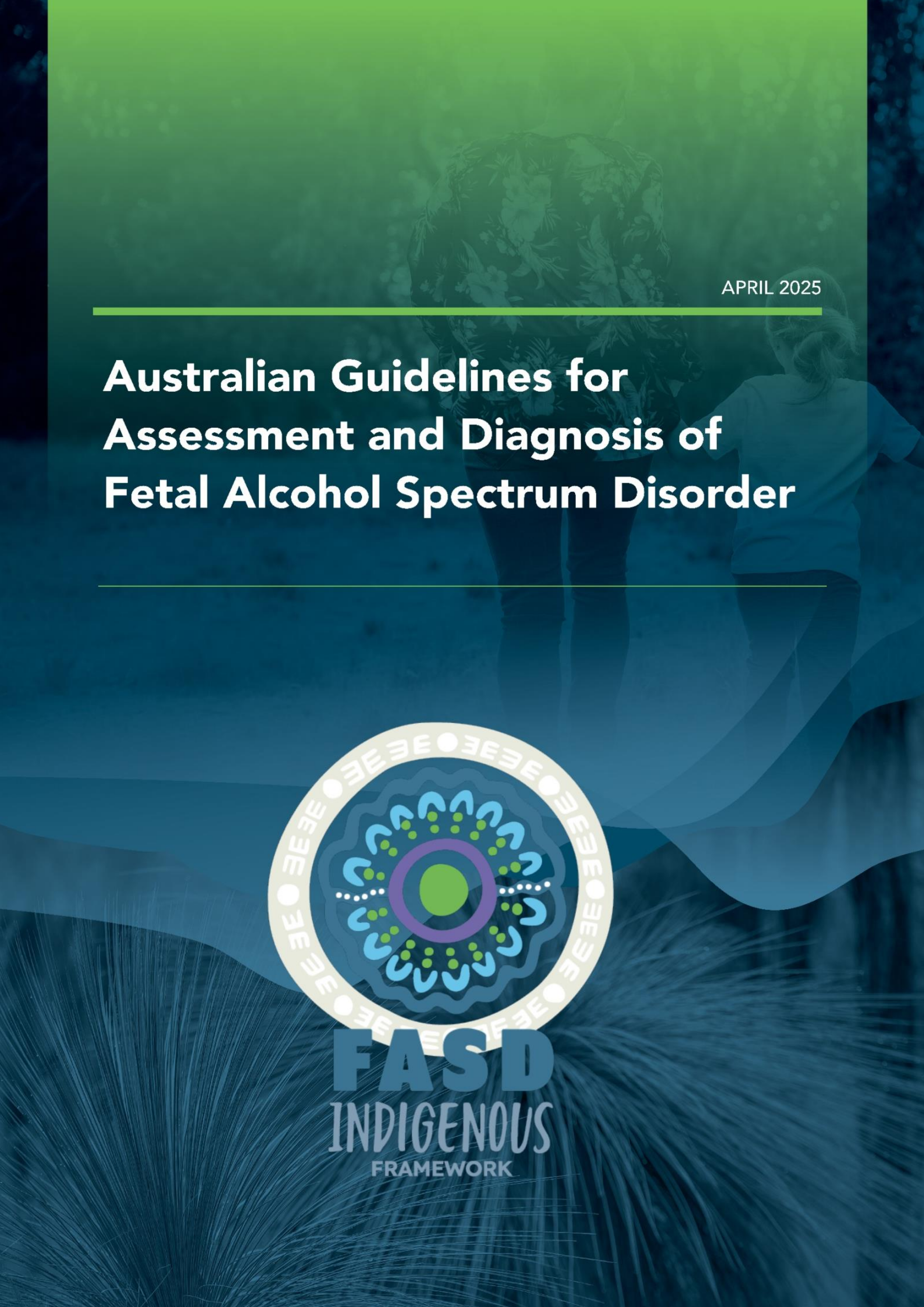

APRIL 2025

Australian Guidelines for Assessment and Diagnosis of Fetal Alcohol Spectrum Disorder

Dr Janet Hammill (aka Jackie Trindell)

This information was developed with the loving, guiding spirit of our special trailblazer Aunty Janet Hammill who passed into the Dreaming in November 2021. Aunty Jan spent a lifetime walking alongside all peoples to bring access to FASD knowledge, assessment, diagnosis, and support. This Framework is a testament to her legacy and her inevitable and ongoing shenanigans in the Dreamtime.

A Dream
By Menessia Henry Nagie

There is a dream who walks this life
A dream of wonder and inspiration
So many in dreams this life has touched
So many of love and deep admiration

Through the mist of time she walks
Through the ultra-haze of life
Her presence brings an awe unexpected
Her aura of beauty, of pure clear light

What words can write of pain and glory
That truly express their deeds
What words can speak an untold story
A message to pay heed

Fond to the hearts of those you touched
Endeared to the memories of time
Amazed by the feats of strength and survival
Known for the courage of mind

We are the flowers that bloom in Spring
And dance beneath your feet
We are the flowers that colour your world
And blossom whenever we meet

To all this pleasure her presence brings
Captured in a moment of time
A heart of truth
A heart to belong
A soft gentle whisper
Her spirit heart song

Dr Lorian Hayes (*Murrindji*)

The knowledge held on these pages was informed by the unwavering generosity and ancient wisdom of Aunty Lorian. Her bush name *Murrindji* means 'holder of language, lore and knowledge' as it relates to health. Language in this context refers to the knowledge and Lores held around FASD and translated to diverse communities. When representing *Murrindji*, an unfolding occurs of the many cultural dimensions of what it means to gift knowledge and how such a gift instils a vibration of health that resonates with those present. There is not a single area of the Aboriginal FASD space that has not been touched by the ripples of *Murrindji* in the past 53 years. Aunty Lorian, thank you for your profound work of yesterday, today and tomorrow and for your cheeky humour that sustains our spirits along this journey.

It is important to highlight that the information in this Framework is not new by any measure, it embodies a lifetime of work by Aunty Jan and Aunty Lorian and the pathways they relentlessly forged to bring hope and healing to Aboriginal communities. Aunty Lorian and Aunty Jan are both respected Knowledge Holders by both Western and Aboriginal measures. All those that walk in their footsteps, do so with honour and a deep sense of gratitude for the softer path.

The existence of this Framework reflects their success in telling the silent stories of our people.

Cultural Advisory Group

Our sincerest thank you to the Cultural Advisory group who informed every step of this project – thank you for your incredible generosity in sharing your time, wisdom, experience and expertise – Australia's first FASD Indigenous Framework would not have been possible without you.

A very special thank you to Jade Houghton (Speech pathologist, Murri School), Prue Walker (FASD Consultant), Isaac Simon (Aboriginal Communications specialist) and Daniel Richards (Digital Design artist) who also made significant contributions to enrich the information shared in this document.

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June Riemer	Gumbaynggirr - Dunghutti woman, Deputy CEO of First Peoples Disability Network
Dr Sharynne Hamilton	Ngunnawal academic, University of Technology Sydney
Dr Michael Doyle	Bardi academic, University of New South Wales
Lorelle Holland	Mandandanji academic, University of Queensland
Sarah Goldsbury	Māori academic and FASD clinician of Ngāti Porou and Te-Aitanga-a-Hauiti whakapapa (descent), Māori/Indigenous Health Innovation, University of Otago Christchurch.
Dr Tracey Harbour	Waluwarra and Yirendali academic, Jibija Ung-gwee
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Past members

Dr Janet Hammill	Gomeroi academic and Elder (in the Dreaming)
Sarah Jones, Jess Styles	National Aboriginal Community Controlled Health Organisation
Nirosha Boaden	Non-Indigenous social worker, NT PHN

Design Story

This community-informed design embodies the seamless flow of relationships and knowledge in Aboriginal and Torres Strait Islander communities and honours the strength of layered reciprocity and support that exists to nurture new life. The colours reflect the healing qualities of water and the vibrant and flourishing colours of new vegetation. The design captures the continuity of culture and encompasses the whole support process in communities to reflect that everything is supported through connections with culture.

