Whakakotahitanga | Unity

LITERATURE REVIEW

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
MĀORI PUBLIC HEALTH

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

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Whakakotahitanga | Unifying

LITERATURE REVIEW

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

Executive Summary

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 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 most health and social outcomes as a result.

There are a number of international guidelines for assessing FASD. This review compares four guidelines, the 4-Digit Diagnostic Code, the Canadian, Australian and the 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 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 ongoing colonisation and systemic racism. FASD diagnostic criteria are discussed, including literature around confirmation of PAE, sentinel facial feature, 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". 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 responses to them. Therefore, the requirement for professionals to consider the needs of whānau when delivering information is vital. 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 whānau in navigating health and education systems.

Finally, this review considers models of care and 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 whānau 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 on 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 has 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 way.

Literature Review: Aotearoa (NZ) FASD Guidelines Development

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Glossary of Important Terms

Māori – "Māori, Indigenous New Zealand, Indigenous person of Aotearoa/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).

Mātauranga – Māori knowledge - "spans Māori knowledge, culture, values and world view" (Hikuroa, 2017, p. 1).

Pacific Peoples – 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).

Pacifica – A generic term used to represent many Pacific Island cultures: Samoan, Tongan, Cook Islands Māori, Fijian, Niuean, Tokelauan, and Tuvaluan (Singh & Zhang, 2018).

Pasifika – Refer to Aotearoa (NZ) as home, but continue to have family and cultural connections to Pacific Island Nations (Ministry of Education, 2022).

Pākehā – "New Zealander of European descent – probably originally applied to English speaking Europeans living in Aotearoa/New Zealand." (Te Aka Māori Dictionary, 2023). New Zealand Europeans. Māori term for the descendants of the early white settlers (Sibley et al., 2011).

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).

Tāngata whenua – used to describe the Indigenous peoples of Aotearoa (NZ). 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).

Te ao Māori – Māori world, Māori world view.

Te Tiriti o Waitangi – "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.

Tikanga – the correct way, meaning, method of customary practice.

Introduction

This literature review has been drafted to support the development of FASD Diagnostic Guidelines for Aotearoa (NZ). This project was administered by Hāpai te Hauora with funding from the Ministry of Health. The aim of the guidelines is to enable clinicians in Aotearoa (NZ) to understand how to follow best practise in FASD assessment and diagnosis from the latest international research, embedded within the cultural and health context of Aotearoa (NZ). Guidelines for Aotearoa (NZ) must be grounded within a Te Tiriti o Waitangi framework. This local settler and Indigenous partnership framework also apply to the way these guidelines have been developed and includes, but is not limited to project leadership and governance, design and process, and consultation with whānau and healthcare practitioners. Te Tiriti o Waitangi obligations go beyond just remedying disadvantage and reducing inequities. Our obligations extend to proactively enabling Māori to flourish and lead their aspirations for health. The guideline document will assist clinicians in referral, screening, diagnosis, and management of FASD as well as assist professionals and whānau to provide support for those with FASD. We recognise the need to consider alternative diagnoses and the impact of other pre-and-post-natal factors, including exposure to trauma and other substances.

Structure of the Literature Review

This document is divided into three sections. The first section provides background on fetal alcohol spectrum disorder (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. The second section is broken into three parts to reflect the three areas of care provision: pre-diagnosis, diagnosis, and post diagnostic support and treatment. Section Two will also consider how four international diagnostic guidelines for FASD approach the three areas of care delivery. The literature which informs these guidelines will also be taken into account along with updated evidence. Finally, Section Three considers models of care delivery including Māori models of care, before exploring the experiences of individuals with FASD, and their whānau, of the diagnostic/assessment process.

Section One

Background

FASD is a multifaceted neurodevelopmental disorder occurring as the result of prenatal alcohol exposure (PAE) leading to wide ranging, lifelong implications in neurodevelopmental, behavioural, emotional, social, and adaptive functioning (Cook et al., 2016; Hoyme et al., 2016), as well as physical and mental health impairments (Himmelreich et al., 2020; Popova et al., 2016). It can also lead to facial dysmorphology and growth restrictions (Grubb et al., 2021). The timing, frequency, and quantity of alcohol consumed impacts on how the disorder presents, but it may be difficult obtaining PAE information, or it may not be reliable information (Bower et al., 2017; Freeman et al., 2019). Without a diagnosis and adequate supports and services individuals with FASD can experience problems with school, legal, independence, housing, and employment issues along with ongoing victimization, trauma, and substance use (Flannigan et al., 2020; A. Mclachlan 2020; Price et al., 2017; Rangmar et al., 2015; Streissguth et al., 2004). 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, Wrath, Ritter et al., 2021; Sanders & Buck, 2010). Importantly, with appropriate supports individuals with FASD can achieve positive healthy outcomes (Flannigan, Wrath, Ritter et al., 2021; Grubb et al., 2021).

Prevalence

FASD can impact individuals from all socioeconomic and cultural backgrounds (Connor et al., 2020; McRae et al., 2019; Popova et al., 2018). Globally, prevalence rates are estimated at 0.77% of the population, and 2.0 – 5.0% in Europe and North America (Lange et al., 2017; May et al., 2018; McCarthy et al., 2021; Popova et al., 2019). Rates are thought to be substantially higher, particularly in special populations, including children in care, special education, and correctional populations (Bower et al., 2018; Marcellus & Badry, 2021; K. McLachlan et al., 2019; Popova et al., 2019), suggesting increased screening in those areas is vital to provide appropriate support and interventions specific to needs (Popova et al., 2019) as well as prevention (McQuire et al., 2020; Popova et al., 2020). There is limited research on prevalence rates of FASD in Aotearoa (NZ). Although a recent study by Romeo et al. (2023) combined self-reported alcohol consumption during pregnancy for 2012/2013 and 2018/2019 with risk estimates for FASD from a meta-analysis from either case-ascertainment or clinic-based studies in seven other countries to estimate prevalence rates in this country. Estimated rates in the general population ranged from 1.1% to 3.9 %. Prevalence rates for Māori were estimated at 1.7% to 6.3%, 1.3% to 4.6% for European/other, with rates lower among Pasifika (0.5% to 1.7%) and Asian (0.2% to 0.6%) populations. Rossen et al. (2018) estimates that between 600 and 3000 babies are born each year with FASD in this country. In addition

to children born in New Zealand with FASD, Gibbs (2010) notes that around 670 Russian born children have been adopted by New Zealanders since 1992. Whilst this population is relatively small, research suggests prevalence rates of FASD in this community are high (Colom et al., 2021; Koren & Ornoy, 2021). These figures underscore the need for more awareness raising, together with screening and diagnostic services to be available in this country (Gibbs & Sherwood, 2017).

Prevalence rates of FASD have also been reported to be higher in Indigenous populations (Fitzpatrick et al., 2017; Lange et al., 2017; Roozen et al., 2016; Shankar, 2015). There are a number of factors to consider in regard to these findings. For example, while research has found higher rates of FASD in some Indigenous populations some argue this may be the result of FASD work being prioritised, leading to higher rates of FASD diagnosis (Dunbar Winsor, 2021), or as the result of academic bias and discriminatory assumptions (Boychuck & Mott, 2018; Hankivsky et al., 2014; Hunting & Browne, 2012). Caution is therefore advised when linking high rates of FASD diagnosis to higher prevalence in Indigenous communities (Boychuk & Mott, 2018; Dunbar Winsor, 2021; Flannigan et al., 2018; Salmon, 2011). High rates of FASD in Indigenous populations also need to be considered within the context of stigmatisation and the ongoing intergenerational trauma that impacts on health and well-being (Gonzales et al., 2021; Paradies, 2016), along with ongoing inequality and marginalisation that maintains and perpetuates trauma and loss in Indigenous populations, including Māori in Aotearoa (NZ) (A. Mclachlan et al., 2020; Pihama et al., 2014; Reid et al., 2014). The impact of systemic racism also needs to be considered, leading to significant inequalities across multiple settings, including justice (Fernando, 2018; McIntosh & Workman, 2017), education (Bishop et al., 2009; Peterson et al., 2016), and health (Bastos et al., 2018; Came et al., 2017; Cormack et al., 2018; Lavoie et al., 2016; Mohamed Shaburdin et al., 2022; Nath et al., 2021). In Aotearoa (NZ) research suggests that the impact of colonisation, along with historical and contemporary trauma experienced by Māori in Aotearoa (NZ) have led to Māori being over-represented in a clinical sample of children experiencing FASD (Crawford et al., 2020; Espiner et al., 2022).

Aotearoa (NZ) Background

Demographics

Māori are the Indigenous people of Aotearoa (NZ) and comprise 18% of the population (Environmental Health Intelligence New Zealand (EHINZ), 2022; Census New Zealand, 2018). The other major ethnic groupings are Asian (15.1%), Pasifika (8.1%), Middle Eastern Latin American and African (1.5%), and European (70.2%) (many being the descendants of settlors of Aotearoa (NZ) from Britain, Scotland, Ireland, and Wales) (EHINZ, 2022; Census New Zealand, 2018). Today, there is also a large and ethnically diverse migrant population in Aotearoa (NZ) that is projected to increase in diversity over time (Cameron & Poot, 2019). Statistics NZ (2023) estimate that the national population of Aotearoa (NZ) on 30 September 2023 is 5,269,200. Currently Māori make up 18% of the population but this is projected to increase to 21% by 2043, because of higher fertility rates and a much younger age structure (due to higher proportion of tamariki and rangatahi compared to kaumātua). By 2043 one in three children in Aotearoa (NZ) are projected to be Māori (Stats NZ, 2023).

History of Aotearoa (NZ)

Many Māori are thought to have arrived and settled in Aotearoa (NZ) from 1300 AD (Walker, 2004), although Walter et al. (2017) suggests that mass migration did not occur until 1400AD. Kupe is regarded by many Māori as an historical exploring ancestor from Hawaiki who discovered Aotearoa (NZ). Upon his return to Hawaiki four years later, Kupe is said to have provided instructions by which others could voyage to Aotearoa (NZ) (Toitū Te Whenua Land Information New Zealand, 2022; Walker, 2004). It would be another 800 years before the first European ship captained by Abel Tasman would arrive accidentally in 1642. While initially Māori set up profitable trading with the Europeans by the 19th century, as settlor numbers increased, so too did the introduction of alcohol, tobacco, musket warfare, and disease (Durie, 1998; Walker, 2004). Further, increased land demand by the settlors led the Crown to instigate the process of colonisation and land acquisition (Walker, 2004). By 1860, the settlors who became commonly known as Pākehā outnumbered Māori; and by 1880 the life expectancy of Māori was around 30 years less than that of Pākehā (Moewaka Barnes & McCreanor, 2019). Currently, while the life expectancy differential between Māori and Pākehā has closed, a gap still remains for both Māori and Pacific populations in comparison to Pākehā (Walsh & Grey, 2019).

Te Tiriti o Waitangi

Māori chiefs and the British Crown signed Te Tiriti o Waitangi in 1840 making Aotearoa (NZ) a British colony (Houkamau et al., 2017). Māori signed the treaty expecting a mutually beneficial partnership with Pākehā settlers, which would enable them to continue to self-govern and to retain sovereignty over their land, natural resources, and people (Houkamau et al., 2017; Huygens, 2016). Instead, they experienced Pākehā domination and Māori subordination and subjugation (Walker, 2016). Further, the Crown overlooked, and ignored its responsibilities under Te Tiriti o Waitangi. The articles within Te Tiriti o Waitangi detail these responsibilities as:

Preamble. Provide governance. Protect Māori tribal rangatiratanga, and Māori land ownership (Waitangi Tribunal, 2022).

Article 1 kāwanatanga including equitable participation and/or leadership of Māori.

Article 2 tino rangatiratanga recognise and actively protect Māori authority and taonga (everything that is of value).

Article 3 ōritetanga Māori rights of equity as citizens.

Article 4 (wairuatanga) acknowledges the importance of wairua (spirit) and rongoā (Māori medicine) in well-being.

The interpretation of the articles of Te Tiriti o Waitangi are contested, mainly regarding inconsistencies between the te reo Māori version and the English version and the intent conveyed in the different versions. What is clear though is that the treaty is a mutually beneficial agreement (Mulholland & Tawhai, 2010; Wilson et al., 2021).

The failure of the government to fulfil these responsibilities led to the decimation of the Māori population, the dispossession of their land, language, and culture (Walker, 2004), resulting in wide ranging disparities in social, economic, cultural, education and health that are present to this day (Durie, 1998; Houkamau et al., 2017; Marriott & Sim, 2015; Orange, 2022). This situation has led to successive and ongoing calls for the Crown to honour their responsibilities of Te Tiriti of Waitangi and in 1975 the Waitangi Tribunal was formed to provide a means for Māori to seek compensation for breaches of their Te Tiriti o Waitangi rights (Houkamau et al., 2017).

