs. Rather than him being singled out as that naughty kid or whatever."

A kaimahi shared that assessment should provide:

> "An understanding of the 'why' of their child's behaviour – i.e. linking neuropsychological test results to everyday behaviour (that whānau have shared of their child). Depending on specific situation, diagnosis/assessment may help support a paradigm shift of a child's behaviour from 'won't' to 'can't."

Importantly, a whānau member highlighted the impact that having that information can have:

> "so the new information, which came really quite late for us, was really powerful in thinking about new strategies for us as a whānau. If you know when they're little, you can be given those and, and the whole trajectory can change."

The ability to then be able to share this information to improve other people's understanding of FASD was also raised by stakeholders. It was clear that having access to information and being able to share it with whānau had led to a considerable change in understanding by the whānau:

> "Because 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./ 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 we then got more support."

Providing diagnosis/assessment information also enabled whānau to advocate on behalf of their child. For example, a whānau member commented:

> "It helps to give you the language to advocate. Because the reality is we're always going to have to be advocators. 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.

Stakeholders expressed the need for information to be delivered in ways that met their needs. For instance, a whānau member explained:

> "I think [what] is really important is 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."

This perspective was shared by a whānau member who underscored the importance of professionals considering how they communicate information noting "when they are receiving this kind of life changing information [...] slow it down [...] deliver it differently in different ways and do it more than once.". Whānau also commented "I'm a picture person, so reading a document, like the report with numbers and little graphs. I struggle to read those things. Stakeholders identified that they would like more time with professionals after a diagnosis of FASD has been shared. The impact of receiving a diagnosis was shared by a whānau member who responded in the whānau survey "It took us several days to process that we had the diagnosis (for two children), but also several reads to get a grip with the complexity and volume of symptoms".

A number of stakeholders raised the desire for more than one meeting with the practitioner after the assessment report has been provided. This view was explained by a whānau member who commented, "I would have liked to have had the opportunity to go back and speak to the clinicians a second time." The desire of whānau to have more time and support to understand the assessment report was underscored by professionals from the Pasifika hui who explained:

> "Families say they need more time with explanations and diagnoses – this is not just for FASD but all neurodevelopmental assessments. Once people hear a diagnosis has been given – time stops, and they may find it difficult to listen to what other information is being shared".

While good communication was seen as essential, a number of stakeholders pointed out issues with current practice. For example, stakeholders commented, "can't understand the report" and "too many professionals without a language that whānau understand." Supporting this view, a kaimahi raised the difficulty of communicating a diagnosis of FASD expressing uncertainty of how damaging sharing the diagnosis may be and suggesting that some professionals may appreciate guidance on how to communicate information to whānau around FASD.

> "But to tell her that her children have got FASD will break your heart you know, so it's really difficult. I'm finding it quite difficult and I'm not too sure how to, you know, how to approach that".

2.4 Development of Clinical Knowledge and Practice

Another key theme identified by stakeholders was the development of clinical knowledge and practice. Included under this theme was the need for FASD informed multidisciplinary teams, along with the critical need for cultural safety and competency in clinical practice. The need for a holistic, strengths-based, approach to meet the needs of whānau was also highlighted. To support clinical practice and cultural safety a supervision model was recommended. Once again considerable barriers were identified within this theme including, time constraints, a lack of clarity and consistency around practice and difficulty with information gathering and lack of knowledge and awareness of FASD by professionals.

2.4.1 Coordinated Multidisciplinary Approach

The need for assessment practice to be carried out by a multidisciplinary team was raised by a number of stakeholders who advised "multidisciplinary teams are identified as being important. The specialist skills which are brought are valued in those teams," and that good practice would "ideally be by a multidisciplinary team." Stakeholders recognised the importance of consulting with other professionals "professionals that diagnose [should] liaise with other professionals that can continue to tautoko whānau on their journey." However, the need to support clinicians was also identified by a kaimahi who noted "Support for people carrying out assessment as work is really complex, burnout in this group is high. Need for a team". As already discussed, whānau navigators were recommended as an important role within the team to support whānau not only after the immediate assessment process, but also to ensure ongoing continuity of care.