Meaning of the specific elements:

	new life, the baby
	mother and father, also Mother Earth and Father Sky
	family and community sitting down in a yarning circle, enveloping the new baby and parents with positive cultural support, knowledge and expertise.
	represents the Aboriginal and Torres Strait Islander workforce that are translating knowledge and navigating the Western biomedical system to ensure that knowledge and access is meaningfully understood by family and community. The wavey component reflects the vibrations experienced by local workforce in deciphering specialist language and blend information with grass roots culture.
	clinical services and specialists

An Australian Indigenous FASD Framework

This resource is targeted at building the capacity of both non-Indigenous practitioners and Aboriginal communities to deliver and access FASD knowledge, resources, assessments, diagnosis and support services.

The Framework will firstly unpack what non-Indigenous clinicians need to know, be and do in order to deliver trauma-aware and healing-informed culturally responsive assessments and diagnosis to Aboriginal peoples. In a FASD context, 'healing-informed' is about how strength-based practices with spiritual underpinnings (i.e., connection to culture, country, community, kinship) can be applied to bring a layer of healing to Aboriginal peoples. While healing-informed approaches support trauma-informed approaches, actions are not defined and determined by trauma experiences of the person on the receiving end. 'Trauma-aware' is used to specifically highlight that it is important practitioners critically understand Australia's violent history and the pervasive role trauma continues to play in the current realities of Aboriginal peoples. Practitioners are central to healing the impacts of colonisation by applying strengths-based, healing-informed and culturally responsive approaches.

The Framework also shares learnings from Aboriginal Knowledge Holders of the past, present and future to support Aboriginal workforce and communities in what they need to know, be and do to access FASD knowledge, assessments, diagnosis and support services. It is important to note, that this is not an educational document that contains all the necessary information to develop one's knowing, being and doing. That requires a vast amount of critical information and a personal, inward journey that resonates with where you, as the reader, are at. This Framework aims to succinctly highlight what the knowing, being and doing journey involves in relation to FASD among Aboriginal peoples and encourage people to reflect further on what this means for you and your practice. It is hoped that in the future a more detailed set of training modules will be developed to further support implementation of the current FASD Indigenous Framework.

Note for Practitioners:

The Cultural Advisory Group recognises many practitioners will be in positions governed by the pressures of the Western health system, where time is limited, and the wait-list pressures are immense. We would like to emphasise that it is not expected that you would apply everything in this Framework, that is unrealistic without systemic change. This Framework offers what we currently know about creating equitable access to assessments and diagnosis. It invites you to consider what you ***can*** apply, however small, with the time and resources you have. Even the smallest shift in your mindset can build trust in profound ways with Aboriginal peoples and requires no resources beyond a willingness to go inward and through the uncomfortable process of growing within oneself. The advocacy section is where, as health professionals, you can support the external shifts that you would like to see, including at the systems level. Having clear directions for advocacy can support both Aboriginal and non-Indigenous practitioners to step in the same direction, together. This is how we work in solidarity to shift systems and ensure future generations do not experience the same challenges that this Framework aims to overcome.

The need for an Australian FASD Indigenous Framework

In the spirit of genuine reconciliation and justice, the project team recognises that in order to facilitate equitable access to culturally responsive assessment and diagnostic services, Aboriginal voices must be prioritised and privileged throughout the Australian assessment and diagnostic process.

Given that the work we all do is on the unceded, sovereign lands and waters of Aboriginal and Torres Strait Islander peoples it is especially critical that we are inclusive and respectful of the ancient and ongoing ways of knowing, being and doing of Australia's Traditional Custodians. It is also important to recognise that non-Indigenous peoples have and continue to benefit from these lands, waterways and skies as facilitated by the systems which privilege Western worldviews. This has come at great cost to the health and wellbeing of Aboriginal and Torres Strait Islander peoples, who have endured cycles of subjugation, oppression and marginalisation (Australia & Wilkie, 1997).

> There is an entrenched myth that FASD is an "Aboriginal problem", a belief which has detrimental consequences for non-Indigenous peoples in misdiagnosis or under-diagnosed conditions as well as Aboriginal peoples in over-diagnosed or avoided diagnosis for Aboriginal peoples.

The FASD Indigenous Framework presents an opportunity for all Australians to walk alongside each other, in solidarity, to heal the impacts of FASD on the Australian community. This can be achieved by drawing on the wisdoms of strengths-based Aboriginal approaches that are grounded in holistic and integrated support and the wisdoms of Western health approaches and therapeutic models to create new knowledge and practice that offers immense benefit to the quality of assessment and support for all Australians who are neurodivergent.

Development of the Framework

This Framework was borne to address the significant lack of Aboriginal and Torres Strait Islander voices in the FASD Diagnostic story (Hewlett et al., 2023). To inform this Framework, national and international published and grey literature was reviewed and mapped against the knowing, being and doing principles of Indigenous Allied Health Australia Culturally Responsive Framework (Indigenous Allied Health Australia, 2019). This framework is a high-quality action-oriented, Aboriginal and Torres Strait Islander approach to cultural safety.

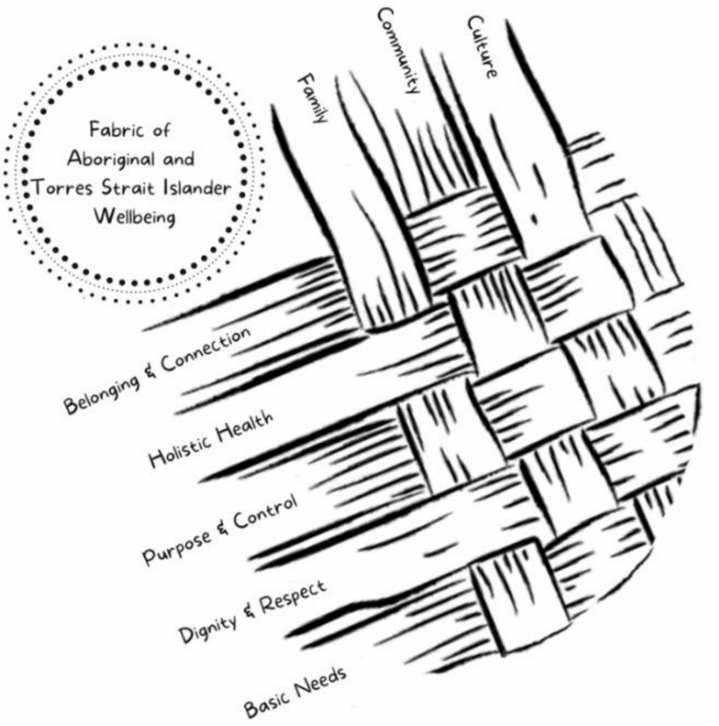
The Culturally Responsive Framework is intrinsically transformative and grounded in three driving principles:

1. Knowing (knowledge – what do we need to **know** to be culturally responsive)
2. Being (self-knowledge and behaviour – what do we need to **be** to be culturally responsive)
3. Doing (action - what do we need to **do** to be culturally responsive)

This framework was also adapted to map what Aboriginal communities needed to know, be and do in order to understand and access assessment and diagnosis of FASD.

To cultivate a strengths-based approach in assessments, the literature was also mapped against the *Fabric of Aboriginal and Torres Strait Islander Wellbeing* model (Garvey et al., 2021; see the visual summary below). Specifically, by strengthening the threads of belonging and connection, holistic health, purpose and control, dignity and respect, and basic needs, Aboriginal peoples can enhance and build connectedness to culture, community and family.

To summarise the information based on what Aboriginal communities need to *know*, *be* and *do*, collaborative group yarns were undertaken over a 2-year period with the Cultural Advisory Group. Additionally, seven individual yarns with key experts from the Cultural and Clinical Advisory Groups were held, recorded and transcribed. For further details on the



development of this Framework, please see the associated publication (Hewlett et al., 2023).[1]

Why only Aboriginal perspectives?

There was no published or grey literature available regarding Torres Strait Islander peoples and FASD. Although efforts were made, we could not find a Torres Strait Islander person to speak on the issue of FASD. Thus, with deepest respect and in the spirit of honesty and transparency, the current version of the FASD Indigenous Framework speaks only from an Aboriginal perspective. However, it is hoped the next iteration will better embody a Torres Strait Islander worldview as it relates to FASD. As such, it is titled the FASD *Indigenous* Framework and the visual design and its elements were developed to resonate and reflect Aboriginal and *Torres Strait Islander* ways of knowing, being and doing.

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[1] https://www.mdpi.com/1660-4601/20/6/5215.