Alcohol use in Aotearoa (NZ)

Alcohol was used as a tool of the coloniser (Muriwai et al., 2018), and was involved in unfair land exchanges (Mcdowell, 2015). Indeed, in 1874 Haimona te Aotearangi, along with 167 other concerned Māori men and women, petitioned the government to do something about the harmful impact of alcohol, stating "It muddles men's brains and they in ignorance sign important documents". Notably, the petition also states, "our babies are not born healthy because the parents drink to excess and the child suffers" (Petition to the General Assembly, 1874, p. 1). Critically, Hutt (1999) argues that the loss of land, cultural identity and family connection experienced by Māori led to an increase in alcohol consumption. More recently, research suggests that Māori are less frequent drinkers of alcohol compared to non-Māori, but those who do drink are more than twice as likely as non-Māori to regularly consume large quantities of alcohol and to engage in binge drinking or hazardous drinking (Clark et al., 2013; Ministry of Health, 2015a, 2015b; Muriwai et al., 2018). Importantly, an association has been found between experiences of racial discrimination and hazardous alcohol use in Māori (Winter et al., 2019). Finally, Australian evidence suggests that Indigenous populations experience twice as many alcohol related health problems compared to non-Indigenous populations (Wilson et al., 2010) highlighting that the harmful impact of alcohol continues to this day. Of note research indicates that the harm from alcohol is compounded by other factors such as the considerable inequity experienced by Indigenous populations in income, education, health and housing.

There is considerable risk when discussing patterns of alcohol consumption in regard to FASD as it can lead to blame, judgment, and stigmatisation of women, particularly when research often argues that FASD is a completely preventable disease due to the fact that alcohol consumption is voluntary (for example, see Ungerer et al., 2013; Williams et al., 2018). However, this is a harmful oversimplification of a complex issue which needs to be considered in terms of the context in which alcohol consumption occurs (Badry & Felske, 2013; Watts, 2021). Numerous risk factors have been identified for women who drink during pregnancy, including intimate partner violence, poverty, stress, trauma, abuse, discrimination, and mental health challenges (Badry & Felske, 2013; Cloete & Ramugondo, 2015; Currie et al., 2020; Gosdin et al., 2022; Leonardson & Loudenburg, 2003; Meulewaeter et al., 2019; Racine et al., 2021; Waddell & Karatzias, 2019; Watt et al., 2014). Further, the role of paternal alcohol consumption has been found to play a considerable role in maternal drinking through social facilitation (McBride & Johnson, 2016).

Gonzales et al. (2021) assert that alcohol use in Indigenous cultures needs to be considered from an intergenerational perspective taking into account the harm and trauma caused by complex sociocultural factors and systemic inequalities that continue to impact Indigenous communities' health and well-being. This reflects earlier research by Shahram et al. (2017) who suggest alcohol may be consumed during pregnancy as a coping mechanism in response to intergenerational trauma experienced by Indigenous women who are pregnant. Gonzales and colleagues recommend a shift away from the dominant western medical model that can shame and blame individuals, and treats FASD as an individual-level problem, ignoring multiple levels of harm. They further note, that focusing at the individual level also fails to consult with, and consider the needs of, underrepresented communities. Further, inconsistent messaging around alcohol consumption during pregnancy can lead to confusion over whether it is safe to consume alcohol during pregnancy (Alcohol Healthwatch, 2007; Bagley & Badry, 2019; Popova et al., 2022).

Aotearoa (NZ) has high rates of hazardous drinking, with research noting rates among young woman has increased over time (Huckle et al., 2013). Alcohol consumption remains highest in men with 85% of Pākehā men and 80% of Māori men consuming alcohol. The Ministry of Health (2018a) reports that 1 in 5 adults drink hazardously in Aotearoa (NZ), although notably rates in young people have begun to decline (Huckle et al., 2020). Pākehā women are more likely to drink than Māori and Pasifika women, although they are less likely to binge drink. While woman in affluent areas are more likely to consume alcohol daily, women in deprived areas are more likely to drink hazardously (Rankine, 2013). Research has highlighted alcohol consumption as a considerable risk factor in unplanned pregnancies (Connery et al., 2014; Francisco et al., 2016; Yu et al., 2021). Critically, Aotearoa (NZ) has high rates of unplanned pregnancies (Hohmann-Marriott, 2018; Mallard et al., 2013), with the Ministry of Health (2015a) estimating that over half of all pregnancies may have been alcohol exposed. Research suggests that there are higher rates of alcohol consumption in the first trimester often because a person is unaware of their pregnancy (Rossen et al., 2018; O'Keeffe et al., 2015). The Growing up in New Zealand (GUiNZ) study found that while 23% of women drink during their first trimester, most women reduce their drinking during pregnancy, with 13% continuing to drink to some degree after the first trimester (Rossen, 2018).

While rates of binge drinking tend to be higher in lower socio-economic populations, international research highlights that higher socioeconomic status and higher education are associated with a greater likelihood of moderate alcohol consumption during pregnancy than in the general population (Dumas et al., 2017; Lanting et al., 2015; Mårdby, et al., 2017; Skagerström et al., 2011; Stanesby et al., 2018), highlighting Popova et al's. (2018) assertion that FASD does not just occur in disadvantaged groups, but "is found throughout society, regardless of socioeconomic status, education, or ethnicity" (p. 239). These findings are also significant as the Ministry of Health (2018b), in line with international recommendations, warns that even low amounts of alcohol are harmful to the unborn baby and advises abstinence from drinking during pregnancy.

Importantly,

"Women do not deliberately choose to harm their unborn child. They may not be aware of their pregnancy; they may use alcohol to self-medicate, to deal with fears or stresses relating to the pregnancy or other aspects of their life, they may not be aware of the damage their substance abuse is causing; or they may have received advice that alcohol was not as big a problem as everyone makes out" (Stuart & Rogan, 2006, p. 6, cited in Stuart, 2009).

Current Inequity in Aotearoa (NZ)

As discussed, there is a well-established pattern of inequity in Aotearoa (NZ), with Māori experiencing significant health (physical and mental) and socioeconomic disadvantage as the result of colonisation and systemic racism (Houkamau et al., 2017; Reid et al., 2019; Talamaivao et al., 2020). Likewise, Pacific people living in Aotearoa (NZ) experience similar inequity (Marriott & Sim, 2015, Simpson et al., 2016). For example, Māori and Pacific communities' experience lower rates of school completion and higher rates of poverty and unemployment than their European counterparts, along with higher rates of family violence and suicide rates among Māori, and higher infant mortality rates (although these figures are dropping), and higher rates of household crowding in both Māori and Pacific communities (Kruger et al., 2004; Lievore et al., 2007; Marriott & Sim, 2015; Ministry of Health, 2015b; Pihama et al., 2016; Simpson et al., 2016). Māori and Pacific People also have a higher risk of hospitalisation for COVID -19 than non-Māori and non-Pacific people (Steyn et al., 2020). Māori experience higher rates of substance use (Ministry of Health, 2013, 2016) and are twice as likely to experience racial discrimination than non-Māori (Ministry of Health, 2015b). As already noted, research has found an association between experiences of racial discrimination and rates of hazardous alcohol use among Māori (Winter et al., 2019). Māori also experience disability at higher levels than any other population (Ministry of Health, 2015b). One in three Māori experience some form of disability, yet they receive less health and disability supports and services (Hickey & Wilson, 2017). Moreover, 62% of children in foster care are Māori compared to 25% of the general population (Keddell & Davie, 2018). Māori and Pacifica also experience high rates of contact with the criminal justice system (loane et al., 2016) and these high rates of contact have been linked to cultural and institutional racism (Love, 2017). As previously noted, high rates of FASD have been found in institutional care and foster care, as well as prison populations (Popova et al., 2019).

In Aotearoa (NZ), A. McLachlan et al. note the need for specialist services to increase their understanding of the realities of low socioeconomic communities and co-occurring issues that impact on health. Andre McLachlan and colleagues recommend "working in a whānau-centred approach with whānau as a collective entity, based on Māori foundations; understanding intergenerational dynamics; and endorsing a group capacity for self-determination" (p. 106).

Impact of COVID-19

Internationally research suggested alcohol consumption in both men and women increased during the pandemic (Calina et al., 2021). In Aotearoa (NZ) there was a considerable increase in alcohol consumption in some populations during the level four lockdown, with some continuing to drink at higher levels post lock down (Health Promotion Agency, 2020). Rehm et al. (2020) argues that the impact of the pandemic will have considerable implications for alcohol use both immediately and in the long-term, including increased consumption as a way to cope with the ongoing impacts from the pandemic. In addition, an increase in alcohol related disorders have also been noted (Da et al., 2020). During the pandemic there was also an increase in maternal mental health problems, domestic violence, and women were at greater risk of losing their income than men (Kotlar et al., 2021). An increase in alcohol consumption and an increase in risk factors associated with alcohol consumption during pregnancy raises alarms over an increased risk of FASD. A concern highlighted by Calina et al. (2021) who suggest that an increase in alcohol consumption during the pandemic is likely to lead to a considerable increase in new cases of FASD, a fear also raised by Sher (2020).

Section Two

"Diagnosis managed from a strengths and opportunities perspective can open doors of hope and possibility"
(Choate & Badry, 2019, p. 45).

Areas of Care Delivery

This section is broken into three areas of care delivery needed to support individuals and whānau affected by FASD. These areas of care are defined by Mukherjee (2021a) as pre diagnosis, diagnosis, and post diagnostic support/therapy . Importantly, Mukherjee (2021a) asserts there are a number of challenges faced by family support in these areas of care including difficulties navigating systems to access appropriate diagnosis and care. To align with the whānau centred aspirations of the guidelines project the three areas of care delivery will be defined as: Engagement, Assessment, and Support.

The engagement (pre-diagnosis) section will consider information gathering, including screening tools and biomarkers used to identify the presence of PAE. The assessment (diagnosis section) will consider the impact and value of a FASD diagnosis, along with challenges to diagnosis, including different diagnostic systems, and the impacts of stigma, colonisation and systemic racism. Recommendations for the assessment of FASD will be considered as well as a comparison of how different international guidelines approach assessment. Evidence from the Australian FASD systematic review and meta-analysis, which reviewed the association between PAE and physical size, dysmorphology and neurodevelopmental outcomes, will be considered (Hayes et al., 2023). Finally, the support (post diagnostic support/therapy) section will outline the feedback provided by professionals to whānau after the assessments have been completed, along with management and referral pathways.

International FASD Diagnostic Guidelines

Currently, there are a number of FASD diagnostic frameworks being used internationally, with considerable variation amongst them (Coles et al., 2016). This review will consider the 4-Digit Diagnostic Code (Astley, 2013), the Canadian (Cook et al., 2015, 2016), and Australian (Bower et al., 2017) guidelines as these are the guidelines known to be used in clinical practice in Aotearoa (NZ) (Gibbs & Sherwood, 2017; Popova et al., 2023). The Scottish Clinical Guidelines (Scottish Intercollegiate Guidelines Network, 2019) is also included as another example where Canadian Guidelines have been adapted for a local context. The focus of these guidelines is on assessment and diagnosis of FASD, although the Canadian, Australian, and Scottish guidelines also include recommendations on timing of diagnosis, screening tools, management and follow up. Overall, there are a number of features that are consistent across the guidelines, particularly the Canadian, Australian, and Scottish guidelines. Although there are some noteworthy differences in the specificity of recommendations, criteria, and clinical cut offs (thresholds to be met for severe impairment indicating a FASD diagnosis is appropriate) (Cook et al., 2015). Indeed, Mukherjee and Aiton (2021) point out that all the diagnostic systems utilise the four same basic parameters of facial characteristics, growth, neurocognitive deficits and PAE, differences therefore relate to sensitivity and specificity and occur around thresholds.

Comparison tables of the four different approaches in relation to key guideline recommendations are reported in Appendix 1 which provides tables on the following areas of comparison:

- Table 3 - Special Considerations in the Assessment of Adolescents and Adults
- Table 4 - Multidisciplinary Team
- Table 5 - Diagnostic Categories
- Table 6 - Lip-philtrum Measurement
- Table 7 - PAE Confirmation
- Table 8 - Neurodevelopmental Domains
- Table 9 - Neurodevelopmental Criteria
- Table 10 - Direct and Indirect Assessment
- Table 11 - At Risk Category
- Table 12 - Cultural Considerations/Contexts
- Table 13 - Management and Follow Up

Engagement (Pre-Diagnosis)

There are a number of factors involved in pre-diagnosis care that need to be considered to ensure positive outcomes across all areas of care delivery. These include the importance of establishing positive relationships, which can empower families (Chamberlain et al., 2017), meaningful communication (Temple et al., 2015), including a clear pathway that spans the diagnostic journey (Evans et al., 2022), and the valuing of whānau and individual goals (Baskin et al., 2016).

Mukherjee (2021a) highlights that prior to diagnosis there is a variety of information on the child that will be useful and should be collected including:

- Alcohol exposure information as accurately as possible.
- Other drug and medication exposure in pregnancy as accurately as possible.
- ·History of early upbringing and developmental milestones, including considering neglectful and traumatic experiences.
- Medical records of other investigations and observations made, including genetic, (p. 264).

Mukherjee (2021a) asserts that a number of agencies can support broader information gathering whilst there is a need for General Practitioners (GP's) to support families in accessing diagnostic services by being aware, and able to refer to appropriate clinicians. Further, as information is collected by different agencies, there is a need for the information on the child (such as record of PAE) to follow the child so it does not need to be collected again. Rutherford et al. (2021) also recommend that pre-diagnosis families should be provided with relevant information, such as neurodevelopmental information via leaflets and website links, as well as what to expect at an appointment. Further, the Ministry of Health's (2016) action plan recommends cross agency co-ordination and partnerships with individuals and whānau to ensure timely and accurate diagnosis and effective outcomes. How information is communicated to whānau is critical and will be discussed in section three, 'Lived Experience of Diagnostic Process' (p. 50).