Unfortunately, the lack of coordination across the services was raised by stakeholder groups. For example, a whānau member highlighted "fragmented services" and stakeholders were in agreement about a lack of coordinated services/roles" or "cross-agency strategy". The lack of co-ordinated services was also mentioned by a kaimahi commenting "there is no sense of continuity across sectors. Youth Justice, Oranga Tamariki. There is a rather siloed and limited way of looking at things". The lack post-diagnosis support was also raised by whānau who explained:

"I actually had a social worker come into work with us and she was from the children's team, and she said I am going to go away, and I am going to contact all these agencies and in the next two weeks we are going to have a wraparound service for you. She came back two weeks later, and she said I am really sorry, but I have contacted everybody. I have exhausted all my resources and there is no help out there for you."

The impact of the lack of services available after a diagnosis was meant some questioned the utility of having an assessment or diagnosis "I suppose I'd rather not have a diagnosis, because to have a diagnosis and then there is nothing else for me. No support, no recognition, and I'm still fighting." This view was also held by another whānau member who stated, "[there is]no point in having more clinicians who can diagnose if you're not going to wrap around them, the varying services that are required to support the whānau to support the child."

2.4.2 Cultural Safety/Competence/ Responsiveness in Assessment Practice

The vital need for culturally safe, competent and responsive clinicians and practice was also identified across all rōpū. For example, stakeholders explained that "all professionals (including psychologists) [should] have cultural competence" "and Tiriti o Waitangi [training]."and be "committed to delivering culturally responsive practice - otherwise 'models and frameworks for cultural responses aren't worked with meaning."

A kaimahi also suggested "consider including having cultural connectors. E.g., Māori Health unit as part of the assessment." To help assist with cultural safety by clinicians and other professionals, stakeholders suggested "the hui process and Meihana models could be applied easily to FASD assessment." They also mentioned "Mahi a Atua, Powhiri Poutama, Te Whare Tapa Wha, Fonofale" and "Te ara Whakamana as an assessment tool."

A kaimahi also raised concerned about non-Māori professionals lacking cultural safety, commenting "the issue is there isn't enough Māori workforce, at the same time, many non-Indigenous professionals may not be culturally competent or provided with a culturally safe environment to work with Indigenous People."

Many of the rōpū commented that current assessment practice lacks cultural responsiveness. Whānau and kaimahi advised that the assessment process "was not fit for purpose [as it is] made for professionals not whānau [and used overseas models and materials." The need for culturally appropriate assessment tools was also identified across all rōpū. For example, the professionals noted "facial feature aspect of diagnosis is limited to Caucasian and African data sets." A lack of culturally appropriate assessment tools was also raised by stakeholders who explained "we have no 'NZ'/Māori norms for our measure [they are] not specific to Māori/Pasifika – Aotearoa (NZ)." A kaimahi also mentioned "A complete lack of NZ cultural context" in current guidelines from Canada and Australia. To acknowledge the current lack of appropriate norms, a respondent from the professional survey suggested that "when assessing Māori, consideration of including an appropriate 'rider' in the report about the limitations of the neuropsychological/psychometric assessment tools when assessing Māori/Pasifika whānau."

2.4.3 Safe Spaces

A number of stakeholders raised the need to carry out assessment in appropriate spaces. For example, one rōpū noted the need to "make [spaces] less clinical, with more ea o i," while other stakeholders commented "ideally in a welcoming space with a good introduction at the start to explain the process and ensure that whānau are onboard." Stakeholders suggested that assessments could be "Done within child's time and place, in their home" as well as "with their whānau safe base." Similarly, a kaimahi shared "I'd go to the marae and meet them at the marae, and I meet them with their support people around them." Stakeholders further highlighted the "need for a culturally safe, Māori-led space to have these tapu [sacred] conversation with whānau". This process links back to the importance of whānau engagement. For example, rōpū suggested the need for the "removal of strict boundaries between professional/whānau-protect mauri, but still create/maintain/protect positive relationships."