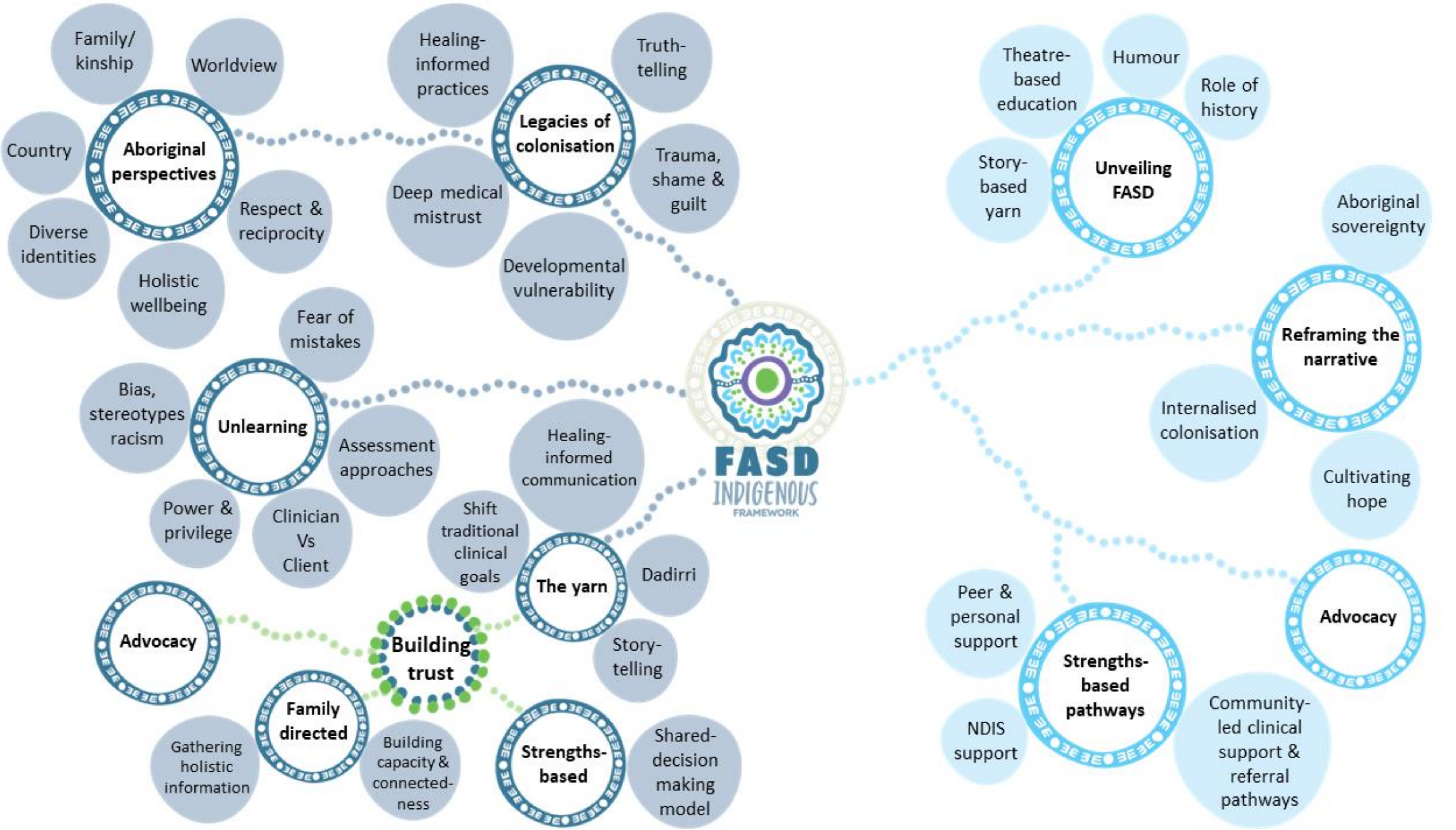

Figure 1. The current Australian FASD Indigenous Framework summarises the shifts non-Aboriginal clinicians and Aboriginal peoples need to make in their respective knowing, being and doing to facilitate access to FASD knowledge, services, and support among Aboriginal peoples. The dark blue circles represent the shifts that non-Aboriginal clinicians need to make in their knowing, being and doing to deliver culturally responsive, healing-informed, and trauma-aware FASD knowledge, services, and support to Aboriginal peoples. The light blue circles represent the shifts that Aboriginal communities need to make in their knowing, being and doing to access FASD knowledge, services, and support. The FASD Indigenous Framework visuals were designed by Worimi communication specialist Isaac Simons and non-Aboriginal graphic artist Daniel Richards. This community-informed design embodies the seamless flow of relationships and knowledge in Aboriginal and Torres Strait Islander communities and honours the strength of layered reciprocity and support that exists to nurture new life. The colours reflect the healing qualities of water and the vibrant and flourishing colours of fresh vegetation. The design captures the continuity of culture and encompasses the whole support process to highlight that everything is supported through connections with culture.

Creating equitable access

The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) was adopted by the United Nations (UN) General Assembly in 2007 (United Nations, 2008). It establishes a universal framework of minimum standards for the survival, dignity and wellbeing of the Indigenous peoples of the world. It is particularly significant because Indigenous peoples, including Australian Indigenous peoples, were involved in drafting the UNDRIP (*The Community Guide to the UN Declaration on the Rights of Indigenous Peoples*, 2010).

The UNDRIP establishes a framework for addressing the health and wellbeing of Indigenous peoples that includes the obligation of UN member states both to provide accessible, quality healthcare to Indigenous peoples, and to respect and promote Indigenous health systems, each of which must be fulfilled in order to ensure the health of Indigenous peoples (United Nations, 2008).

With regards to health and healthcare, UNDRIP includes the following rights for Indigenous peoples:

- An equal right to the enjoyment of the highest attainable standard of physical and mental health.
- The right to promote, develop and maintain their institutional structures and their distinctive customs, spirituality, traditions, procedures, practices and, in the cases where they exist, judicial systems or customs, in accordance with international human rights standards.
- The right to traditional medicines and to maintain their health practices, including the conservation of their vital medicinal plants, animals and minerals.
- The right to access, without any discrimination, all social and health services.

UNDRIP is key as it forms the foundation for a 'rights-based' approach which is essential in supporting culturally-responsive access to assessments and diagnosis of FASD. It is important for practitioners to understand the rights that Australian Indigenous peoples have with respect to health and access to services, and how colonisation has and continues to undermine these rights.

What do non-Indigenous practitioners need to **know, be** and **do** to deliver culturally responsive assessments?

KNOWING

Legacies of Colonisation

To genuinely and respectfully connect with Aboriginal peoples, it is essential that you are coming from a place of truth. This truth is contingent on having a critical understanding of history and the profound legacies of trauma, shame, guilt associated with colonisation and the attempts to eradicate Aboriginal culture.

Truth-telling

- Ignoring or denying the genocidal atrocities committed during the violent invasion and ongoing occupation of Australia not only hinders practitioners' ability to understand the socio-cultural, historical and interpersonal context of trauma shared by Aboriginal peoples today but also perpetuates the blame-and-shame attitudes that underpin unconscious and conscious bias, discrimination and racism.
- It is crucial for practitioners to bring cultural understandings, such as the impacts of colonisation, to the forefront of the conversation with Aboriginal peoples. Research shows that failing to do so can undermine trust and cause harm in the assessment process (Hamilton, Maslen, Watkins, et al., 2020).

Role of Intergenerational Trauma, Shame and Guilt

- Alcohol has played an insidious role in colonisation, initially used as a form of currency, power and control and later as a means of coping with the ongoing impacts of racism, intergenerational trauma and profound grief and loss. (d'Abbs & Hewlett, 2023). Circumstances the alcohol industry overtly targets to capitalise and profit from (Crocetti et al., 2022).
- Alcohol continues to exacerbate cycles of intergenerational trauma. For example, an older generation may drink harmful levels of alcohol to soothe the emotional, cultural and spiritual stress and pain caused by historical trauma. The neglect, abuse and vulnerability that can result, in turn, causes emotional, cultural and spiritual pain for the next generation. When the younger generation adopts alcohol use as a socially normalised habit, coping mechanism, and treatment for accumulated layers of pain and distress, the

cycle continues. This thoughtful 4-minute animation by Healing Foundation highlights how intergenerational trauma cycles began and how to bring about intergenerational change: https://youtu.be/iQMZZ8ng7oI

- Underpinning many past and present policies are the outspoken and unspoken narratives that being Aboriginal is 'shameful' and 'less than'. These narratives stem from various scientific theories in the late 1800s that viewed Aboriginal peoples as 'animals' and 'savages,' to the Assimilation policies of the 1910s-1970s, which aimed to "breed out the black" and eliminate all cultural practice and connections among Aboriginal peoples.