For pre-diagnosis it is important to consider that obtaining pre-natal alcohol history can be difficult. For example, for foster/adopted children where the biological mother cannot be located or is unable to confirm drinking during pregnancy due to a fear of consequences/ blame and being stigmatised. When asking about pre-natal exposure, Smith and Jones (2021) encourage paediatricians to keep the biological mother's perspective in mind as how they engage can impact on the ability of families to achieve the best outcome for the child. Although Stevens et al. (2020) note that while sensitive questioning was found to be better at early stages of the pregnancy, the use of objective biomarkers may be more useful in late pregnancy for identifying risk of PAE. For example, measuring ethanol biomarkers in meconium (Abernethy et al., 2018), or PEth (phophatidylethanol) blood concentrations (Howlett et al., 2017). Another consideration

is that many individuals with FASD lack the facial features associated with FASD (Dawe et al., 2023; O'Neill et al., 2022; Trathen, 2021). Stevens et al. (2021) note the need for multiple tools and methods to identify PAE across the pregnancy. Other forms of detecting PAE that do not rely on birth-mother informants or on facial characteristics, have been investigated (Trathen, 2021), such as the use of some neurobehavioural scales like the Behaviour Rating Inventory of Executive Function (BRIEF) (O'Neill et al., 2022).

Timing of Diagnosis

Popova et al. (2020) note that "the domains of impairment in FASD change across the life span" (p. 817), indicating that a single diagnosis provided and at one point in time may not be adequate in the assessment and management of the disorder across a lifetime. Popova and colleagues further assert that follow-up of individuals with FASD within their community will be required to meet their individualized needs. Similarly, Wynn et al. (2020) argue that repeat screenings are necessary over time as FASD characteristics develop to ensure all children affected are identified. Likewise, Taylor and Enns (2018) contend that due to the heterogeneity of FASD, characteristics can present differently across the life span requiring age dependent diagnostic processes and neurodevelopmental assessment tools/test battery. Concern has been raised that currently diagnostic guidelines are aimed at children and adolescents but that there is no accepted tool to diagnose FASD in adults and limited diagnostic services for them (Widder et al., 2021). Indeed Connor (2021) argues that due to a lack of awareness of FASD and limited diagnostic capacity many individuals with FASD will not be diagnosed in childhood, highlighting the critical need for improved diagnostic guidelines and tools appropriate for diagnosing adults. These findings are supported by Hayes et al. (2022) where stakeholders report a need for clearer guidelines to assess and diagnose FASD in adults, and K. Mclachlan, Amlung et al. (2020) who call for more research to explore the sensitivity of screening FASD among adults in justice settings.

The 4-Digit guideline makes very little mention of special considerations for diagnosing adolescents and adults with FASD. However, the revised Canadian guidelines have included special consideration for diagnosing FASD, not only in infants and young children, but adults as well. Recommendations of which have been adopted by the Scottish guidelines. The Australian guidelines also note special considerations when diagnosing adults. Both the Canadian and the Scottish guidelines state that the diagnostic criteria for FASD are the same for adults as for younger individuals.

See Appendix 1 - table 3 for a comparison of the four international guidelines on Special Considerations in the Assessment of Adolescents and Adults.

Screening Tools

The Canadian guidelines note that there are few screening tools that can help identify FASD, but that new screening tools are being developed. The guideline further notes that screening is not diagnosis. So, all positive screens for FASD need to be referred for further investigation. Similarly, the Australian guidelines note there are no validated standardised screening tools for FASD. Like the Canadian guidelines they indicate that further research is required to develop reliable validated screening tools. For example, Ronen et al. (2022) note a number of challenges screening for FASD using the Neurobehaviour Screening Tool (NST) in populations with high co-morbidities, noting that the tool was not highly sensitive, calling into question the usefulness of the NST as a screening tool for FASD. The Canadian and Scottish guidelines both note that a reliable and accurate maternal alcohol history is the best screening tool for identifying risk of FASD.

Research has begun to consider ways to make an earlier identification of FASD including biomarker identification (Kaminen-Ahola, 2020) analysing facial shape for neurocognitive correlates (Suttie et al., 2018), placental markers (Holbrook et al., 2019) and the use of EEG (Dylag et al., 2021).

Biomarkers

Ongoing research into the use of biomarkers to identify PAE may yield alternative methods in screening and diagnosis (Popova et al., 2020). Although there is limited evidence currently to support a reliable connection between markers and PAE, especially when exposure levels are low (Howlett et al., 2017; McQuire et al., 2016). Neither the 4-Digit or Australian guidelines specifically mention the use of diagnostic biomarkers. In contrast, the Scottish Guidelines note that biomarkers, such as CDT (carbohydrate deficient transferrin) and PEth (phophatidylethanol) should be considered, but further feasibility studies are required regarding the use of meconium and placental biomarkers (Scottish Intercollegiate Guidelines Network, 2019). Whereas the Canadian guidelines note that research is ongoing into the effectiveness of biomarkers for diagnosing FASD. Notably, Popova (2023) asserts that biomarkers for PAE are urgently needed due to the number of children in out-of-home care where reliable PAE histories are often unavailable.

Diagnosis

Early diagnosis of FASD, along with individualised intervention and support services, are key protective factors identified in reducing exposure to, or mitigating the impact of, adverse experiences (Fitzpatrick & Pestell, 2017; K. Mclachlan, Amlung et al. (2020); Popova et al., 2020; Streissguth et al., 2004). Grubb et al. (2021) suggests that early identification of FASD in children and adolescents may also provide other benefits, including increased access to suitable supports, improved understanding of strengths and challenges, creation of peer and caregiver support networks and improved communication between parties. Also, diagnosis provides identification of co-morbid and co-occurring conditions, and the ability to access supports and services including, vocational support, housing and financial assistance, psychological interventions, and specialized legal counselling (Wozniak et al., 2019a). Appropriate services and supports can help prevent or mitigate the impact of secondary conditions (Banerji & Shah, 2017; Wozniak et al., 2019a), which occur due to the lack of environmental support for individuals with FASD (Gibbs & Sherwood, 2017), including academic failure, social problems, criminal behaviour, alcohol and drug use disorders, and employment difficulties (Wozniak et al., 2019a). Therefore, the earlier a diagnosis can be provided the better the outcome. It is important to understand that for some, obtaining a diagnosis can cause considerable anxiety and stress, and for some may lead to feelings of guilt (Helgesson et al., 2018).

Some studies have suggested that disorder specific pathways are less favourable compared with general neurodevelopmental pathways as the mainstream pathways facilitate assessment of other conditions such as ADHD and ASD alongside FASD. The researchers suggest that given the complexity of overlaps and high prevalence of these conditions using mainstream diagnostic pathways are a sensible and cost-effective solution to diagnostic services (Schölin et al., 2021). Although, of note many clinicians/practitioners have indicated that they lack the expertise to diagnose FASD (Mukherjee et al., 2015).

Challenges to Diagnosis

There are a number of challenges to obtaining a diagnosis of FASD. For example, a diagnosis requires a medical evaluation and neurodevelopmental assessment be carried out by a multidisciplinary team (Cook et al., 2015), yet Shanley et al. (2019) argue that high prevalence rates, and geographically remote practitioners mean this model is not always feasible. Further, a lack of clinical capacity and the cost of services have also been highlighted as barriers to diagnosis (Kent et al., 2023). While a lack of awareness by many professionals, including those in healthcare (Chamberlain et al., 2017; Gilbert et al., 2021; Howlett et al., 2019; McCormack et al., 2023; Mukherjee et al., 2015; Schölin et al., 2021; Williams & Badry, 2023) mean they miss the indicators of FASD and attribute the disorder to other factors such as trauma (Hanlon-Dearman et al., 2020; Mattson et al., 2019) or dismiss concerns

raised by caregivers (Chamberlain et al., 2017; Hayes et al., 2023; Thomas & Mukherjee, 2019). Literature from an Aotearoa (NZ) context reflects international findings, specifically, that there is limited access to best practice multidisciplinary FASD diagnosis, the high cost, and services are not available particularly in regional and remote areas (Bagley, 2019). Although, Canadian research by King et al. (2023) suggests that a virtual assessment framework would be beneficial for families in rural and remote settings. High rates of FASD, a lack of diagnostic capacity and training, along with high rates of misdiagnosis in children suggests that FASD is considerably under-diagnosed (Chasnoff et al., 2015; Lange et al., 2017; Popova et al., 2020; Webster et al., 2020; Wozniak et al., 2019a). Challenges to obtaining a diagnosis of FASD are further exacerbated due to limitations of self-reported drinking, infrequency of diagnostic dysmorphic facial features, and a lack of biomarkers. Also, there are multiple diagnostic systems with a lack of agreement over diagnostic criteria (Brown et al., 2019; Wozniak et al., 2019a).

Different Diagnostic Systems

There are a number of different diagnostic systems being utilised in different countries, meaning there is currently no consensus on diagnostic procedures (Hemingway et al., 2019; Martyniuk & Melrose, 2018). The Canadian Guidelines have been widely adopted by clinicians in Canada and in other countries (Watkin et al., 2013), including Aotearoa (NZ), although there is no government directive to do so (McGinn & McLaren, 2015). Globally, multiple diagnostic systems and differing diagnostic criteria play a role in the considerable variation in diagnosis and identification of FASD (Coles et al., 2023; Coles et al., 2016; Guilmette et al., 2020; Viljoen et al., 2018), which Wozniak et al. (2019a) argue highlights the urgent need for international agreement on a diagnostic framework to improve research and diagnostic capability. Notably, there is considerable support from clinicians for a unified approach to assessing FASD to standardise global management of FASD and improve patient care and research outcomes (Reid, Shanley et al., 2022).

Research has highlighted issues with the convergent validity of the different diagnostic frameworks. For example, there is considerable disagreement between the various diagnostic systems, with only "fair" to "moderate" agreement on diagnoses when the same participants are diagnosed utilising the various systems (Coles et al., 2016). These inconsistencies make it difficult to compare prevalence figures, evaluate interventions, and validate FASD diagnoses (Chudley, 2018; Popova et al., 2023). Connor (2021) also notes that neuropsychological assessment protocols in various guidelines vary in specificity, and that cut off points used to quantify levels of impairment can also vary between guidelines supporting the call for a standardised diagnostic guideline. Further, research suggests that there are considerable differences in screening approaches and performance characteristics, connected to different diagnostic tools (Lim et al., 2022).

It is argued that utilising one global diagnostic system would improve consistency and accuracy in the diagnosis of FASD (Coons-Harding et al., 2019; Mattson et al., 2019). Of note, Watkins et al. (2013) assert that the Canadian guidelines are already widely adopted by clinicians in Canada and other countries. Although Okulicz-Kozaryn et al. (2021) point out that the guidelines have all been developed and tested within a North American context which can differ considerably from other populations and healthcare systems. Whereas Hayes et al., (2022) note the need for alternative assessment processes that are culturally sensitive, safe, and appropriate for communities that experience access barriers including Indigenous communities. Importantly, in Aotearoa (NZ), one of the key aims of developing national guidelines is to reflect this countries unique geographical and socio-political makeup, and the support required for whānau. This differs from the international opinion where there is a move towards international consensus irrespective of culture and country-specific systems.

Impact of stigma on a diagnosis

The stigma associated with FASD can also function as a barrier to diagnosis and support (Bell et al., 2016; Choate & Badry, 2019; Dunbar Winsor, 2021; Zizzo & Racine, 2017). Research suggests professionals can be reluctant to provide a diagnosis due to the stigma attached to FASD (Mukherjee et al., 2015; Ninomiya, 2015), a finding reflected in Aotearoa (NZ) specific research (Bagley, 2019; Bagley & Badry, 2019). Also, professionals may be uncomfortable discussing the topic, or may not prioritise a diagnosis of FASD as important (Corrigan et al., 2019). While others believe a diagnosis will not improve outcomes for the individual (Ninomiya, 2015). In contrast, diagnostic bias in some populations including Indigenous communities, and children placed in foster care, can mean clinicians are more inclined to diagnose FASD in these populations and may overlook other neurodevelopmental conditions (Bell et al., 2016). Concerningly, having a diagnosis of FASD can lead to additional experiences of stigma (Bell et al., 2016; Dunbar Winsor, 2021; Hamilton et al., 2020). Women who are pregnant may be reluctant to seek support for alcohol dependence or disclose alcohol consumption during pregnancy as the result of fear from being judged (Dunbar Winsor, 2021; Helgesson et al., 2018; Roozen et al., 2020), and because of care and protection implications and the fear of having children uplifted (Dunbar Winsor, 2021; Gonzales et al., 2021; Rutman & Van Bibber, 2010; Stone, 2015). Likewise, biological parents may be hesitant to seek out or accept support for their child once a diagnosis of FASD has been received due to experiences of judgment and stigmatisation (Choate & Badry, 2019). Critically, being diagnosed with FASD can come with an inherent association between the mother's drinking behaviour and the child's disability, which Bell et al. (2016) argue can reinforce fatalistic stereotypes about the family. Whilst Helgesson et al. (2018) assert a diagnosis of FASD can undermine a person's confidence in what they can achieve.