The Importance of Ig assessment practice right for whānau was underscored by a kaimahi who shared that assessment practice should provide a "safe journey." The lack of culturally competent/safe assessment spaces and clinicians was highlighted by stakeholders who explained that " ea o Māori was non-existent in diagnostic spaces" further noting that "whānau are forced to move in the foreign world view". Stakeholders noted that assessment practice was often "clinical, cold, no feeling. So should be the opposite – caring, with warmth, feeling, and no judgment."

2.4.4 Holistic

"Let the uniqueness of the child inform our mahi" (Whangārei wānanga)

The need for the assessment process to be holistic, person and whānau centred was a common theme across all rōpū. For example, stakeholders recommended that guidelines be "More holistic – takes into consideration more than just the brain and the body, e.g., wairua", likewise a stakeholder from the Pasifika group mentioned that "the Pasifika Disability research has identified it is important to have a whole family holistic approach". While a kaimahi noted the need to "incorporate models that look at the whole person and their whānau rather than medicalised, individual-focused western model." Unfortunately, across all rōpū stakeholders said current assessment practice does not acknowledge whakapapa. A whānau member advised that a "rangatahi shared there was no emphasis on acknowledging her whakapapa Māori" suggesting more needs to be done to consider the individual from a broader deeper cultural perspective as part of the holistic approach.

The importance of the assessment practice to place the person at the centre of the process was repeatedly raised by stakeholders. For example, stakeholders argued the need for "person before diagnosis." This meant that the stakeholder felt that the assessment process needed to "consider the goals of the person and whānau" and "recognise what whānau need." Stakeholders also noted the need for the guidelines to be "whānau centric" and to view the "child as part of whānau." The need to see the child within the context of the whānau was also raised across rōpū and stakeholders noted the need for "a whānau catered plan for the assessment." Some stakeholders felt that the current guidelines did not provide the opportunity for holistic assessment "I think the guidelines aren't working as people are using them as a tick box. That nuance isn't coming out".

As part of this holistic approach, the need for a strengths-based approach was also frequently raised across all wānanga. For example, stakeholders explained "FASD diagnosis should start with 'strengths,' 'likes' and 'good ats,' 'opportunities' – NOT what's 'wrong' with them." This group also noted issues with current guidelines that use "deficit focused models [with] questionnaires that emphasise deficits not strengths." A concern shared by a whānau member who explained:

"Not just to be deficit focused [...] because all of the strategy is around being strengths based. If you don't know what they are it's very hard to put those strategies into place. So, I think that it's really important that the diagnostic communication also has the strengths-based stuff."

Although all noted the need for assessments to provide an understanding of the challenges a child may face along with strengths. For example, "the primary thing is what's going on for this young person? Where are their strengths? Where aren't their strengths?", suggesting a complete profile of both strengths and challenges is important.

2.4.5 Supervision Model

To ensure effective and culturally safe clinical practice, a number of different rōpū identified the need for a supervision model. For example, a kaimahi suggested:

"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."

Stakeholders noted the need for a review panel noting "if you have a case that you'd worked with colleagues, and you found this and you had the family support, could you take it somewhere that it could be reviewed to see whether it meets the criteria". Supervision and review were also recommended to ensure cultural safety and competency as well. For example, a stakeholder suggested "seek consultation from those that are qualified in both these areas". Similarly, other stakeholders highlighted the need for "monitoring of clinicians regarding Te Tiriti and clinical practice." Stakeholders said, "A Māori practitioner – is needed as part of the assessment practice" and noted "having cultural support as part of assessment teams" is very important.

2.4.6 Barriers to Good Clinical Practice

Along with a lack of culturally appropriate assessment practice and tools, a number of other barriers were identified that hindered good clinical practice. These barriers included time constraints, a lack of clarity around diagnostic criteria, which included a lack of consistency, and difficulty in gathering information. Finally, a lack of knowledge and awareness of FASD was also identified as a barrier to good clinical practice.