- These policies, combined with frequent experiences of racism and stereotyping, as well the dominant culture's failure to stand up against these injustices, have led to various burdens of conscious and unconscious shame and guilt among many Aboriginal peoples today. This often results in feeling "too shame" to speak up, stand out or access help and support. These feelings can be compounded by guilt for not being 'strong enough' to stand up or speak out.

- Developing your understanding of the intergenerational trauma, shame and guilt perpetuated by colonisation can support your journey of compassion. This understanding highlights the importance of your role in bringing healing-informed practice and, consequently, justice to Aboriginal individuals attending assessments.

> *"You know the truth is. Our mob didn't wake up one day and decide I want to be a drunk for the rest of my life. The journey took them there and if you talk to anyone down the creek there, they have got the most horrendous journeys. They would have you crying. So, we have to be mindful when we are working with our mob and really look at the history of their journey."*
>
> ~Aboriginal Community Member[2]

Developmental vulnerability

- Trauma can be passed from generation to generation, embedding itself in the brain and nervous systems of each affected generation. When unrecognised and therefore untreated, it can manifest in post-traumatic stress disorder symptoms, insecure attachment styles, depression, impulsivity, anxiety, harmful substance use, low self-esteem, chronic dysregulation, or self-destructive and risky behaviours (Evans-Campbell, 2008).

- Given Australia's dark history, Aboriginal children are more likely to be developmentally vulnerable and present with behaviours similar to FASD.

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[2] p. 6. Reid, N., Hawkins, E., Liu, W., Page, M., Webster, H., Katsikitis, M., Shelton, D., Wood, A., O'Callaghan, F., Morrissey, S. & Shanley, D. (2020). Yarning about fetal alcohol spectrum disorder: Outcomes of a community-based workshop. *Research in Developmental Disabilities, 108,* p.6.

- It is important to always consider that challenging behaviours may be due to trauma, genetics, other prenatal factors, childhood illness or injury and not necessarily prenatal alcohol exposure.
- This is a vital knowing to incorporate into your being to ensure that you enter assessments without assumptions and unconscious influences of bias and stereotypes.

> *"The impairments that these kids had were not necessarily solely related to FASD. You know they have backgrounds of significant trauma and that might also be a significant contributing factor for why they might be impulsive, or why they can't sit still or focus. You can't diagnose FASD and wrap it all up in a nice shiny package with a ribbon on top. Untreated trauma is a significant issue that has major implications for a child's neurodevelopment."*
>
> *Dr Sharynne Hamilton, Ngunnawal academic*

Deep Medical Mistrust

- The traumas of massacres attempted cultural genocide, dispossession, and child removal, all sanctioned by the Western system, are reflected deeply in the entrenched institutional racism frequently experienced by Aboriginal peoples today.
- Although excluded from health services and treatment, Aboriginal peoples were subjected to medical experimentations and 'anthropological investigations' resulting in extensive human rights abuses (Robson, 2018).
- It is important to note that historical policies and practices were enacted by 'practitioners' of the system. Due to the recency of these practices and the oral tradition of passing down stories and knowledge among Aboriginal peoples, fear of the medical system is deeply ingrained. For many family lines, this fear has been a means of survival.
- This deep mistrust of the medical system, which continues to be validated for many Aboriginal families, makes it difficult for families to trust practitioners and freely disclose and discuss personal information. Often, Aboriginal families fear and have come to expect punishment and consequence when accessing support from the medical system. At the forefront, is the validated fear of Aboriginal families having their children removed, as was legislated and enforced under Assimilation policies until 1970s (see *Stolen Generations*). Many Aboriginal peoples feel the Stolen Generations continues today in the form of 'child protection' (Funston & Herring, 2016).
- Knowing the history of how the West broke the trust of Aboriginal peoples, and how ongoing treatment keeps that trust broken, will help you realise the

fundamental role of building trust in any engagement with Aboriginal peoples.

Strengths-based approaches as healing-informed practices

- It is critical to understand that poor health outcomes in Aboriginal communities are not simply an individual problem, but rather are always connected to the historical and communal contexts in which we live (Gonzales et al., 2021).
- Focusing on deficits and negative experiences contributes to a sense of shame, victimization, and suffering, which often adds to the stigma associated with FASD (Choate & Badry, 2019).
- Internalised stigma can damage self-esteem, positive identity development, self-efficacy, and self-determination, which in turn may reduce quality of life for individuals with disabilities including those with FASD (Flannigan et al., 2021).
- In the context of FASD, strengths-based approaches have been shown to reduce stigma, cultivate hope and resilience and promote healing (Skorka et al., 2020).
- This Aboriginal understanding of disability aligns with other models of disability such as social model of disability (Social model of disability - People with Disability Australia (pwd.org.au).
- Knowing the importance of strengths-based approaches and understanding how these types of approaches can transform your practice, enables you to meaningfully support the diverse needs of individuals from all cultures attending for assessment.

Aboriginal perspectives

The second **knowing** that is required to deliver culturally responsive assessments is around Aboriginal perspectives. Understanding Aboriginal ways of knowing, being and doing builds respect for, and pride in, the oldest living culture in the world. Leaning into the ancient wisdoms of Aboriginal culture not only challenges unconscious and conscious stereotypes but offers an opportunity where all Australians benefit.

Aboriginal worldview

- The Aboriginal worldview is inherently strengths-based and collective. Many communities typically adapt and change according to the different abilities of those in the community (i.e., see page 48 more information). This is why certain behaviours may not be identified as 'problematic' or 'challenging' in communities until such time as a child comes in contact with a non-Indigenous system.

- Connectedness is paramount in Aboriginal understandings of the world, and it is inextricably interwoven with one's identity. These reciprocal connections to family, kinship, culture and Country provide strength, resilience, spirituality and a place of belonging.
- Understanding these cultural strengths and finding ways to embed them in your practice will go a long way in supporting a culturally-responsive and healing-informed approach.

Importance of Country

- 'Country' here refers to more than just land; it includes all living creatures and relates to all aspects of existence – culture, spirituality, language, law, family and identity. It is a way of believing.
- Many Aboriginal peoples do not separate their identity from the lands and waters from which they descend. Although many Aboriginal peoples have been relocated and/or no longer live on Country, this does not diminish one's cultural and spiritual connections to Country.
- Many Aboriginal peoples are entrusted with the knowledge and responsibility to care for the land, which provides a deep sense of identity, purpose and belonging. In this way, Country offers a place of healing, nourishment and 'wholeness' for many Aboriginal peoples but especially so for those with FASD.

> *"We don't own the land, the land owns us. The land is my mother, my mother is the land. Land is the starting point to where it all began. It's like picking up a piece of dirt and saying this is where I started and this is where I'll go. The land is our food, our culture, our spirit, and identity"* [3]

- Holding assessments outside, amongst the natural elements of any Country, will make Aboriginal peoples more comfortable.

Holistic Wellbeing

- While Western biomedical constructs of health and wellbeing typically focus on the individual and the absence of disease, Aboriginal views of health are holistic and multidimensional. All social, emotional, physical, cultural and spiritual dimensions of our being are inextricably linked and interconnected to land, culture and spirituality (Gee et al., 2014).
- The Fabric of Aboriginal and Torres Strait Islander wellbeing (Table 1) highlights how the parts of life most important to wellbeing for many Aboriginal peoples are deeply interwoven by three interconnected threads: **family**, **community** and **culture** (Garvey et al., 2021).
- The relationships and connectedness between these threads are vital, illuminating the interrelated link between wellbeing and identity for

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[3] Knight S., (1996). Our Land Our Life, card, Aboriginal and Torres Strait Islander Commission, Canberra

Aboriginal peoples. Cultural identity plays a critical role in developing a positive sense of self and serves as an important source of strength and resilience among Indigenous peoples with FASD (Flannigan et al., 2021; Rogers et al., 2020).