Impact of Colonisation and Systemic racism

Another important consideration in access to diagnosis is the impact of colonisation and the ongoing systemic racism present in many government colonial systems including, as discussed, health, education, and justice which perpetuate disparities for Indigenous Communities (Bastos et al., 2018; Crawford et al., 2020; Reid et al., 2021; Ward et al., 2023; Wirihana & Smith, 2019). Given the considerable disparities in the provision of healthcare services previously mentioned, it is important to consider the impact such disparities have on the provision of appropriate diagnostic pathways. For example, a recent study by Williams and Badry (2023), which considered the gaps and disparities in responding to Aboriginal children living with a lifelong disability, noted a lack of diagnosis and FASD-informed care in the child welfare system. These findings support earlier research by Banerji and Shah (2017) who found a lack of diagnostic resources for most Indigenous communities, as well as the need for more research on the presentation of FASD, barriers for diagnosis, and available supports and services for Indigenous communities. They also note the need for community partnerships and government agencies to identify and address gaps in diagnosis and services. Similarly, Shanley et al. (2019) note the need for culturally sensitive assessment approaches for remote areas in Australia. Unfortunately, healthcare programmes for FASD are often designed without community consultation, perspective, and experiences. There is a critical need for programs to honour the wisdom of the community and the expertise of cultural bearers (Gonzales et al., 2021). Unfortunately, the current international guidelines provide limited information about the cultural context in which the guidelines had been developed and in which they would be used.

As discussed, there are several international diagnostic guidelines for FASD, leading to a lack of consensus on diagnostic procedures. This next section will compare four international FASD Diagnostic guidelines – The 4-Digit, and the Canadian, Australian and Scottish Guidelines, and consider the literature in relation to these recommendations.

Multidisciplinary Team

All four guidelines note the need for a comprehensive multidisciplinary approach to ensure an accurate diagnosis and appropriate referral and management pathways. These recommendations are supported by research (for example, see: Cook et al., 2015; Coons-Harding et al., 2019; Webster et al., 2020). The Canadian and Scottish guidelines note that the assessment team can be local, central, or virtual; satellite clinics and telemedicine may also be used for remote or rural locations. Also noted is that teams will vary depending on the context of the assessment and age of individuals being assessed.

Members of the team recommended across the guidelines include Physician, Psychologist, Speech Language Pathologist and Occupational Therapist. The Canadian and Scottish guidelines also suggest further individuals who can provide valuable input into the diagnostic process. Included in this list are parents and caregivers, Advocates, Childcare Workers, Clinical Geneticists, Cultural Leaders, Family Therapists, General Practitioners, Learning Support, Mental Health Professionals, Mentors, Nurses (e.g., school, learning disability, etc.), Neuropsychologists, Probation Officers, Psychiatrists, Social Workers, Substance Misuse Service Staff, Teachers, and Vocational Counsellors. Of note, however, recommendations for guideline development and implementation by Hayes et al. (2022) suggest considering alternatives to a multi-disciplinary team to expand access to diagnosis when a team is not feasible.

See Appendix 1 - table 4 for a breakdown of multidisciplinary team across the four guidelines.

Use of FASD as a Diagnostic Term

Reid (2023) notes a lack of agreement around the descriptors used to refer to FASD and the different terminologies currently in use. The 4-Digit Code defines the full range of outcomes as the result of PAE as fetal alcohol syndrome (FAS), partial FASD (pFAS), static encephalopathy/alcohol-exposed (SE/AE), which involves structural evidence of brain damage and/or severe dysfunction, and neurobehavioral disorder/alcohol-exposed (ND/AE), which involves mild–moderate dysfunction and these fall under the umbrella of FASD (Astley, 2013; Davies, 2021). Unlike the 4-Digit Code system, the Australian and Scottish guidelines have adopted the most recent Canadian Guidelines use of FASD as a diagnostic term. The term is further broken down into FASD with sentinel facial features and FASD without sentinel facial features. Of note, Popova et al. (2020) assert that an alternative term should be explored for FASD to reduce the negative impact of the stigma associated with the name. As Choate and Badry (2019, p. 37) point out :

> *"The concern of FASD as a diagnosis and as a term contributes to stigma as it serves to identify the cause and nature of the condition with which the person lives, and this is a lot for anyone to overcome. It is rare that disabilities are named for their cause rather than by the name of the scientists responsible for the discovery."*

Adopting a term that does not specify prenatal alcohol may reduce barriers to self-reporting of alcohol consumption during pregnancy increasing the identification of PAE, which may result in earlier diagnosis (Popova et al., 2020). This is an important consideration given that the frequently deficit rather than strengths-based language used by professionals adds to the stigma of FASD (Choate & Badry, 2019). In Aotearoa (NZ), te reo Māori may also provide a more appropriate name based on the expression of the condition as has been provided for other neurodisabilities such as autism takiwātanga.

FASD Diagnostic criteria

Confirmation of PAE

There is differing standards for confirmation of PAE across the four guidelines. For example, the Canadian guidelines require high PAE, whereas the 4-Digit, the Australian and Scottish require confirmed PAE at any reported level (Hemingway et al., 2019). Whereas, concern has been raised over the stringent criteria proposed by the Canadian guidelines, for example Petryk et al. (2019) found that 70.9% of clients who had received a previous FASD diagnosis would not meet the criteria for a diagnosis of FASD under the revised Canadian guidelines.

See Appendix 1 - Table 7 for Comparison of PAE Confirmation

Typically, PAE is confirmed based on maternal interviews and questionnaires, medical records, clinical examination, and biomarker measurements, including both maternal and/or new-born samples. Of note Brown et al. (2019) argue there is conflicting or limited evidence that supports the current use of tools to confirm PAE. While Freeman et al. (2019) note that confirming PAE for older children with FASD in justice settings can be especially challenging. Similarly, Bakhireva (2018) highlights the difficulty of confirming PAE for children in foster or group home settings.

Dr Natasha Reid and her team at the Child Health Research Centre, University of Queensland conducted a systematic review and meta-analysis of the association of PAE and physical size, dysmorphology and neurodevelopmental outcomes Hayes et al. (2024). Box 1 gives a summary of their findings as stated in their report.

Box 1. Summary of Australian Guidelines for Assessment and Diagnosis of Fetal Alcohol Spectrum Disorder or Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure. Association between prenatal alcohol exposure, Physical size, dysmorphology and neurodevelopment: Systematic Review Report (Hayes et al., 2024)

What is the problem?

Internationally there is no agreed set of diagnostic criteria for fetal alcohol spectrum disorder (FASD). There is also no comprehensive evidence synthesis available to inform decision making regarding the clinical features to include in diagnostic criteria for FASD.

What is the importance?

This systematic review has examined all available outcomes across the variable diagnostic domains for FASD (i.e., physical size, dysmorphology and neurodevelopment) and quantitatively examined their association with prenatal alcohol exposure (PAE) and/or diagnosed FASD. Where specific PAE levels were reported, this has been standardised across studies, allowing for meta-analysis and comparison of outcomes.

What evidence was found?

We included 306 studies published from 1980 to 2023 in this systematic review. There were 106 studies examining physical size across 14 different outcomes that spanned birth to adulthood. Major facial dysmorphology (i.e., of the philtrum, vermilion, and palpebral fissures) was assessed in 43 studies and 32 studies examined minor dysmorphology of other facial and non-facial features. Functional neurodevelopment outcomes were reported in 195 studies and 110 studies examined structural or neurological outcomes.

For physical size, there was a negative association found between heavy, very heavy, and confirmed but unquantified levels of PAE, although the quality of the evidence ranged from very low to moderate certainty of this association. For major dysmorphology, there was a positive association found between moderate, heavy, and confirmed but unquantified levels of PAE, although there was very low to low certainty of the evidence for this association. For functional neurodevelopmental outcomes there was an association found between heavy, very heavy and confirmed unquantified levels of PAE, with very low to moderate certainty of the evidence for this association. For structural and neurological neurodevelopmental outcomes, there was an association found between all levels of PAE, with very low to moderate certainty.

What was the conclusion?

Aside from the domain encompassing physical size, there was a paucity of studies providing high quality evidence across the different levels of PAE and outcomes currently used in the diagnostic criteria for FASD. Associations between PAE and diagnostic outcomes were more consistently observed at heavy and very heavy PAE levels (including confirmed unquantified studies), with occasional associations observed at moderate PAE levels and uncommon single study findings of associations at light PAE levels.

The Australian systematic review (Hayes et al., 2024) noted a lack of high-quality evidence across the different levels of PAE and outcomes currently included in the diagnostic criteria for FASD. The Review noted the need for more research across dysmorphology and neurodevelopmental outcomes, to better understand the association of PAE across the different exposure levels.

Sentinel Facial Features

The evidence from the Australian systematic review (Hayes et al., 2024) suggested that heavy and very heavy PAE was associated with the presence of the three sentinel facial features (smooth philtrum, thin vermilion, and short palpebral fissures). There was a variable association for moderate exposure and no studies were identified that considered light PAE levels.

The FASD criteria for sentinel facial features include:

1. Small palpebral fissure lengths (2 or more standard deviations below the mean)
2. Smooth Philtrum (Rank 4 or 5 on the Lip-philtrum Guide)
3. Thin upper lip (Rank 4 or 5 on the Lip-philtrum Guide)

Presence of facial features are included in fetal alcohol syndrome (FAS), partial FASD (pFAS) of the 4-Digit guide. The Canadian, Australian, and Scottish guidelines all have two subcategories of FASD:

FASD with three sentinel facial features (Canadian, Scottish and Australians all use this terminology)

Criteria for diagnosis under this category:

- Simultaneous presentation of three sentinel facial feature AND
- Prenatal alcohol exposure confirmation or unknown AND
- Evidence of severe impairment in three or more of the identified neurodevelopmental areas of assessment, or in infants and young children, presence of microcephaly
- Growth impairment and other alcohol-related birth defects should be documented if present
- Hereditary, prenatal, and postnatal factors that may influence developmental outcome should be recorded

FASD without sentinel facial features (Scottish and Canadian use this terminology)

- Evidence of impairment in 3 or more of the identified neurodevelopmental domains
- Confirmation prenatal alcohol exposure, with the estimated dose known to be associated with neurodevelopmental effects
- Growth impairment and other alcohol-related birth defects should be documented if present
- Hereditary, prenatal, and postnatal factors that may influence developmental outcome should be recorded

FASD with less than three sentinel facial features (Australian uses this terminology).

Criteria for diagnosis under this category:

- Confirmation of PAE AND
- Evidence of severe impairment in three or more of the identified neurodevelopmental domains
- Presence of 0, 1 or 2 sentinel facial features

Appendix 1 – Table 5 provides more detail about the comparison of diagnostic guidelines.

There is a consensus of all four guidelines over the use of the Lip-philtrum guide to evaluate the lip and philtrum (Hayes et al., 2024; Hemingway et al., 2019). PFL growth charts have been developed for populations overseas. The first Australian Guidelines The Australian FASD Diagnostic Guidelines Review (Bower & Elliott, 2020) suggest using the Scandinavian (Strömland) charts if a child is under 6 years of age and Canadian (Clarren) charts if a child, adolescent or adult is over 6 years. However there is limited evidence regarding the use of normative charts (Hayes et al., 2024). One study found an artificial decrease in short palpebral fissures when the Clarren charts were used from 6 years (Hemingway et al., 2019). An Australian study found the Strömland palpebral charts were the best measure for Aboriginal children in one Australian community. The Australian Diagnostic Guidelines Review states "Based on this limited information available the Strömland palpebral charts are recommended for use across the lifespan." (Hayes et al., 2024).

The 4-Digit guideline indicates the measurement can be conducted directly with a ruler from a photograph, whereas the Canadian (Okulicz-Kozaryn et al., 2021) and Australian guidelines recommend the use of a computerized measurement (the Scottish guidelines give no recommendation). Although, of note Astley (2013) has since acknowledged the use of a ruler to measure PFL's is highly inaccurate. It is important to note that for Aotearoa (NZ) there are no guides or norms that represent our cultural context.

See Appendix 1 - table 7, Lip-philtrum Measurement.

Growth Impairment

The 4-Digit code includes growth impairment as a criterion for diagnosis, however, the Australian (original guidelines), Canadian, and Scottish guidelines have all excluded this feature (Hemingway et al., 2019), due to an inconsistent association with PAE (Cook et al., 2016). Although all three note growth impairment should be recorded if present. While the Canadian guidelines removed growth impairment from their diagnostic criteria, this is viewed as a controversial decision (Akison et al., 2019), which Okulicz-Koaryn et al. (2021) argue was based solely on O'Leary et al.'s (2009) study where the authors refer to small gestational age only. Astley et al. (2016) also disputes the dropping of growth impairment from the Canadian guidelines arguing that the result of their study empirically demonstrates that PAE causes growth deficiency, that growth deficiency is prevalent across the full spectrum, and that growth deficiency is highly predictive of severe CNS justifying its inclusion in the 4-Digit code. Of note, Hanlon-Dearmon et al. (2020) found that most pre-schoolers with confirmed PAE did not meet the growth criteria using the 4-Digit code unless they were diagnosed with FASD. In contrast a recent study by O'Connor et al. (2022) found that no child meeting the facial features, or neurocognitive criteria for pFAS under Hoyme et al.'s (2016) guidelines had growth retardation.

The Australian systematic review (Hayes et al., 2024) found evidence that indicated there was an association between heavy and very heavy PAE levels and small gestational age, low birthweight, lower gestational age, mean birthweight and birth length. Although these findings differed depending on age and different FASD diagnoses (e.g., FAS, pFASD and ARND/Other). Accordingly, growth was included as a specifier, rather than a key criterion, of the diagnostic criteria.