Time Constraints

As already discussed, time constraints were evident as barriers in whānau engagement, but they were also highlighted within assessment practice. This included gathering information and putting together the report. This was particularly evident in the Youth Justice sector where the kaimahi explained "for a legal purpose, we're going down a diagnostic route, and you may or may not get the quality of the information that you need at the time because of that time pressure because of why you're needing it." Time to carry out diagnosis was also raised by kaimahi and how this is always a balance "[with the] need to weigh up time and availability to tools, resources". Another kaimahi commented, "I get really frustrated by the system [that] doesn't allow the kind of time to pause and bring it all together" suggesting time constraints impact considerably on the ability to engage with whānau as well as the diagnostic process. This is particularly salient given that, as discussed previously, whānau have identified the need for professionals to allow for more time in the communication of assessment reports, but also clinicians report balancing the needs of whānau with practice requirements can be difficult.

Lack of Clarity and Consistency around Diagnostic Criteria

A number of complexities were raised with the assessment process. Stakeholders described the need for clarity regarding the diagnostic criteria. For instance, a kaimahi commented "Need for clarity around diagnostic criteria – kids are all so different." While other stakeholders asked, "where does sensory processing fit in the diagnostic guidelines," and "what are we measuring under each domain and how do we interpret the crossover between domains?" Professionals noted the need to take into account a number of factors when interpreting the data stating "social, stigma, strength of the whānau, parental exhaustion and stress [...] all of those kinds of nuances where you're interpreting, you're interpreting, as opposed to just, you know, psychometricianing it." Another kaimahi underscored that the "data has to explain the behaviour" and that assessments should not be a tick box exercise:

"And this is where I think the guidelines aren't working as people are using them as a tick box. That nuance isn't coming out, or what looks like something could actually be explained somewhere else. So, the tick box would look at the number and go, right, they've got a memory problem. I've seen reports [...] where it just doesn't actually make clinical sense."

Issues were raised with current clinical practice including a lack of consistency. For example, a kaimahi stated "Not everyone is using the same guidelines ". This view was also shared by whānau and kaimahi where stakeholders noted the "lack of consistency around information, personal information, is the information asked?" The lack of consistency was explained by a kaimahi: "Geography. We are entirely different. We are so multicultural. We have got such a diverse country. And where we work is completely different geographically, culturally, iwi, public/private".

Difficulty with Information Gathering

Other stakeholders identified difficulties with information gathering. For example, stakeholders pointed out the "difficulty of information gathering – hard to get data." "Issues with confirming PAE." Stakeholders also shared difficulty with obtaining the "history of the child and whānau – piecemeal information." The outcome of these issues was highlighted by a kaimahi who commented that it was "difficult to know what to do about cases where there probably is exposure, but confirmation of exposure isn't possible". In response to this problem stakeholders commented "Need sharp, effective screening processes" while another stakeholder suggested "remove need for alcohol disclosure. Remove mum's whakamā, isolation and inability to discuss use while pregnant." This rōpū also asked "what if we had a way to have midwives documenting antenatal alcohol exposure that is non-judgmental, clear, and more detailed to inform early diagnosis and targeted support?"

Lack of Knowledge and Awareness of FASD by Professionals

A lack of knowledge and awareness of FASD by professionals was raised repeatedly by the different rōpū as a barrier to accessing assessment and other support services. A lack of knowledge and awareness was noted across a number of spaces including health and education. For instance, a stakeholder commented "the guidelines are clear, but the issue is not well known by health care professionals and there is a reluctance to diagnose with FASD." As well as "varied opinions on what is needed to diagnose FASD." Finally, a whānau member stated, "I think it is crucial to make sure all potential and current health and education providers are totally FASD informed."

Stakeholders highlighted a lack of understanding and knowledge about FASD in the education sector. For example, a stakeholder commented "I would say that from my experience, the education sector are the least educated and the least willing to be educated". While a kaimahi noted:

"Just talking about the psychologists where I am, very few know about FASD. Very few have got the training or probably an interest in FASD and don't realise how prevalent it is. And they are likely working with children with FASD, and they don't know it."

This view was also expressed by a stakeholder who commented that there was "no support in schools," "mainstream curriculum doesn't work" and "teachers don't have training" suggesting this is an area of considerable concern for whānau.