- The Fabric of Wellbeing model offers practitioners a practical pathway that highlights how to build cultural connectedness and positive self-identity.

Table 1. Fabric of Aboriginal and Torres Strait Islander Wellbeing model draws inspiration from Aboriginal and Torres Strait Islander weaving traditions, where individual strands are entwined to create fabrics that are both beautiful and strong. The parts of life most important to wellbeing for many Aboriginal and Torres Strait Islander people are interwoven through their families, communities and culture. This model illustrates that the strength of wellbeing comes from both the strength of the individual threads and their connections with each other.

	Belonging & Connection	**Holistic Health**	**Purpose & Control**	**Dignity & Respect**	**Basic Needs**
Culture	Reciprocal relationships with country, family and community and the importance of culture in developing and maintaining a sense of shared experience and understanding	Multidimensional state of wellness determined and attained via the quality and balance of one's connections to family, community and culture	Stability at home, employment and financial security, education, and cultural and familial responsibilities. Family was key in sense of stability.	Perceived and treated by others and this is associated with relationships with others, policies, services, and experiences of racism. Family provides a source of shared strength that empowers and motivates. Also having non-Indigenous systems value and respect culture + being represented positively in media.	Housing, money, access to services, education, employment, opportunities to thrive and justice.
Community					
Family					

Diverse Identities

- It is essential to know that while Aboriginal peoples may have shared understandings and perspectives of the world, each person interprets and experiences these threads differently.
- Each colour on the Aboriginal map (see https://aiatsis.gov.au/explore/map-indigenous-australia) represents a different Aboriginal group. These communities vary not only according to geographic location, environment and resources, but each group has their own unique cultural practices, histories, languages, beliefs, knowledge and kinship systems. This diversity is further layered with the movement of many Aboriginal peoples to urban centres for education and employment.
- Understanding the incredible levels of diversity among Aboriginal peoples is critically important to:
    - reduce the risk of homogenising Aboriginal peoples, which can lead to harmful stereotypes and assumptions that impact on practice.
    - highlight that only the Aboriginal person or family sitting in front of you can tell you what culture, family and community means to them.

Importance of family/kinship

- Family and kinship systems have always been pivotal to the functioning and wellbeing of Aboriginal communities. So much so that many believe family has been key to how our Aboriginal cultures have survived colonisation and continue to survive today.
- The definition of ''family'' is diverse and may include extended family as well as connections and relationships outside of bloodlines.

> *"If we are to work effectively and appropriately with Māori, we need to understand the full context of Aotearoa's history. We need to be aware of the systemic and institutional racism around us and within us. And what impacts of this are for our clients and for our own roles, values and beliefs as clinicians"*
>
> *Sarah Goldsbury,*
> *Māori FASD clinician*
> *and academic*

- For some Aboriginal peoples, family-centred assessments are an important part of delivering a strengths-based, healing-informed and culturally-responsive service. By recognising the importance of family for the individual attending for assessment respects the way Aboriginal peoples relate and connect to one another.
- Developing your **knowing** about the value, meaning and importance of family also offers you an opportunity to connect. Just as you love and value your

family so do Aboriginal peoples and from this space, **common ground** can be found.

Respect and Reciprocity

- If culture (family, community, Country) is the heart of Aboriginal peoples, then respect and reciprocity are the pulse that keeps it beating.
- Underpinning the spirit of Aboriginal culture is a deep knowing that all creation is interrelated and interconnected, making life possible. Our respect serves to maintain interconnectedness through cultural ties and reciprocal relationships. Reciprocity can be described as an action of respect; an exchange of knowledge, honour, belonging and/or identity within the connection.
- A standard protocol when speaking or introducing ourselves is to show respect by acknowledging Custodians of the land and the Elders, Ancestors and Spirits of this place on which we speak. Showing this respect establishes and affirms our identity and creates and honours positive connections between our language groups. Knowing the importance of respect in Aboriginal ways of being, highlights why disrespectful treatment can be particularly harmful for an Aboriginal person.
- You can honour reciprocity in your practice and actively show respect to Aboriginal peoples by showing a genuine interest in learning from your Aboriginal clients. By doing so, the knowledge you gain by listening to Aboriginal peoples with cultural and lived/living experience can be integrated into your practice, benefiting not just future Aboriginal clients but all clients.

BEING

The Western medical system is grounded in a deficit worldview and driven by goals to professionally or scientifically identify and "fix problems". However, what constitutes a 'problem' is determined by the Western system's own definitions, norms and measures. Consequently, developing self-knowledge and behaviour, or our **'being'**, requires an inward and often uncomfortable journey of ongoing critical reflection. This will reveal a personal pathway to understanding the importance and value of unlearning certain Western practices that may impede the ability to deliver culturally responsive assessments.

Unlearning

Bias, stereotypes, and racism

- It is important to recognise that we are all products of the environment in which we have been socialised. These environments teach us how to think about ourselves and others, how to interact, how to know what is expected of us and what happens if we deviate from what is expected. This socialisation is ongoing, complex, and often invisible.
- To manage the vast and complex information of the world, our brains categorise and 'group' information to avoid being overloaded.
- This natural tendency for our brains to categorise the world means that we often oversimplify social groups based on visible features that provide the largest between group variation (e.g., skin colour, accent, socio-economic status, gender, age). These are known as stereotypes and are constructed from direct personal experience or, more commonly, from other people and the media.

> *"When we are diagnosed with any condition, our future is in the hands of others – 'experts' – who often see us an illness at best, a stereotypical statistic at worst"*[4]

- While this is a natural way for our brains to organise information, the negative stereotypes of Aboriginal peoples are persistent and largely perpetuated and reinforced by the Australian media. The *Portrayal of Indigenous Health in Selected Australian Media* study found 74% of articles about Aboriginal health focused on negative stories within communities (Stoneham et al., 2014).

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[4] Terare, M. and Rawsthorne, M. (2020). Country is Yarning to Me: Worldview, Health and Well-Being Amongst Australian First Nations People. *British Journal of Social Work, 50,* 944-960.

- Implicit attitudes based on these stereotypes affect your understanding, actions and decisions in an unconscious manner known as unconscious bias (Webster et al., 2022). For example, unconscious bias could lead to reflexive assumptions of FASD in Aboriginal people attending for an assessment. Without your awareness, your brain could automatically process and filter information to confirm these assumptions and this is known as confirmation bias. Alternatively, your assumptions may cause you to avoid a diagnosis due to your own beliefs about stigma and what families want or need. Both outcomes do not reflect objectivity or truth and are harmful for the individuals and their family.
- If such bias and stereotypes go unquestioned and unaddressed, research shows that they inevitably manifest in maltreatment, miscommunication, and racism (both individual and systemic) towards Aboriginal peoples, whether intentional or not (Jemal, 2017; Webster et al., 2022).

Power and Privilege

- An important part of critically unpacking bias involves understanding the power and privilege practitioners inherently hold and the impact this can have on Aboriginal peoples accessing mainstream services.
- Power, in the context of assessment and diagnosis of FASD, refers to the capacity that you, as a practitioner, have to exercise control over individuals attending for assessment. This includes the ability or power to decide what is best for that individual and who will have access to appropriate resources, knowledge and support.
- If we categorise the world based on our experiences and you have never experienced racism and the subsequent adversities that emerge, these experiences remain invisible to us. This lack of exposure is considered a privilege, commonly referred to as 'white privilege'. White individuals have unearned advantages because they resemble the dominant social group that controls the value systems and rewards in Australian society. The benefits are institutional rather than personal translate to greater and easier access to resources. It is the absence of suspicion, prejudice and other negative behaviours that Aboriginal peoples, who are objects of racism experience. Recognising this privilege is essential, especially in statements such as "FASD is 100% preventable". Such statements overlook the reality that some Aboriginal families are living in cycles of intergenerational trauma, poverty and FASD, compounded by issues such as housing overcrowding, food insecurity, limited access to education and holistic health services. The assertion that "FASD is 100% preventable" assumes all Australians experience genuine self-determination, choice and access to safe healthcare, rendering historical and current inequities perpetuated by Western systems invisible.
- Our learning and experiences shape us and failing to recognise unconscious privilege and power makes it easier to deny their existence. This denial fosters

deficit and disadvantage narratives that blame and shame the individual for the 'choices' they have made and the circumstances they are in.