Neurodevelopmental Criteria

All four guidelines (Australian original guidelines, Canadian, Scottish, and 4-Digit code) require severe impairment in brain structure and neurology as well as impairment across neurodevelopmental domains. All the systems cover the full spectrum of diagnostic outcomes. They also adhere to strict criteria that use the standard medical/statistical definition of severe impairment being 2 or more SDs below the mean or its equivalent ≤2.5th percentile.

See Appendix 1 - table 10 Neurodevelopmental Criteria.

A diagnosis of FASD is given only when there is evidence of pervasive and long-standing brain dysfunction, which is defined by current guidelines as severe impairment (a global score or a major subdomain score on a standardised neurodevelopmental measure that is ≥2 SDs below the mean, with appropriate allowance for test error) in three or more of the neurodevelopmental areas of assessment. The 4-Digit code lists eight domains; executive function, memory, cognition, social/adaptive skills, academic achievement, language, motor and attention. Whereas the Canadian, Australian, and Scottish list 10 domains, with affect regulation, and social skills or social communication added.

Of note, Guilmette et al. (2020) indicate, there is considerable variability and lack of uniformity in the application of performance tests, as well as a lack of consistency in the definition of the term impairment. Inconsistencies in test publishers' recommendations can mean clinicians assigning different labels to the same standard score from different tests to follow the publishers' recommendations. This can lead to inconsistent and confusing reports for those using them. The Australian Review (Hayes et al., 2024) has provided guidance for what constitutes evidence of the definition of severe impairment and this guidance has been included in developing FASD diagnostic guidelines for Aotearoa (NZ).

The following table gives a summary of the association of PAE and neurodevelopmental domains (functional, structural and neurological) as analysed by the Australian systematic review. Note results are limited by difficulty quantifying PAE in the research literature. See Hayes et al. (2024) for full report.

Table 1. Evidence from the Australian Systematic Review: Functional Neurodevelopmental Outcomes

Domain & Outcome evidence
Attention Heavy PAE was associated with increased attention problems ranging from minor to large effects. Increased attention problems as reported by caregivers was associated with confirmed unquantified PAE but this evidence had a low confidence rating.
Behaviour The evidence demonstrated an association between PAE and behaviour problems and externalising behaviour problems, however all results had very low confidence ratings. Results were variable regarding PAE and internalising behaviour problems. FASD diagnosis was associated with increased behaviour problems with very low to moderate confidence. Outcomes also varied depending on exposure.
Executive Function and Working Memory The evidence showed an association with PAE and poorer scores on executive function and working memory measures, particularly for heavy PAE. Poor performance in executive function was found across all FASD diagnostic groups although the pFAS group showed significant variability in results. Overall results were rated as having very low to moderate certainty.
Language There was variability in the evidence but results generally confirmed an association between PAE and language performance with very low to low certainty.
Motor The evidence indicated that very heavy PAE was associated with a reduction in motor ability, although results varied between exposure, with no significant association found for light PAE.
Academic Of the limited studies available, an association was found between very heavy PAE and significant reductions in academic abilities, with very low to low certainty. While there was variability across the diagnostic groups, evidence indicated that as PAE levels increased there was an increase in academic difficulties. More consistent findings were found when academic abilities were separated into reading/literacy and numeracy/maths outcomes.
Memory Heavy PAE was associated with poorer memory abilities with very low to low certainty. No significant effects were found for light or moderate PAE levels. Poorer memory scores were associated with presence of a FASD diagnosis.
Intellectual abilities (i.e., cognitive, IQ scores) Confirmed unquantified PAE was associated with lower full-scale IQ scores. Variable results were found at the very heavy, heavy and moderate exposure groups depending on outcome measure. All FASD diagnoses were associated with lower full-scale, verbal and performance sub-scale and non-verbal IQ scores.
Adaptive behaviour and social functioning Heavy and very heavy PAE levels were associated with lower scores on adaptive behaviour and social functioning No significant association was found for light and moderate PAE levels. Diagnosis of FASD was associated with significantly lower adaptive functioning abilities and increased social problems.
Sensory processing and soft neurological signs Variable results were found with a small effect associated with moderate PAE levels. A diagnosis of FASD was associated with increased sensory difficulties.

Table 2. Structural and neurological Neurodevelopmental Outcomes

Domain & Outcome evidence
Head circumference Very heavy PAE was associated with a clinically significant reduction in head circumference at birth, while very heavy, heavy, and moderate, PAE levels were associated with increased odds of postnatal reduction in head circumference, although there was variability in effect across the exposure levels. Diagnoses of FAS and pFAS were generally associated with lower head circumference at birth and postnatally.
Structural brain abnormalities (clinical MRI) There were limited studies, but evidence demonstrated an association between PAE and increased odds of clinically significant incidental findings. There was variability within the diagnostic categories.
Visual impairment Variable results were found across the different PAE levels. Noted was the variability in definitions of visual impairment which impacted the ability to interpret findings.
Hearing loss While limited studies, the evidence indicated an association between heavy PAE and increased odds of abnormal hearing ability.
Seizures Only one study was available which found no risk of increased seizures was associated with light or moderate PAE, but more than one binge exposure was associated with increased risk.
Cerebral palsy Limited studies available, but findings indicated increased risk.

Direct and Indirect Assessment Methods

FASD is diagnosed when there is evidence of PAE together with significant differences across three brain domains and/or brain anatomy (Scottish Intercollegiate Guidelines Network, 2019). Schölin et al. (2021) note that while best practice recommends a neuropsychological profile of strengths and weaknesses, further research is necessary to identify the most sensitive and specific tests.

All four guidelines indicate the use of both direct and indirect measures where appropriate. Direct assessment is recommended wherever possible by the Canadian guidelines (i.e., formal, standardized, objective tests or physical measurements), and where indirect methods (i.e., informant rating scales, chart review, clinical interview) are necessary (because of age, or other factors), clinicians should ensure that information comes from multiple sources (Cook et al., 2016; Flannigan et al., 2022). This recommendation has also been adopted by the Australian and Scottish guidelines. Of note, Canadian research by K. McLachlan et al. (2023) identified four distinct subgroups of children and adolescents with PAE seen for FASD assessment. As there was considerable difference between the groups in terms of patterns of significant neurodevelopmental impairment, and mental health and physical health needs. The researchers suggest that rather than applying a one size fits all assessment approach a tiered, needs-responsive approach may be more beneficial.

At Risk of Neurodevelopmental Disorder and FASD, Associated with PAE

A key update to the 2015 Canadian guidelines, which have been adopted by both the Australian and Scottish guidelines is the addition of a non-diagnostic designation of "At-Risk for FASD and Neurodevelopmental Disorder" to capture individuals who do not meet the diagnostic criteria for FASD at the time of assessment but are nevertheless at-risk and will require follow-up (Coons-Harding et al., 2019). Of note, McLennan and Braunberger (2017) argue that the use of the phrase "at risk for neurodevelopmental disorder" designation may lead to negative consequences as a result of the label and may prime professionals to attribute concerns to PAE, ignoring or downplaying other potential contributing factors. Cook (2018) responds to this criticism that the "at risk" category provides a number of important benefits, flagging infants and pre-schoolers for an assessment at an appropriate age, providing a management plan, strategies and supports, and consistent care and intervention services. Cook (2018) concludes that the benefits outweigh the concerns raised by McLennan and Braunberger (2017).

See Appendix 1 - Table 12 for a comparison of the four guideline approaches to the "at risk" category.

Co-morbidities and other considerations

There are a number of co-morbid conditions and factors that need to be considered within an FASD assessment. A systematic literature review by Popova et al. (2016) identified 428 comorbid conditions in individuals with FASD. While Weyrauch et al. (2017) noted that individuals with FASD are ten times more likely to have ADHD compared to the general population. In a more recent Australian study by Dawe et al. (2023), over 60% of children with FASD were identified as having two or more comorbid diagnoses. Mukherjee (2021b) also notes others factors that need to be considered when assessing an individual for FASD, included the impact of other prenatal drugs, genetic factors, perinatal trauma, and post-natal neglect, such as seen in children in institutionalized care in Eastern Europe (Koren & Ornoy, 2021; Miller et al., 2006).

Of note, Dawe et al. (2023) highlight that the use of co-morbid diagnosis to fulfil diagnostic criteria area may cloud the clinical picture, as many of the behaviours, such as impulsivity, extreme emotional dysregulation, poor attention and concentration and executive function impairments, are shared diagnostic criteria with for example, ADHD and oppositional defiance disorder (ODD). These behaviours are also seen in children who have experienced neglect, maltreatment and/or trauma (Maguire et al., 2015; Mehta et al., 2023). Dawe et al. (2023) suggest that these factors may increase the possibility of a false-positive diagnosis of FASD because their presence may lead to a "severe"

rating across the neurodevelopmental domains of affect, attention and adaptive functioning.

Cultural Considerations

Kiyimba and Anderson (2022) note the need for embracing cultural difference in accounting for collective ways of healing, and to engage with cultural narratives that reflect a person's world view. Furthermore, Hewlett et al. (2023) share the need for healing informed strength-based practices that build on the spiritual interconnection between culture, community, country and kinship for Indigenous People. Apart from the Australian guidelines, the 4-Digit, Canadian and Scottish guidelines make little mention of cultural considerations and contexts in the diagnosing of FASD. Although, the Canadian guidelines state that it is important that information is communicated in a culturally meaningful manner using appropriate language, a recommendation that the Scottish have included in their guidelines as well. It is critical that consideration be given to differences in the cultural conception of a diagnosis. For example, Australian research by Hamilton et al. (2020) note differences in cultural patterns of response to a diagnosis of FASD. For example, Indigenous parents of children with FASD do not refer to the disorder by name or use medical terms. Furthermore, Indigenous parents talk about the impact of the disorder, not only in terms of the child, but the family and wider community as well. In contrast, non-Indigenous parents of children with FASD only talk about how the disorder impacted specifically on their child. Indigenous parents report more difficulty with the type of language used in the reports, and some report needing to find assistance to understand the report. While another Australian study by Hewlett et al. (2023) highlighted the need for clinicians to provide a shared communication space to enable Aboriginal peoples to explore and share their stories through storytelling and yarning, a factor often inhibited by a lack of time within the assessment process.

Importantly Curtis et al. (2019) highlight the need for health practitioners, healthcare organisations and health systems to be working towards cultural safety rather than cultural competency. This means acknowledging and reflecting on power differentials within society and between health care professionals and the people they see. Cultural safety, unlike cultural competency, moves the focus from the culture of the patient to that of the clinician or the clinical environment and requires the clinician to consider the impact of their own attitudes and biases on the quality of healthcare the patient receives.

To practice with cultural safety Curtis et al. (2019) recommend following these core principles:

- Be clearly focused on achieving health equity, with measurable progress towards this endpoint.
- Be centred on clarified concepts of cultural safety and critical consciousness rather than narrow based notions of cultural competency.
- Be focused on the application of cultural safety within a healthcare systemic/ organizational context in addition to the individual health provider-patient interface.
- Focus on cultural safety activities that extend beyond acquiring knowledge about 'other cultures' and developing appropriate skills and attitudes and move to interventions that acknowledge and address biases and stereotypes.
- Promote the framing of cultural safety as requiring a focus on power relationships and inequities within health care interactions that reflect historical and social dynamics.
- Not be limited to formal training curricula but be aligned across all training/practice environments, systems, structures, and policies.

(Curtis et al., 2019, p. 14)

See Appendix 1 - table 13 for a comparison of the four guidelines approaches to cultural considerations in the diagnosis of FASD.

Feedback from Professionals to Whānau

There are a number of factors which professionals need to consider when providing feedback to whānau. For example, research suggests that diagnosing professionals need to be aware that the diagnostic process is viewed as complex for parents/caregivers and service providers alike (Baskin et al., 2016). Also, there are a multitude of ways individuals will respond so a personalised response is recommended (Rutherford et al., 2021). When providing feedback, professionals need to give parents a balanced perspective of the diagnosis, where they have a realistic understanding of the challenges, but maintain a sense of hope (Baskin et al., 2016). Further, parents/caregivers need to be given adequate time to process and take on board the assessment information (Baskin et al., 2016; Pearson, 2023; Rutherford et al., 2021).

Professionals should provide feedback utilising a number of strategies. For example, visual aids can be used to support verbal feedback as this will help increase caregiver understanding of the unique profile of their child (including strengths and challenges) (Ola et al., 2020). Also, parents should receive written recommendations informed by the child's and family's needs, along with evidence-based recommendations (Ola et al., 2020). Such recommendations are important as research highlights that parents find recommendations provided in the report about their child to be helpful and affirming, providing insight into their child (Chamberlain et al., 2017). Although some parents report feeling overwhelmed by too much information (Pearson, 2023; Pruner et al., 2020).

Professionals need to be aware that for some parents it may take months or years to understand and accept their child's diagnosis. The need to address, validate, and affirm parents' expectations and emotional experiences can play an integral role in supporting them (Baskin et al., 2016). Ola et al. (2020) also recommend that parents receive a number of sessions to help them understand the assessment results, as well as supporting them with their emotional and cognitive processing, and encouraging them to implement recommendations. This type of process can improve parent engagement, enhances parent view of child, and increases self-efficacy. Ola and colleagues also suggest providing referrals, support in applying for services, and coordinating with schools. For adults receiving a diagnosis of FASD Temple et al. (2015), note they will need specific support in dealing with the diagnoses, including feelings of blame toward parents, anxiety, and self-esteem issues. They may also reject or ignore the diagnosis and take several months to return to the clinic. This highlights the need for careful consideration to be given to the delivery of the report, and the follow up support provided. Similar to Ola et al. (2020), Temple et al. (2015) note that two or three follow-up sessions may be required to go over the diagnosis and information given at the initial report session. They also suggest that explaining the diagnosis to adults receiving an FASD report using visual supports and avoiding technical language can be helpful. Likewise, Hamilton et al. (2020) note that Indigenous parents of children with FASD in Australia prefer visual strategies and required assistance to understand the reports (including the type of language being used).