It was clear from the perspectives shared across the different rōpū that more needs to be done to improve knowledge and understanding of FASD within professional communities. For example, one respondent from the professional survey commented:

> *"More education to the GP and frontline health workers, especially midwives. They visit the home and can see issues around alcohol. Also education about the impact of alcohol as even nursing students are shocked when I do a presentation, so the public seems to be a bit naïve and seems to think, one drink is fine, or my mother drank, and I turned out OK!!!!"*

Whānau shared that the lack of understanding of FASD by health and education professionals had a significant impact on them. For example, a whānau member explained:

"I struggle at times because it's just really tiring. You know when you have to do it again and again, year after year. When you [...] think well really you know, teachers should know this" This person also asked, "how do paediatricians not know about FASD." Like how do they not know? It's a serious question?"

The lack of FASD informed professionals is especially pertinent given that the different rōpū raised the need for more professionals who can diagnose FASD. For example, a kaimahi noted "They don't even have enough assessors for a start". This suggests considerable work needs to be done not only to increase knowledge and awareness of FASD but capacity of professionals who can diagnose as well. These findings also support stakeholders who raised the need for a supervision model.

3. Discussion

There was clear direction from stakeholders on what needs to be present within the guidelines, and in clinical practice. Overwhelmingly stakeholders drew attention to multiple gaps in current diagnostic assessment and post-assessment services. As mentioned, while many of these barriers fall outside of the scope of this project it would be remiss if attention were not drawn to these issues as they directly impact on the ability of people living with FASD and those who support them to access appropriate assessment and support services to improve outcomes.

While whakawhanaungatanga was viewed as a priority it was clear from stakeholders that it is absent from current assessment practice, due to time pressure. The Meihana model (Pitama et al., 2014) was seen as a useful adjunct to clinical practice as it has been developed to be used by health practitioners in everyday practice. Another concern is that current practice not being mana enhancing resulting from a medical/deficit assessment framework instead of a more holistic person and whānau centred model that focuses on strengths. There was also a failure to include whānau as assessment partners impacting on their ability for self-determination and empowerment. To provide whānau with support to navigate the diagnostic pathway and a mechanism to be heard a whānau navigator was recommended to walk alongside them.

While the presence of teaAo Māori including Te Tiriti and mātauranga were viewed as critical within the guidelines and clinical practice it was clear that larger systems and a lack of culturally safe practitioners create barriers preventing Te Triti o Waitangi responsibilities from being met. While another critical barrier to assessment services is a lack of adequate funding in both private and public sectors. Notably, even if an assessment could be obtained stakeholders noted the dire lack of post-diagnosis pathways to services with some suggesting that without follow up services there was little point in obtaining a diagnosis.

Clear communication, using whānau language, was considered vital in supporting whānau to understand a diagnosis of FASD. However, whānau stated that current reports are complex and difficult to understand. Stakeholders were clear on what was needed for good clinical practice, including the collaboration of multidisciplinary teams. However, a lack of co-ordinated services was repeatedly raised and without a wraparound team, stakeholders questioned the value of having a clinician who can diagnose FASD without providing post-diagnosis support services.

Culturally competent clinicians and culturally safe spaces were highlighted as priorities in clinical practice, however a lack of cultural competency by non-Māori professionals impacted the provision of culturally safe spaces. Along with a lack of cultural competency and safety, the lack of culturally appropriate assessment tools, and appropriate cultural norms was raised. Also highlighted was a lack of FASD informed professionals and a lack of consistency across diagnostic practices was also raised. Finally, the lack of clinicians both Māori and non-Māori, along with a lack of supervision (including cultural supervision), were seen as significant gaps in current practice.

4. Conclusion

Stakeholder consultation was carried out across Aotearoa (NZ), via wānanga, online hui, interview and survey, to ask whānau and kaimahi what they believed were the most important factors in having an assessment and making a diagnosis of FASD. A number of clear themes were identified. These included the importance of partnering with whānau, recognising te ao Māori, accessibility, and the development of clinical practice and knowledge. Of note stakeholders raised a number of points that did not fall within the scope of this project but nonetheless were important to include within this discussion as they have considerable implications for how the guidelines are perceived and utilised. These points largely centre around the current lack of pathways to diagnosis and the lack of supports and services for people with FASD and their whānau. There was widespread concern that without funding and training to increase clinical and cultural capacity, and without adequate FASD informed, and culturally safe/competent, services in place to support whānau the guidelines would be of limited use. It is therefore critical that these issues are addressed to ensure whānau receive the support they require to promote positive outcomes for those impacted by FASD.