- If we are not aware of our bias, privilege, and power then research shows practitioners' unconscious beliefs and behaviours can create "clinical" environments that trigger Aboriginal peoples (S. L. Hamilton et al., 2019). Additionally, a lack of awareness can affect clinical decisions and undermining practitioners' ability to provide assessments grounded in equity, accuracy and objectivity.

Selecting Assessment Approaches

- Bias, privilege, and power can also unfold in how practitioners select assessment tools and approaches.
- For some Aboriginal families, Western frameworks and measures work well and they are comfortable to use and respond to them. However, for other families, Western tools and approaches are not appropriate in terms of conducting an accurate assessment or in making the families feel comfortable.
- It is important that practitioners engage in ongoing critical reflection on the role their unconscious bias plays in selecting assessment tools and approaches. It is the responsibility of the practitioner to have conversations with the family about assessment options so that they can make an informed decision about what will be the culturally safest journey for them to undertake. The power should be with the family to decide what is best for them, not for the practitioner to assume that they know.

> *"We should assess kids by how well they do the things they are used to. So, thinking about assessing fine motor skills using handwriting, or with pencil and paper. In some cases, kids that were being assessed came from very, very remote communities, where using a pencil and paper would have been very foreign to them. If their fine motor skills were assessed by, say, tying fishing line it could have been a very different outcome"*
>
> *Dr Sharynne Hamilton,*
> *Ngunnawal academic*

- Many tests, processes and practices have clear biases and racism underpinning them. In accordance with the Australian Health Practitioner Regulation Agency (Ahpra) National Law, practitioners are expected to exclude any measures that risk culturally unsafe practice to Aboriginal and Torres Strait Islander peoples (https://www.ahpra.gov.au/About-Ahpra/Ministerial-Directives-and-Communiques/National-Law-amendments/Joint-statement.aspx#).

Practitioner versus Client Relationship dynamic

- Two-way learning acknowledges and respects the presence of two expert perspectives during an assessment: the practitioners' Western understandings and the family's values, beliefs and experiences.
- Instead of the separateness brought about by the practitioner *versus* family dynamic, we want to foster connection through the practitioner *and* family working together and being on the same page. Practitioners do not have to have all the answers, which may be a contrary message to what practitioners trained in the Western health system are led to believe. However, Aboriginal peoples do not expect practitioners to have all the answers and insisting that you do, even from a place of goodwill can create a disrespectful and culturally unsafe environment. Attempting to "tell" us about our lives, is an act of dominant power and control stemming from your privilege.
- Addressing the inherent power imbalance by surrendering control and knowledge authority/superiority during an assessment will go a long way in creating a safe, respectful environment that Aboriginal families will trust and feel comfortable in.

> *"Non-Indigenous clinicians must do much more than simply learn about the Indigenous cultures that they work with. It is essential they look within and identify their own cognitive biases from their life experiences and their clinical frameworks, and work to consistently unlearn and retrain responses stemming from these."*
>
> *Sarah Goldsbury,*
> *Māori FASD clinician and academic*

Fear of making mistakes

- Part of genuinely relinquishing your power and building trust, is *being* comfortable with making mistakes.
- Admitting your lack of knowledge about a person's life and acknowledging your mistakes shows humility, honesty and grace - qualities that all humans can connect to. In Aboriginal culture, as explained in the knowing section (page 15), bringing these qualities to the exchange ensures that when you

make mistakes or say something wrong, you will receive grace and respect in the spirit of Aboriginal reciprocity.

- This approach also invites those in front of you to teach you, creating an opportunity for you to learn, enabling the two-way learning we aim for in culturally responsive assessments.
- For Aboriginal peoples, when non-Indigenous practitioners refuse to blindly follow traditional Western practices and beliefs and instead are open and curious, it can be particularly transformative in the level of trust built in the relationship.

DOING

After embarking on a journey of developing your knowing and being, which is an ongoing process of growth, you will be better prepared to hold a safe and respectful space with Aboriginal peoples as part of your **doing**. You will also intuitively understand why **building trust** is so important and should be at the heart of your practice. Below you will find a range of practices, and each will accumulatively build trust. While it may be unrealistic to incorporate all of these practices at once, this section is about identifying what practices you can embed to make the most difference with the time and resources you have available. Finding a way to embed even one of these practices will have profound impacts on your connection with Aboriginal families and your ability to deliver a trusted and culturally responsive assessment in a healing-informed way.

The Yarn

All advice on creating culturally safe dialogue is contingent on this essential truth – the ability for non-Indigenous peoples to have a two-way, equal exchange with respect and a genuine openness to deep listening and learning. This is yarning, an ancient yet timeless way of Aboriginal knowing, being and doing. It's a conversational exchange or process that involves deep listening and quiet still awareness (also known as Dadirri – see below), which leads to the creation of new knowledge and understanding (Bessarab & Ng'andu, 2010; Ungunmerr-Baumann et al., 2022). Each person in the yarn is equal and treated as a respected Knowledge Holders in their own right. Sharing of that knowledge is holistic and reciprocal while layers of meaningful reflection, trust, and connection, are being built. In this way, yarning embodies spiritual, cultural, social, and emotional wellbeing. As such, the yarn offers an opportunity to not only build a culturally responsive connection on a sensitive and potentially triggering topic as FASD, but more importantly, it can be profoundly healing.

> *"How can I trust someone I don't know? If a doctor, clinician – anyone really – doesn't understand the power of my story and the importance of listening to who I am, how can they possibly offer worthy knowledge to advise me?"*
>
> *Dr Lorian Hayes, Iningai and Bidjera academic*

Healing-informed communication

- It is not enough to be "trauma-informed" and simply avoid triggering clients; we must raise the bar. True justice, reconciliation and reciprocity lies in the spirit of healing, not in the bare minimum practice of avoiding further harm. Many of you reading this are indeed healers. While the Western system may label you as 'psychologist', 'general practitioner', 'social worker', 'researcher' and so forth, at the heart of your role is the purpose to bring some level of healing to a person, family, or community.

- Applying healing-informed communication requires non-Indigenous peoples to somehow **acknowledge history** when yarning with Aboriginal peoples. Research shows that trust is established when non-Indigenous practitioners can acknowledge history in their practice (S. L. Hamilton et al., 2019). To begin, you might start a session by saying "before we begin, I would like to acknowledge that today we are on [name of Traditional Custodians] Country and I understand and respect that sovereignty was never ceded." With practice, you will grow and find your own genuine rhythm in how you will embed an acknowledgement of history into your practice. It's also important to emphasise that perfect pronunciation is not necessary, nor is there a "perfect statement" What matters is the spirit sitting behind it – Aboriginal peoples feel the spirit, not the words. As mentioned earlier, we have limitless grace for such intentions.

- **Using Plain language** is part of showing respect in healing-informed communication. It is important to remember that English is an introduced language to these lands and Aboriginal peoples were systematically excluded from English education until the 1960s. This was due to the belief that Aboriginal students "were not capable of coping with intellectually intensive work" (p.96, Duncan, 1969). Instead, schooling focused on Aboriginal boys being labourers and girls being domestic servants, entrenching educational disadvantage for Aboriginal peoples. Aboriginal languages reflect Country. Country is our mother, and like mothers, she nurtures us and taught Aboriginal peoples the many dialects of language. These dialects reflect the diverse vibrations of the lands and waters we descend from. The land does not speak in letters, which is why you have never seen Aboriginal peoples record things in anything but art (i.e., paintings, weaves, stories, dance). **Using visuals, metaphors** (i.e., using English to paint a picture/visual) and **speaking plainly** demonstrates respect for Aboriginal cultural ways of knowing, being and doing.

> *"….the position I held …. placed me in a constant state of awareness of the need to demonstrate respect to community members. Speaking in a respectful tone, at an unhurried pace, and waiting respectfully for a response, were appropriate communication styles that yielded forthright and thoughtful responses"*[5]

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[5] p.161 Hayes, L. (2019). An Aboriginal woman's historical and philosophical enquiry to identify the outcomes of prenatal alcohol exposure and early life trauma in Indigenous children who live in Aboriginal communities in Queensland [PhD Thesis, The University of Queensland].