Finally, Australian research by Doak et al. (2019) found that while the provision of feedback is viewed by caregivers as providing positive benefits, they also reported difficulties accessing recommended supports, or found that recommendations were impractical for their family's situation or felt overwhelmed by all the information and lost in the process (Doak et al., 2019). Similar findings have been reported in other international studies (Bower et al., 2018;

Fitzpatrick & Pestell, 2017; Michaud & Temple, 2013; Waddell et al., 2018), and in Aotearoa (NZ) (Alcohol Healthwatch, 2007; Bagley, 2019; Gibbs & Sherwood, 2017).

The Australian guidelines note that diagnosis may be confronting, and appropriate consent should be gathered beforehand and appropriate support be provided during and after diagnosis (Bower et al., 2017). Similarly, the Canadian and Scottish guidelines note that the psychosocial impact of receiving a diagnosis should be discussed. Hayes et al. (2022) assert guidelines need to be user friendly, use patient centred and non-judgemental language, while Passmore et al. (2016) maintain that it is crucial for information that is gathered through the diagnostic process to be communicated back to the individual. It is critical that parents are supported through the assessment, which can be an intense process, not only for the parent's well-being, but for the long-term outcome of the child and family (Baskin et al., 2016).

Post Diagnostic Support/ Therapy

"It is important to recognise however, the diagnosis is not an end point but only really the start of the journey for improving the outcomes for these children. A diagnosis in itself is often not enough" (Mukherjee, 2021a, p. 262).

Once a diagnosis has been provided and an understanding of the strengths and challenges of the individual has been gained, management of needs should be delivered by a variety of methods and approaches. Across sector support is often required from social care, education, criminal justice system and housing (Mukherjee, 2021a).

Management and Referral Pathways

"A diagnosis and management plan can contribute to positive long-term outcomes for the child and their family" (Bowers et al., 2020. P. 52).

Follow up after a diagnosis is a key area of consideration as caregivers report concern over the lack of adequate professional support after their child has been diagnosed with FASD (Chamberlain et al., 2017; Pearson, 2023; Weinmann et al., 2021). Indeed Wozniak et al. (2019b) assert that a diagnosis without available follow-up treatment and support is of limited utility. Mukherjee and Aiton (2021) assert that current management and post diagnosis support services are inadequate and that there is a critical need for supported structures to be in place along with therapeutic interventions. This reinforces earlier research by Chamberlain et al. (2017) who note that caregivers report wanting more ongoing long-term support after a diagnosis of FASD has been provided. While this need has been identified, research also highlights that parents/caregivers experience difficulties navigating health and education systems with communication across these systems being uncoordinated and difficult (Baskin et al., 2016). Indeed, Masotti et al. (2015) argue there is a need for automatic sharing of information between systems of care to increase information sharing across different sectors of support. Of note, research conducted in Aotearoa (NZ) by Bagley (2019) highlights that professionals working with individuals with FASD report a gap in services for FASD-affected families.

As previously discussed, a multidisciplinary team is considered crucial in providing appropriate assessment and diagnosis support (Cook et al., 2015; Coons-Harding et al., 2019; Rutherford et al., 2021), and is also recommended for management once a diagnosis of FASD has been made (Skranes & Løhaugen, 2021). Children, adolescents, and adults with FASD can present with a range of complex and substantial needs when undergoing a diagnostic assessment. These needs will require the provision of ongoing needs-based services across the lifespan (K. McLachlan, Flannigan et al., 2020), especially during transitions (Rutherford et al., 2021). Research has identified a number of support services, activities and needs including "promoting and maintaining client health and safety, supporting basic needs (including supportive housing), assisting with service navigation, increasing advocacy, offering case management and mentorship, delivering life skills programs and support groups, developing collaborative intervention and follow-up plans, and promoting overall wellbeing" (Flannigan, Wrath, McFarlane et al., 2021, p. 13). Unfortunately, there is limited research when it comes to the clinical management of FASD regarding both standardised tailored management programs, as well as recommendation plans/guidelines for the provision of healthcare, educational and social services (Skranes & Løhaugen, 2021). Hayes et al. (2022) report the need for improved feedback/reports and post assessment support, including more guidance on completing an effective management plan, easy access to available support services that are accurate and knowledgeable, and follow up to provide ongoing insight into best practice for managing FASD. Similarly, Pearson (2023) identified the need for a 'key worker' or 'co-ordinator' role to provide ongoing assistance in the management of recommendations made in the assessment report as well as to support families transitioning from the clinical diagnostic team to community services.

All four of the diagnostic guidelines recommend a follow up plan be developed after the assessments have been completed. While the 4-Digit guidelines only refer to the need for a management plan, the other three guidelines provide greater detail on developing a management plan. For example, the Australian guidelines recommend that after completing a diagnostic assessment, irrespective of outcomes, health professionals should coordinate the diagnostic process. This includes discussing the outcome of the assessment, developing a management plan, and including referral, management strategies and review dates.

See Appendix 1 - table 14 for a comparison of the guidelines management and referral pathway recommendations.

Section Three

This next section will consider models of care, and discussion of whānau experiences of the diagnostic process.

Models of Care

Pei et al. (2021) highlight that currently there is difficulty in fitting those with FASD into current systems of care delivery. Pei and colleagues suggest the policy makers need to incorporate overarching principles into such systems including the need for consistency within agencies, collaboration between systems of care, responsiveness to needs, along with proactivity in anticipating needs. Similarly, Reid, Crawford et al. (2022) note the lack of specialised support service required to support the needs of individuals with FASD and their families across multiple systems of care, and for the lifespan. Reid, Crawford et al. (2022) assert, firstly, that families need to be empowered in the management process to improve outcomes. Secondly, models of care are needed that facilitate professionals and families working collaboratively to equip families with the skills needed to effectively support their child with FASD. Finally,Reid, Crawford et al. (2022) note models of care also need to consider historical and contextual factors that can impact on the ability of families to provide appropriate support. Reid, Crawford et al. (2022) also suggest that a range of factors need to be considered to inform targeted recommendations and supports for an individual with FASD, including physical, social, cultural, mental health and well-being factors as part of holistic assessment process. Reid, Crawford et al. (2022 propose a model of care that focuses on a family directed intervention approach which seeks to identify the specific strengths and needs of the family. Professionals can apply components of the model in a flexible and individualised way, collaborating with family and community leaders to provide compassionate support and appropriate interventions. See figure 1 for Reid, Crawford et al. (2022) proposed integrated theoretical framework to support professionals in collaborating with families in the provision of services for children with FASD. Note: The aqua section represents the family social economy (p. 11)

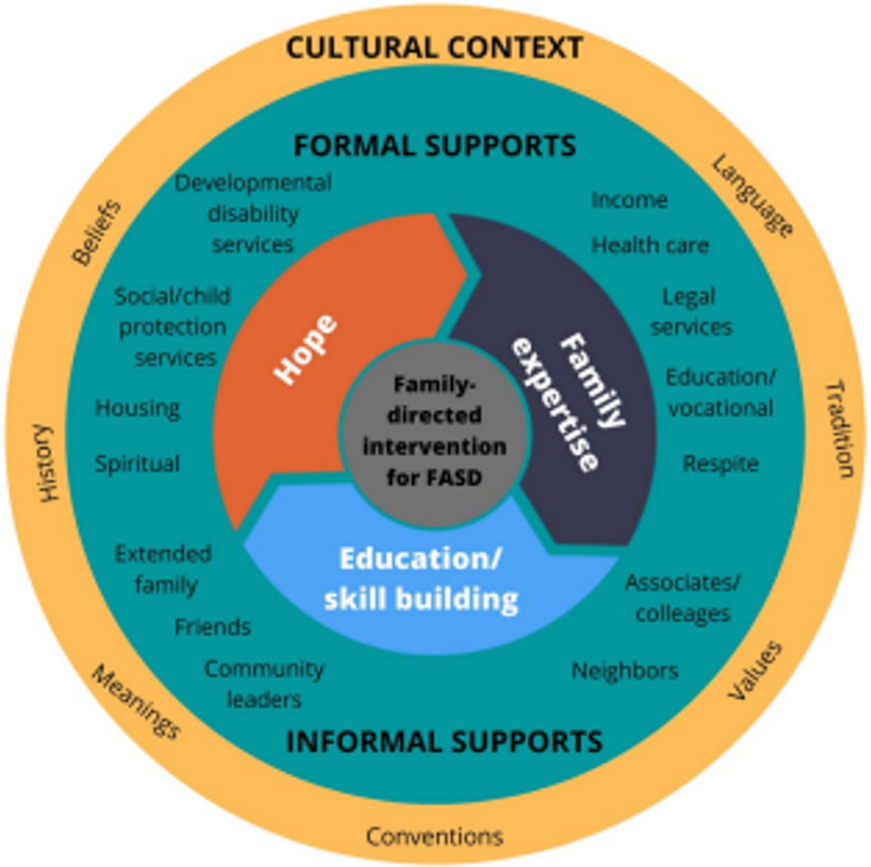

Figure 1. Integrated Theoretical Framework of Care in the Provision of Services for FASD. Reprinted with permission.

In Aotearoa (NZ) Whānau Ora ('healthy families) is a policy response to making a more responsive and effective health system for Māori and other marginalised communities by reducing inequity and promoting the well-being of whānau. Whānau Ora is a whānau centred approach that focuses on cross-sector collaboration, building and strengthening capabilities within whānau, and addressing health and well-being needs at the whānau level (Health Quality and Safety Commission, 2019; Smith et al., 2019). The underlying philosophy of the Whānau Ora framework recognises the multiple factors that can support whānau well-being. The framework is underlined by seven key principles:

- ngā kaupapa tuku iho (the ways in which Māori values, beliefs, obligations and responsibilities are available to guide whānau in their day-to-day lives)
- whānau opportunity
- best whānau outcomes
- whānau integrity
- coherent service delivery
- effective resourcing
- competent and innovative provision.

The framework and principles aim to support whānau goals of self-managing, living healthy lifestyles, participating fully in society, confidently participating in te ao Māori, and being economically secure and successfully involved in wealth creation and cohesive, resilient and nurturing. The model also highlights the crucial role of leadership (whānau, hāpu and iwi), funding, government, whānau-centred services and whānau engagement in supporting whānau ora, along with the reciprocal relation between these factors and whānau ora. For example, how strong leadership can enhance whānau ora, and likewise whānau ora can enhance strong leadership (Durie et al., 2010, p. 19) (see figure 2).

Figure 2. Whānau Ora Framework (Durie et al., 2010, p. 19).

Whānau ora, whilst originally conceived as a Māori response to Māori needs, has evolved to encompass all those in need in Aotearoa (NZ) (Smith et al., 2019).

When looking at models of health and well-being it is important to understand differences in worldview and cultural orientation and how these impact a person's view of health (Wilson et al., 2021). In Aotearoa (NZ) health services follow a biomedical model that is individualistic, problem based, and tends to focus on physical well-being alone (Durie, 1998; Health Quality and Safety Commission, 2019). This approach contradicts the holistic, relational based worldview of Māori on health and well-being (Jansen et al., 2008; Rochford, 2004) and fails to take into account the holistic dimensions of Māori health which are wairua (spiritual), whānau (extended family network), hinengaro (the mind), and tinana (physical) (Wilson et al., 2021). While biomedical models may be relevant and meaningful within some cultures and contexts, Māori models which provide Māori centred relational models of care, that build relationships that include whānau, may be more relevant and meaningful for Māori (Wilson et al., 2021). Holistic Māori models of care have been developed to provide culturally competent care and help reduce disparities (Al-Busaidi et al., 2018). For example, Te Whare Tapa Whā, (Durie, 2011; Rochford, 2004), and the Meihana model (Pitama et al., 2014, 2017), provide frameworks for clinical history taking that can aid Māori and non-Māori practitioners gain a broader understanding and work more effectively with Māori (Al-Busaidi et al., 2018; Pihama et al., 2017). Dawson et al. (2019) assert that including important ethnic/cultural values of Māori in measures designed to redress health inequity are a way of meeting responsibilities of Te Tiriti o Waitangi.

Lived Experience of Diagnostic Process

> *"Diagnosis matters to people seeking and receiving assessment. However, the process is experienced differently, and sometimes it is positive, while at other times it may be challenging" (Rutherford et al., 2021 p. 13).*

People can experience a range of emotions when receiving a diagnosis of a disability or chronic disease, including shock, grief, stress and feeling overwhelmed and distressed (Boyse et al., 2014; Edwards et al., 2018; Hummelinck & Pollock, 2006; Jessup et al., 2016; Nelson Goff et al., 2013). Similarly, parents report getting a diagnosis of FASD can be a struggle (Chamberlain et al., 2017; Coons, 2013; Sanders & Buck, 2010), with some families and caregivers finding the assessment process confronting (Bower et al., 2017). Biological mothers report experiencing grief and guilt upon receiving the diagnosis (Sanders & Buck, 2010), a finding supported by Aotearoa (NZ) research of biological mothers of children with FASD (Salmon, 2008). Young people have expressed anger about being diagnosed with FASD (Knorr & McIntyre, 2016). While adults receiving a diagnosis of FASD experience anxiety, self-esteem issues and a sense of blame towards their parents (Temple et al., 2015). In a more recent study Temple et al. (2021) noted that adults with FASD felt the diagnosis overall had been helpful in accessing supports, and led to improved insight and understanding of themselves, however some still struggled with what would happen to them in the future. In other studies families report a sense of relief at receiving a diagnosis of FASD (Salmon, 2008; Sanders & Buck, 2010).