Glossary

Aotearoa	*Māori name for New Zealand.*
Aroha	*Compassion, love, empathy.*
Atua pūrākau	*Myth, ancient legend, story (about ancestors).*
Awhi	*To embrace, hug, cherish, to surround.*
Hauora hinengaro	*Mental health.*
He awa whiria	*The Braided Rivers Model developed by Angus McFarlane. Uses the metaphor of the streams of a river to describe the complex and dynamic relationship between kaupapa Māori and Western Science approaches (Trewartha, 2020).*
Hui	*Meeting.*
Iwi	*Extended kinship group, tribe, nation, people, nationality, race.*
Kaimahi	*Worker, employee.*
Kanohi ki te kanohi	*Face to face, in person.*
Karakia	*Prayer, chant.*
Karanga	*To call, call out, shout, summon.*
Kotahitanga	*Unity, togetherness, solidarity, collective action.*
Kaumatua	*Adult, elder. A person of status within the whānau.*
Kete	*Basket, kit.*
Mahi a Atua et al., 2020).	*Indigenous Māori approach to promote emotional well-being and mental health (Kopua*
Mana	*Essence, presence, status, authority.*
Manaaki	*To support, take care of, give hospitality to, protect, look out for.*
Māori	*Tāngata whenua. Indigenous New Zealander.*
Mātauranga	*The body of knowledge originating from Māori ancestors, including the Māori world view and perspectives. Māori creativity and cultural practices.*
Mauri	*life principle, life force, vital essence, special nature.*
Ōritetanga	*Equality, equal opportunity.*
Ōtautahi	*Christchurch.*
Pākehā	*English. Foreign. Introduced from or originating in a foreign country. New Zealander of European descent.*
Rangatahi	*Younger generation of leaders, youth.*
Rōpū	*Group.*
Tāne	*Offspring of Papatūānuku (earth) and Ranginui (sky) who creates the world of light. Also, husband, male, man.*
Tāngata whenua	*Local people, hosts, Indigenous People – people born of the land.*
Tāngata tiriti	*Translated means 'treaty people' and is defined as "all people who came to Aotearoa/New Zealand under the authority of the Treaty of Waitangi" (Treaty Resource Centre, 2007, p. 8).*
Tāmaki Makaurau	*Auckland.*
Te ao Māori	*The Māori world.*
Te reo	*Māori language.*
Te Papaioea	*Palmerston North*
Tikanga	*Correct procedure, custom, habit, lore, practice, protocol.*
Tino rangatiratanga	*Self-determination, sovereignty, autonomy.*
Te Tiriti o Waitangi	*An agreement between tāngata whenua and British Crown signed in 1840.*
Tautoko	*Support, backing.*
Waiata	*Song, change, psalm. Sing.*
Wairua	*Spirituality/beliefs.*
Wānanga	*Discussion.*
Whakamā	*Shame, embarrassment.*
Whakataukī	*Proverb, significant saying.*
Whakawhanaungatanga	*Relationship building.*
Whanaungatanga	*Relationship, kinship, sense of family connection.*
Whānau	*Family, family group.*
Whenua	*Land, country.*

Unless otherwise stated meanings of Māori words are taken from Te Aka Māori Dictionary (2023)

References

Pitama, S., Huria, T., & Lacey, C. (2014). Improving Māori health through clinical assessment: Waikare o te Waka o Meihana. 127(1393), 14.

KEY STAKEHOLDER FINDINGS

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

2024

Literature Review: Aotearoa (NZ) FASD Guidelines Development

Te Whatu Ora
Health New Zealand

HĀPAI TE HAUORA
MĀORI PUBLIC HEALTH

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