- Of critical importance, using medical jargon in your practice with Aboriginal peoples, can trigger feelings of shame. This shame may be around not feeling educated or smart enough to understand you or be tied to a lifetime of being saturated in messages of being called “stupid” or a “dumb black”. Regardless of what triggers the shame, using medical jargon can belittle clients and clearly highlight the power imbalance between the practitioner and the person in front of you.
- The final component of healing-informed communication is creating a space where the person or family is **driving the conversation.** Only they can tell you what culture, quality of life and spirituality means to them, as these are as **unique as a fingerprint** for each person. Some Aboriginal peoples may prefer western models of care and be very comfortable using non-Indigenous services. However, for others, especially if English is not their first language or they have had a history of negative experiences with Western systems (i.e. Child Protection), you will need to spend much more time building trust. If you do not have this time, work together with Aboriginal outreach teams, liaisons or interpreters.
- Every time you speak with an Aboriginal person, there is an opportunity to bring a layer of healing, whether this conversation is in a professional or social context. In turn, and in accordance with yarning reciprocity, using healing-informed approaches will also bring healing and growth to you, as a practitioner and as in our holistic way, you will find that you profoundly benefit both professionally and personally.

Storytelling

- Storytelling is at the heart of a yarn and has played a key role in sharing knowledge and sustaining Aboriginal culture for over 60,000 years. Yarning creates a safe space for Aboriginal peoples to share their feelings, hopes, and fears using stories. As a practitioner, it also provides an opportunity for you to share your story. For Aboriginal peoples and many cultures, storytelling is a bridge to building intimacy, trust, and connection. However, this must be two-way and typically be initiated by you in this setting.
- For most Aboriginal peoples, connecting with all forms of life is as automatic and unconscious as blinking. The authenticity of these connections depends on the authenticity of what or who we are connecting to. By sharing your story, something true about where you come from, who your family is, and what makes you, *you,* not only provides an opportunity to **find common ground to connect** but also extends an unspoken invitation to the Aboriginal person or family in front of you to share something true about themselves. This exchange fosters mutual respect, power-sharing, connection and understanding which, if nurtured, leads to trust.

- From this safe and connected space, the story of assessment and diagnosis can be told in a way that can not only be meaningfully understood but build the capacity of families to live well with FASD.

Dadirri

- Central to building knowledge and finding pathways to meaning in a yarn is Dadirri; an Aboriginal practice of deep listening and still awareness (Ungunmerr-Baumann, 2002).
- Listening deeply and sitting in still awareness requires you to quiet the noise in your own mind, which often stems from discomfort. It is important to recognise how your mind reacts when you feel uncomfortable or nervous and how it manifests in your behaviour. Those trained in the Western medical system tend to express feelings of discomfort (i.e., caused by feelings of inadequacy, incompetence and/or nervousness) by overcompensating with energetic talking. This can result in a one-way exchange where someone is speaking *at* another person which silences the other person's voice and presence. An Aboriginal person may remain silent and nod to appear engaged and understanding, but this is often a learned survival reflex: the more agreeable we are, the faster we will be able to leave this clinical setting. It is important to get comfortable with silences. For many Aboriginal peoples, especially those that do not speak English as a first language, it takes time to reflect and respond to questions. **If you fill those silences with your voice, you will not hear theirs.**
- Finding your own, personal way to quiet the noise in your mind will support your ability to genuinely listen. Truly listening to the Aboriginal person in front of you and developing a deep awareness of what is close to their heart, and what they enjoy talking about provides insights into how they view the world. Only by deeply listening will you gain profound understandings on how to communicate, tailor the assessment and meaningfully explain assessment outcomes back to the person or family so they can understand and make informed decisions.

> *"In our Aboriginal way, we learnt to listen from our earliest days. We could not live good and useful lives unless we listened. This was the normal way for us to learn – not by asking questions. We learnt by watching and listening, waiting and then acting.*
>
> *My people are used to the struggle, and the long waiting. We still wait for the white people to understand us better. We ourselves had to spend many years learning about the white man's ways. Some of the learning was forced; but in many cases people tried hard over a long time, to learn the new ways.*
>
> *We have learned to speak the white man's language. We have listened to what he had to say. This learning and listening should go both ways. We would*

> *like people in Australia to take time to listen to us. We are hoping people will come closer. We keep on longing for the things that we have always hoped for – respect and understanding…*
>
> *To be still brings peace – and it brings understanding…Our culture is different. We are asking our fellow Australians to take time to know us; to be still and to listen to us…"*
>
> *Aunty Miriam-Rose Ungunmerr-Baumann, 1988*

Shift in traditional clinical goals

- Your ability to quiet your mind and be comfortable with silences will be undermined if you are driven by specific outcomes. Shifting the traditional clinical goals from outcome-based diagnosis to focusing on the quality of connection can profoundly improve the level of trust with a family, thereby optimising the quality of the assessment and support, overall.
- Western training and education can lead to entrenched beliefs about what it means to be a "healthcare practitioner". These beliefs might include, but are not limited to:
    - Having all the answers as the 'expert' and being in control
    - Administering specific 'validated' measures to assess and diagnose all people against the same criteria
    - Person or individual focused rather than family-focused
    - Setting and delivering on goals according to 'evidence-based' measures
    - Adhering strictly to specific boundaries and guidelines around 'building rapport'
    - Meeting targets (time, client, diagnoses etc) that are demanded by the system
- Not only is this culture of the 'healthcare practitioner' established on foundations of rigidity and systemic bias, but it also creates an institution of behaviours that exacerbate power imbalances and inequities. While the guise may be around best patient outcomes or quality service delivery, the reality is far from that for most Australians.
- Put simply, if you enter a room with a series of questions that you need answered within a specific timeframe, you will not build connection, let alone trust. As abovementioned, many Aboriginal peoples have very real and *validated* fears that their children will be removed and/or they will be in some sort of trouble with police based on what they say to you. For an Aboriginal person, being drilled with questions that you may not fully

understand, while in a fearful and triggered state, not knowing if your responses will bring more pain and trauma, is the fastest way to erode a culturally safe environment. Letting go of traditional clinical processes and outcomes in this environment can go a long way in helping to alleviate these fears.

- Part of shifting orthodox clinical goals involves being able to surrender control during an assessment. In a yarn, the level of information exchange is controlled by your client; they set the tone and decide what information is shared. This is fundamental to building purpose and control as part of a strengths-based approach to enhancing Aboriginal wellbeing, which is especially important given the limited control many of the Aboriginal people coming to your service may have.
- Genuinely yarning and shifting the goal from outcome-based diagnosis to the quality of connection and the level of trust built requires **time**. Leaning in and surrendering to the rhythms of Aboriginal timing demonstrates respect, which as mentioned earlier, is the cultural currency of Aboriginal peoples.

> *"Forget the questions, because you will never get the answers or an honest account of what's going on – these kids will tell you what they think you want to hear. Talk to them like you are talking to your own kids"*
>
> *Dr Sharynne Hamilton*
> *Ngunnawal academic*

- Time is what Aboriginal peoples need to read your heart and place you in the world and, which helps people to understand you. Even within 15-minute appointments can you build a relationship *over* time by demonstrating respect and being fully present. Aboriginal peoples remember and experiences are always shared in the community. You may be establishing a relationship of trust with one Aboriginal person, but our interconnectedness means more than likely, this one relationship extends well beyond that individual. Communication is so much more than what is spoken and that can never be emphasised enough.

> *"I've learnt over time, that you have to step back and go, you know what? This kid just wants to tell me about the YouTube video he watched last night and that's fine. And if that's what we get through today then hey he's leaving happy"*
>
> Jade Houghton,
> Non-Indigenous clinician,
> Murri School, Qld

Family-directed yarns

As illustrated by the *Fabric of Aboriginal and Torres Strait Islander Wellbeing* model and supported by extensive other evidence (Biles et al., 2024), Aboriginal health and wellbeing is intrinsically tied to family and/or kinship, where belonging and connection, purpose, identity, and culture are all interwoven. Many Aboriginal peoples function as a collective and share a rhythm when it comes to wellbeing. When it comes to FASD or any neurodevelopmental assessment, family- directed yarns, assessments and supports may be culturally safer, more accurate and elicit far greater strength-based, supportive, and sustainable outcomes for Aboriginal families living with FASD.