A diagnosis can also lead to better understanding of challenges faced by the child (Baskin et al., 2016), although this does not necessarily lead to improved understanding by professionals (Baskin et al., 2016; Chu et al., 2022). Diagnosis may also allow a "legitimate claim" for supports and services (Hamilton et al., 2020; Temple et al., 2021), however, this may not always be the case (Baskin et al., 2016), especially if they do not meet the criteria to qualify for disability and education support services (Petrenko et al., 2014; Turchi et al., 2018). Currently in Aotearoa (NZ), FASD is not recognised as a disability, and individuals do not have access to funded disability support services unless the person has a co-morbid Intellectual Disability or other funded diagnosis like autism (Alcohol Healthwatch, 2007; Gibbs & Sherwood, 2017).

Research indicates that families will have an immediate and ongoing need for information after receiving a diagnosis of FASD (Brown et al., 2005; Chamberlain et al., 2017; Coons et al., 2016). Unfortunately, parents can feel that they are not receiving enough information from professionals (Mukherjee et al., 2013), and that there is a lack of ongoing information, particularly around transitions and developmental and anticipatory guidance (Pruner et al., 2020). Of note, some parents report being overwhelmed by information, especially when large lists of resources are provided to parents after they have received their child's diagnosis (Pruner et al., 2020). It is therefore critical to consider how assessments are conducted, and how information is communicated to whānau. Research suggests that information should be provided in a way that is appropriate and supportive of caregivers, allowing them to gain a good understanding of the information (Doak et al., 2019). Information should avoid using jargon and technical or medical language (Hamilton et al., 2020; Pei et al., 2013; Temple et al., 2015). Unfortunately, research in Aotearoa (NZ) has indicated that parents/caregivers struggle with the length and complexity of diagnostic reports (Parsonage et al., 2015; Rogan & Crawford, 2014; Salmon, 2008). Importantly, information should also be tailored and specific to the family and their unique circumstances (Doak et al., 2019), including, as already noted, taking into account cultural differences in how diagnostic information is interpreted and applied (Hamilton et al., 2020).

Conclusion

FASD is a complex neurodevelopmental disorder with wide ranging, life-long impacts. It occurs as the result of prenatal alcohol exposure. While prevalence rates very and are higher in special populations, FASD is found across all socioeconomic groups, ethnicity and education levels. Receiving a diagnosis of FASD is considered critical in supporting positive outcomes. Currently there are a number of international diagnostic guidelines for FASD, but none that take into account Aotearoa's cultural and social contexts of health and wellbeing. Research highlights a number of issues within pre-diagnosis engagement, assessment and post-diagnostic areas of care. Currently a lack of diagnostic capacity, different diagnostic systems and the impact of stigma, colonisation and systemic racism create barriers to receiving a diagnosis of FASD. While a lack of culturally safe and meaningful assessment tools, and a lack of knowledgeable and culturally competent professionals impacts on experience of assessment services for whānau. Finally, the considerable lack of post diagnostic pathways to supports and services leave individuals and their whānau with ongoing needs that are not being met, further exacerbating the impact of FASD.

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Appendix 1: Comparison of International Guidelines

Table 3. Special Considerations in the Assessment of Adolescents and Adults

4-Digit Code	Canadian	Australian	Scottish
Little mention of special considerations in adulthood, except that adults may not be able to reconstruct their early histories.	Assessment and diagnosis of adults (adults are defined as age of majority and onwards) require special considerations to address the many challenges and barriers that often present, including limited family support, poverty, homelessness, mental health addiction, legal problems, and parenting challenges. Referrals for the assessment may be initiated by a variety of sources including the individual, their family, community services agencies, medical service providers, and government departments and ministries such as Mental health and Addictions Services, Justice, and Children's' service. The referral source is often an indicator of the type of challenges or secondary disabilities the individual is currently experiencing or can be a reflection of their life stage, such as a youth transitioning to adulthood or an adult with aging parents and can provide important information for the management plan to ensure maximum success. · When it is not possible to obtain a formal adaptive behaviour measure or when there is no suitable informant, historical or current information, derived from a file review, may be used as a proxy. · The diagnostic criteria for FASD are the same for adults as for younger individuals. · Recommendations following the assessment must address basic and immediate needs of the client and assist them in accessing required resources. · When young adults are transitioning to independent living situations, it may require that they undergo a reassessment to identify changes in their adaptive function and to make subsequent adjustments to their management plan.	Special considerations in the assessment for FASD in adolescents and adults include: · Changes in physical characteristics that occur with age, e.g., facial features. · Obtaining information about the pregnancy (including prenatal alcohol exposure) and early childhood may be difficult. · Adolescents/adults may require different types of assessment than children. · Functional manifestations of FASD may differ in adolescents/adults e.g., problems with sexual behaviour, psychological and mental health, substance misuse, vocational training and employment, risk taking behaviour, independent living, and contact with the legal system. · Social and family situation e.g., living independently, in supervised residential care or detention, may impact on validity of testing using observer reports. Evaluation of general and sexual health, substance use, protective factors and risk-taking behaviour is important to assess the individual's overall health and well-being and may provide supporting indirect evidence for impairment in FASD domains. For example, poor judgement and limited experiential learning may suggest impairment in executive functioning. There are also some specific considerations when assessing the domain of Adaptive behaviour, social skills or social communication in older adolescents and adults.	Due to the current under-recognition of FASD in Scotland, presentation may occur at a later stage. Adopted Canadian recommendations: · The diagnostic criteria for FASD are the same for adults as for younger individuals. · When it is not possible to obtain a formal adaptive behaviour measure or when there is no suitable informant, historical or current information, derived from a file review, may be used as a proxy. · The length and structure of the assessment must accommodate the needs and capacity of the individual being assessed. It is important to recognise, for example, if the individual gets frustrated or tires easily; situational factors could invalidate the assessment. · The core principles of bioethics, including autonomy and consent, confidentiality, beneficence, and non-maleficence must be carefully applied.

Table 4. Multidisciplinary Team

4-Digit Code	Canadian	Australian	Scottish
Diagnosis by a multidisciplinary team of professionals (physician, psychologist, speech-language pathologist, occupation therapist, etc).	**Infants (<18 months)** · Paediatrician/physician. · Child development specialists with skillset to conduct physical and functional assessments (e.g., speech -language pathologist, physiotherapist, Occupational therapist, Clinical psychologist). **Pre-schoolers (18 months – 5 years)** · Paediatrician/physician. · Occupational therapist. · Speech-Language Pathologist. · Psychologist. **School Aged children (6 yrs. – age of majority)** · Paediatrician/physician with expertise in FASD and differential diagnosis. · Occupational Therapist. · Speech-Language Pathologist. · Psychologist. **Adults** · Physician. · Psychologist. · Speech-Language Pathologist · Psychologist. Additional individuals who can provide valuable input into the diagnostic process may include addiction counsellors, childcare workers, cultural interpreters, mental health professionals, parents or caregivers, advocates, mentors, probation officers, psychiatrists, teachers, vocation counsellors, nurses, clinical geneticists or dysmorphologists, neuropsychologists, social workers, nurse practitioners and family therapists.	Clinicians participating in a diagnostic assessment may include, but are not limited to: A Paediatrician, Psychologist, Speech and Language Pathologist and an Occupational Therapist. Ideally assessment is performed by a multidisciplinary team that includes a Paediatrician or Adolescent Physician and Psychologist and any combination of Speech Pathologist, Occupational Therapist, Social Worker, and Physiotherapist depending on availability of trained professionals. Referral to Psychiatrist, Clinical Geneticist or Neurologist may be required if clinically indicated.	Removes lifespan approach but includes: · Neonatologist/Paediatrician/Physician with competency in assessment of FASD. · Child development specialists with skillset to conduct physical and functional assessments (e.g., Speech and Language Therapist, Occupational Therapist, Clinical Psychologist, Educational Psychologist. · Further individuals who can provide valuable input into the diagnostic process may include parents and carers, Advocates, Childcare Worker, Clinical Geneticist, Cultural Interpreters, Family Therapists, General Practitioners, Learning Support, Mental Health Professionals, Mentors, Nurse, Neuropsychologists, Probation Officers, Psychiatrists, Social Workers, Substance Misuse Service Staff, Teachers, and Vocational Counsellors.

Table 5. Diagnostic Categories

4-Digit Code	Canadian	Australian	Scottish
Fetal alcohol syndrome (FAS), partial FASD (pFAS), static encephalopathy/ alcohol-exposed (SE/ AE), which involves structural evidence of brain damage and/ or severe dysfunction, and neurobehavioral disorder/alcohol-exposed (ND/AE), which involves mild–moderate dysfunction and these fall under the umbrella of FASD.	FASD with 3 Sentinel Facial Features · Prenatal alcohol exposure confirmed or unknown. FASD without Sentinel Facial Features · Confirmation of prenatal alcohol exposure, with the estimated dose at level known to be associated with neurodevelopmenttal effects.	FASD with 3 Sentinel Facial Features · Prenatal alcohol exposure confirmed or unknown. FASD with< 3 Sentinel Facial Features · Prenatal alcohol exposure confirmed.	FASD with sentinel facial features (short palpebral fissures, smooth philtrum, and thin upper lip) · Prenatal alcohol exposure confirmed or unknown. FASD without sentinel facial features · Confirmation of prenatal alcohol exposure.

Table 6. Lip-philtrum Measurement

4-Digit Code	Canadian	Australian	Scottish
Clinical cut-off for palpebral fissure length and which lip/philtrum guide is used.	FAS = PFL ≤ 2.5th percentile /2 SD below the mean; Lip and Philtrum Rank 4 or 5 University of Washington Lip-philtrum guide. pFAS = Two of PFL, lip, and philtrum ≤ 2 SD below the mean, and the other feature >-2 SD and < -1 SD .	FASD with the three sentinel facial features = PFL ≤ 3rd percentile/2SD below the mean; Lip and Philtrum Rank 4 or 5. University of Washington Lip-philtrum guide.	FASD with the three sentinel facial features = PFL > 2 SD below the mean; Lip and Philtrum Rank 4 or 5. University of Washington Lip-philtrum guide.

Table 7. PAE Confirmation

Diagnostic Criteria

Inclusion of specific level of prenatal alcohol exposure required for diagnosis.

4-Digit Code	Canadian	Australian	Scottish
Two accepted levels of PAE confirmation; (a) PAE is consistent with the medical literature placing the fetus at "high risk" OR (b) PAE is confirmed but in lower amounts than above or exact amounts unknown. FAS: unknown PAE accepted.	PAE with an estimated dose at a level known to be associated with neurodevelopmental effects. Appendix states: threshold known to be associated with neurodevelopmental effects is 7 or more standard drinks per week, or any episode of drinking 4 or more drinks on the same occasion. Because the effect sizes seen with a single binge episode are relatively small, a threshold of 2 binge episodes is recommended as a minimum for diagnosis. Threshold 7+ standard drinks per week (9.5 NZ std drinks) or Any episode 4+ std drinks (5.4 NZ std drinks). FASD with sentinel facial features: unknown PAE accepted.	No specific level of PAE is required for diagnosis. Confirmed exposure – Audit-C score = 1-4 but less than confirmed high risk for FASD. Confirmed high risk for FASD 1. IAUDIT-C score = 5+. 2. Reported consumption of 5 or more standard drinks on one occasion. 3. Other reliable evidence of high consumption. FASD with sentinel facial features: unknown PAE accepted.	Full spectrum: No specific level of PAE is required for diagnosis. FASD with sentinel facial features: unknown PAE accepted.

Table 8. Neurodevelopmental Domains

4-Digit Code	Canadian | Australian | Scottish
motor cognition language academic achievement memory attention executive function social/adaptive skills	motor skills cognition language academic achievement memory attention executive function (including impulse control and hyperactivity) affect regulation adaptive behaviour, social skills or social communication

Table 9. Neurodevelopmental Criteria

Guideline

Definition of impairment in neurodevelopment – structure and function.

4-Digit Code	Canadian	Australian	Scottish
Brain structure and neurology: Rank 4: Microcephaly = OFC ≥ 2 SD below the mean or Significant brain abnormalities of presumed prenatal origin (i.e., hydrocephaly, heterotopias, change in shape and/or size of brain regions) or Seizures not due to a postnatal insult or other postnatal process or Other hard neurological signs of presumed prenatal origin. **Brain function:** Rank 3: Significant impairment (≥ 2 SD below the mean) across three or more domains including, but not limited to: executive function, memory, cognition, social/adaptive skills, academic achievement, language, motor, attention, or activity level. Scores must come from standardized psychometric tests. Rank 2: Evidence of delay/dysfunction that suggest the possibility of CNS damage, but data to this point do not permit a Rank 3 classification. Evidence can come from standardized psychometric tests, observational data, and/or caregiver interview. FAS, pFAS, Static encephalopathy = Rank 3 or 4. Neurobehavioral disorder = Rank 2.	Canadian Brain structure and neurology: OFC = < 3rd percentile or ≥ 2 SD below the mean or Structural brain abnormalities associated with PAE or Seizures not due to a postnatal insult or other postnatal process. Brain function: Severe impairment (≥ 2 SDs below the mean) required in 3 areas of: brain structure/neurology; motor skills; cognition; language; academic achievement; memory; attention; executive function (including impulse control and hyperactivity); affect regulation; adaptive behaviour, social skills or social communication or A significant discrepancy (seen in less than 3% of the population) between major subdomain scores on language, memory, or cognition testing, or for academic achievement in relation between cognition and any subject. All diagnoses: Severe impairment in at least 3 neurodevelopmental domains (brain structure/neurology or functional).	Brain structure and neurology: OFC = < 3rd percentile or ≥ 2 SD below the mean or Structural brain abnormalities associated with PAE (i.e., overall brain size, corpus callosum agenesis or hypoplasia, reduced gyrification or surface area of the cerebral cortex, reduced volume in cerebellum, hippocampus, basal ganglia) or Seizures not due to a postnatal insult or other postnatal process or Significant neurological diagnoses (i.e., cerebral palsy, visual impairment, etc.) without other etiological cause. Brain function: Severe impairment (≥ 2 SDs below the mean, or less than the 3rd percentile) on a global or major subdomain score on a validated neurodevelopmental scale required in 3 areas of: brain structure/neurology; motor skills; cognition; language; academic achievement; memory; attention; executive function (including impulse control and hyperactivity); affect regulation; adaptive behaviour, social skills, or social communication or A significant discrepancy (seen in less than 3% of the population) between major subdomain scores on language, memory, or cognition testing, or for academic achievement in relation between cognition and any subject. All diagnoses: Severe impairment in at least 3 neurodevelopmental domains (brain structure/neurology or functional).	Brain structure and neurology: OFC = < 3rd percentile or ≥ 2 SD below the mean or Structural brain abnormalities associated with PAE or Seizures not due to a postnatal insult or other postnatal process. Brain function: Severe impairment (≥ 2 SDs below the mean) required in 3 areas of: brain structure/neurology; motor skills; cognition; language; academic achievement; memory; attention; executive function (including impulse control and hyperactivity); affect regulation; adaptive behaviour, social skills or social communication or A significant discrepancy (seen in less than 3% of the population) between major subdomain scores on language, memory, or cognition testing, or for academic achievement in relation between cognition and any subject. All diagnoses: Severe impairment in at least 3 neurodevelopmental domains (brain structure/neurology or functional).

Table 10. Direct and Indirect Assessment

4-Digit Code	Canadian	Australian	Scottish
Utilises both direct and indirect measure. Refers to direct and other measures for measuring facial features. Mention the need to routinely enquire into the patient's capabilities when completing the CNS section of diagnoses form as it is useful to compare this subjective assessment to the psychometric profile. Has both standardized and non-standardized assessment methods.	Direct standardized measure should be used to assess brain domains whenever possible, and this is recommended for the majority of evidence for brain dysfunction. In cases where it is not possible to use direct, indirect assessment methods such as informant ratings, clinical interview, or historical assessment through file review may be used. When using indirect methods of assessment clinicians should ensure that information comes from multiple sources rather than a single informant. Direct testing refers to standardised testing or physical measurements. Advantages: relative objectivity and lack of observer bias. Disadvantages: absence of ecological validity, test environment may not translate to real world situations. Indirect Assessment Advantages: more ecological validity. Disadvantages: Risk of subjective bias.	When available, standardised assessment tools should be used that are appropriate for the age, developmental or educational level of the child, and their cultural and linguistic background. Indirect assessment uses a combination of clinical observation or examination, and evidence from multiple sources and/or standardised observer or self-report rating scales to measure the functional manifestations of neurodevelopmental impairment (e.g., parent and teacher rating scales to measure inattention or adaptive behaviour, and observation to assess quality of social communication during play). Direct assessment is preferred; however, in assessing some domains (e.g., Attention) a combination of direct and indirect assessment can be used. Use of indirect assessment alone is indicated when standardised tests are not available (e.g., when using DSM-5 (30) diagnostic criteria to document depression and anxiety for the Affect regulation domain).	Clinical training required to interpret test results and experienced clinicians will evaluate scores within the context of a complete assessment picture. Direct testing refers to standardised testing or physical measurements. Advantages: relative objectivity and lack of observer bias Disadvantages: absence of ecological validity, test environment may not translate to real world situations. Indirect Assessment Advantages: more ecological validity Disadvantages: Risk of subjective bias Recommendation is to follow Canadian Guidelines: i.e., direct standardised measure should be used wherever possible, but in some case, indirect assessment methods, such as informant ratings, clinical interview, or historical assessment may be more appropriate. When using indirect methods of assessment, clinicians should ensure that information comes from multiple sources rather than a single informant.

Table 11. At Risk Category

4-Digit Code	Canadian	Australian	Scottish
No 'at risk' category included.	At Risk of Neurodevelopmental disorder and FASD, Associated with Prenatal Alcohol Exposure. Not a diagnosis but a designation that should be given to individuals when: · There is confirmation of prenatal alcohol exposure, with the estimated dose at a level known to be associated with neurodevelopmental effects. · CNS criteria are not met. · There is some indication of neurodevelopmental disorder in combination with a plausible explanation as to why the neurodevelopmental assessment results failed to meet the criteria for significant impairment (e.g., patient was too young; assessment was incomplete). · This designation may also be considered for individuals with all 3 sentinel facial features, who do not yet have documentation or evidence for the requisite 3 or more neurodevelopmental domain criteria or true microcephaly. · This designation should never be considered when PAE confirmation absent. For this designation, a person may have FASD, but it cannot be determined at this time. A full reassessment, including the neurodevelopmental assessment, must be performed at a later date, as appropriate. At risk designation can be withdrawn if individual does not show a true neurodevelopmental disorder in later years. Growth impairment and other alcohol-related birth defects should be documented if present. Hereditary, prenatal, and postnatal factors that may influence developmental outcome should be recorded.	In some circumstances, a clinician may identify individuals who, despite having undergone assessment, fail to fulfil criteria for diagnosis for FASD at the current time, but may nevertheless potentially have FASD. Some example situations include: · Neurodevelopmental assessment is incomplete or inconclusive. · Despite confirmed PAE, neurodevelopmental impairment is present in fewer than three domains. · Neurodevelopmental impairment is present in three or more domains, but impairment is insufficiently severe to meet criteria. · Comprehensive, age-appropriate neurodevelopmental assessment is impossible or unavailable e.g., in infants and young children. Growth impairment and other congenital anomalies should be documented if present Hereditary, prenatal, and postnatal factors that may influence developmental outcome should be recorded.	The designation 'at risk for neurodevelopmental disorder and FASD, associated with prenatal alcohol exposure' was created to describe individuals who have confirmed prenatal alcohol exposure and some indication of neurodevelopmental concerns, but who do not meet the criteria for either of the FASD categories. The designation 'at risk for neurodevelopmental disorder and FASD, associated with prenatal alcohol exposure' should be given to individuals when: · There is confirmation of prenatal alcohol exposure · The CNS diagnostic/descriptive criteria for FASD are not met · There is some indication of neurodevelopmental disorder in combination with a plausible explanation as to why the neurodevelopmental assessment results failed to meet the criteria for significant impairment (for example patient was too young; assessment was incomplete etc). Growth impairment and other congenital anomalies should be documented if present. Hereditary, prenatal, and postnatal factors that may influence developmental outcome should be recorded

Table 12. Cultural Considerations/Contexts

4-Digit Code	Canadian	Australian	Scottish
Consideration of race/ethnicity when assessing OFC, otherwise no other mention of culture.	No specific mention of cultural contexts or considerations. In updated version (But the 2005 guidelines note that treatment and follow up be done in a culturally sensitive manner using appropriate language.	Assessment of neurodevelopmental impairment must take into consideration the linguistic and cultural background of the child, adolescent or adult being assessed, as well as their educational experience within the schooling system. This includes ensuring cultural safety in the assessment process and a process of seeking informed consent that is culturally and linguistically appropriate. This may be achieved using verbal or written communication and may require an interpreter or cultural consultant or liaison officer. The process and implications of the assessment, the regard for confidentiality and restricted access to the results, and the way results will be used should be discussed with families. This is critical for all individuals undergoing assessment for FASD, but requires additional consideration when patients have diverse cultural or linguistic backgrounds. Ideally, clinicians will have had cultural awareness training and have achieved a level of competency relevant to the family's background prior to the FASD assessment process. This will help maximise rapport and ensure awareness of relevant familial, historical, social, and legal factors that may affect individual and family engagement with and performance during the assessment. This is particularly important for Australians who identify as Aboriginal and Torres Strait Islander because their current or prior experience with health care practitioners and researchers may impact on their willingness to engage in FASD assessment. Furthermore, intergenerational, and current trauma, high rates of chronic stress, mental health disorders, social disadvantage and marginalisation and contact with legal system or incarceration affect many Indigenous communities. These factors may impact on both neurodevelopment and interaction with the healthcare system. Clinicians should also be aware of ways in which their own cultural and linguistic backgrounds, beliefs and experiences may influence how they engage with individuals and families and conduct assessments. Assessment strategies for people of diverse linguistic or cultural backgrounds might include use of: · Appropriately trained interpreters during direct assessments to enable use of the individual's first or preferred language if possible. · Psychometric tests that are untimed, non-verbal, do not rely on acquired knowledge, involve spatial processing, and are not influenced by culture, particularly if they provide a practical context (e.g., use pictures). One example is the Universal NonVerbal Intelligence Test (UNIT). (37) · Observer reports or rating scales that are contextualised within the cultural or learning environment of both the patient and the observer. · Specific professional guidelines regarding cross-cultural assessment, e.g. The Australian Psychological Society's Guidelines for the provision of psychological services for Aboriginal and Torres Strait Islander people of Australia (2003). · Acknowledge culture and recommend: · Adopt a consulting style that enables the person and their caregivers to participate as partners in all decisions about their healthcare and take fully into account their race, culture, and any specific needs.	Only mentions that in recording pattern of alcohol consumption that ethnicity should be noted, otherwise no specific mention of cultural considerations or context. Does note that the assessment should accommodate the individuals needs and capacity. Adopts Canadian recommendation: · Education about the impact of FASD and appropriate support for the individual and those involved with their care is recommended. The range of potential issues that might be expected to arise as a result of receiving the FASD diagnosis/ descriptor should also be discussed. It is important that this information is communicated in a culturally sensitive manner using appropriate language.

Table 13. Management and Follow Up

4-Digit Code	Canadian	Australian	Scottish
Mentions Multidisciplinary team to develop an intervention plan after completing assessment. Provides generic summaries for each of the 22 Clinical Diagnostic Categories to be provided to families.	Results of assessments should be present to the family of the person being assessed (if minor) and to the individual, if an adult. A decision by the clinical team should be made with regard to whether and how to present the findings to an adolescent. The results should be presented in a written report that documents the social history, medical findings, results of the neurodevelopmental assessment, and diagnosis. Recommendations: · Education about the impact of FASD and support for the patient and those involved with their care is recommended. The potential psychosocial issues that might be expected to develop as a result of receiving the FASD diagnosis should also be discussed. It is important that this information is communicated in a culturally sensitive manner. · A member of the diagnostic team should follow-up within a reasonable length of time to ensure that the recommendations have been addressed and to provide further support if needed. · Individuals with FASD and their caregivers should be linked to resourced that can improve outcomes. However, just because availability of services is limited, an individual should not be denied an assessment and management plan. Of the diagnosis is the impetus that leads to the developmental of resources. · When young adults are transitioning to independent living situation, it may require that they undergo a re-assessment to identify any changes in their adaptive function scores and to make any subsequent adjustment of their management plan. Long-term Management: Diagnostic clinics may consider implementing staged management plan across the lifespan, with the opportunity to review a patient's current situation and anticipate upcoming problems at predetermined time intervals	After completing the diagnostic assessment, irrespective of the diagnosis, it is recommended that the health professional/s coordinating the diagnostic process: · Discuss with individual/parents/caregivers the outcome of the medical assessment and any reports from other health professionals involved in the assessment. · Discuss the diagnosis, as applicable, and develop a Management Plan, incorporating parent/caregiver and patient goals, referrals, management strategies and review dates. · Provide the individual/parents/caregivers with a written report. · Discuss how this information may be important to share with relevant service providers and school staff. Parents/ caregivers will need to provide consent for any reports to be sent directly to others; however, the parent/caregiver may take their copy of the reports to the school or other organisations, to develop an appropriate plan and access services, for example through the education system or the National Disability Insurance Scheme. · Provide contact details for follow-up communication with the clinic, if required. · If FASD has been diagnosed, provide written information about FASD and contact details for the National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD) Australia https://www.nofasd.org.au/ or phone 1800 860 613, and/or Russell Family Fetal Alcohol Disorders Association http://rffada.org/ or phone 0412 550 540. · Consider the need for referral for individuals or family members with alcohol use disorders, as appropriate. · Appendices provided for information and resources for individuals/parents/ caregivers and clinicians for a management plan after a diagnostic assessment.	Has adopted and adapted the Canadian Guidelines.

LITERATURE REVIEW

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.