Build capacity and connectedness of the whole family

- Family-directed yarns involve all the family and kin in the assessment process. It is important to emphasise that only the person attending for assessment can define and define who is family to them, they may not necessarily be a blood relative or Aboriginal. You, as the practitioner, can work in collaboration with the family to develop a plan for the assessment as well as what strategies and supports you all believe would be most helpful. By acknowledging and building the capacity of the natural roles and responsibilities each person has within their family to support the person living with FASD, you offer a respectful, strengths-based approach. This approach strengthens the connectedness of the family as a dynamic support resource.

- It is important to consider how an assessment and diagnosis are communicated to families, including the language that will be used and who is most appropriate to communicate key information. The family may prefer the practitioner to talk to other family members directly or it may be more appropriate for the practitioner to build the capacity of a caregiver to communicate and translate information to family members, key stakeholders and to the child themselves. When children are attending for assessment, practitioners need to discuss with the family what is the most appropriate way to provide feedback to the child, including whether the parents want to be part of that feedback. Families may prefer for the practitioner to provide feedback and then discuss it together with the child after. Different families have different preferences.
- It is also important to be aware that a diagnosis of FASD can sometimes raise questions for parents themselves or other members of the family. During the assessment process, it is not unusual that other members of the family learn they have FASD also. Appropriate supports and referrals need to be planned to effectively support the whole family during this process.
- Globally, there is a significant lack of FASD knowledge, support, and specialised services across the lifespan. For Aboriginal peoples, barriers to accessing the already limited FASD supports is compounded by poor social determinants of health and ongoing experiences of exclusion, racism, discrimination, stigma, shame and guilt. These experiences can erode a family's confidence, hope and ability to access supports and resources.
- While it is important to recognise the strengths of Aboriginal families and build their capacity to access opportunities as they arise, it's also important to realise the context of significant and accumulative psychosocial stress and systemic barriers that may be experienced by the family. The legacies of colonisation have created a fertile ground for many Aboriginal families to be in a state of crisis, often operating in survival mode. These families may need material resources and support to have their basic needs met before they can engage in any recommended parenting reflexive practices. Further, it is important to highlight that for Aboriginal caregivers, building their ability to self-reflect and self-regulate is more likely to lead to processing traumatic experiences and/or coping with their own social and emotional wellbeing needs. This emphasises the need for emotional support and validation of the challenges they encounter in their daily lives.
- Developing the knowledge, skills, and confidence of families to live with FASD not only equips caregivers with increased abilities to advocate and access support but it also builds dignity, respect, purpose, and control. These elements are critical for promoting hope, a key ingredient in achieving positive outcomes. Figure 2 illustrates an integrated family-directed model for FASD (Reid et al., 2022). Table 2 presents ways in which you might apply family-directed assessments and supports to strengthen the family social

economy, promote hope, acknowledge family expertise, and provide education and skill building.

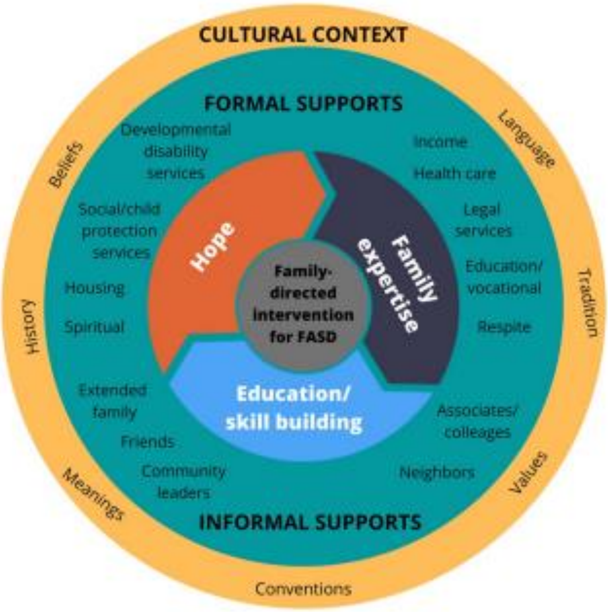

Figure 2. Integrated family-directed theoretical model for FASD. Key components are the following: (1) strengthening the family social economy; (2) promoting hope; (3) acknowledging family expertise; and (4) providing education and skill building. It acknowledges that interventions must be grounded in the cultural context of the family. Reproduced from Reid et al. (2022)

Table 2. Practical ideas to support the application of the family-directed model

Strengthening family economy	○ Assess the current level of formal and informal supports in contextually and culturally appropriate ways. ○ Develop a collaborative plan for how to build these supports as needed. ○ Collaboratively broker, refer and engage with culturally supports and services that strengthen family resources and address basic needs. ○ Where specific FASD-related formal supports are not available, in partnership with families provide education to available service providers to help create and integrate FASD-informed care into existing systems of care.
Promoting hope	○ Engage in raising FASD awareness and decreasing stigma with a wide range of stakeholders who are involved with the child and their family. ○ Gather authentic information regarding child and family strengths. This could include the use of standardised and

	functional assessments tools[a] while also assessing and seeking guidance as to the cultural appropriateness of these tools. ○ Provide a balance of accurate and realistic information about areas of challenge in combination with discussions and ideas for how these challenges can be accommodated an/or remediated. ○ Help caregivers, children, and young people recognise their individual and family strengths and see how these can be utilised to help support their areas of challenge. ○ Provide caregivers, children, and young people with examples of positive and hopeful examples of people who have FASD[b].
Acknowledging family expertise	○ Recognise the knowledge, expertise, and lived experience of all types of caregivers regarding FASD, but also their individual child's preferences and needs. ○ Engage caregivers as 'co-therapists' to achieve authentic collaboration and attitude change. ○ Take time to develop strong therapeutic alliances with children, caregivers, and other family members while acknowledging the cultural context for both the family and the practitioner. ○ Employ motivational interviewing skills and the general 'spirit of Motivational interviewing' as a helpful tool build relationships, highlight caregiver and family knowledge and expertise and promote caregiver directed change. ○ Utilise self-reflection to examine own attitudes towards alcohol, addiction, stigma, and prenatal alcohol exposure/FASD. ○ Facilitate the use of compassion-focused and parent regulation approaches.
Providing education and skill building	○ Support caregivers to understand their child's unique neurodevelopmental profile of strengths and challenges and how this impacts their daily activities now and in the future. ○ Incorporate positive behaviour support approaches. ○ Use available skills, strategies, resources and services to support children to develop their self-regulatory and adaptive skills[c].

	○ Dedicate time to effectively understand and support caregiver needs, create community, build caregiver advocacy skills and ability to deal with stigma.

[a] e.g. The Children's Assessment of Participation and Enjoyment (CAPE) and the Preferences for Activities of Children (PAC); The Family Goal Setting Tool or Adolescent Goal Setting Tool https://autismqld.com.au/resources/the-family-goal-setting-tool-fgst/

[b] e.g. The FASD Change Makers; https://www.nofasd.org.au/community/cj-lutke-blog/

[c] Depending on your discipline and context, a range of different strategies to build self-regulatory and adaptive skills can be included here (e.g., arousal modulation type approaches, such as the ALERT Program (https://www.alertprogram.com/); meta-cognitive type approaches, such as Goal, Plan Do, Check or FAR – Focus and plan, Act and Reflect from GoFAR; mindfulness-based games and activities; and creative use of easily available child-friendly games that parents can play with their children such as Simon Says, Jenga, or freeze tag).

Note. Reproduced from Reid et al., 2022.

Gathering holistic information

- An essential part of family-directed yarns is gathering all available information from the lived experience experts – the family. All pieces of information and perspective are required to create a full picture.
- Valuing all information shared by the family not only strengthens connection and understanding but better equips you as a practitioner to assess needs and develop strategies that meaningfully build the capacity and connectedness of each unique family. It also provides insights into the family's preferred communication methods, including what helps their understanding.
- One of the most important components of the family-directed yarn is your ability to translate and share the assessment findings back to the family in the same way that you gathered it – holistically. This involves presenting the assessment information in a way that is meaningfully and easy for the family to understand and use. Gathering holistic information throughout the assessment journey facilitates a successful feedback process. Below, further information is provided to support this process.

Applying a strengths-based wellbeing approach

All the learnings you have undertaken around your knowing, being and doing are to build your capacity to apply a strengths-based wellbeing approach in neurodevelopmental assessments with Aboriginal peoples and/or families.

While Western medicines can help support neurological and physiological health, they are unable to address the social, emotional and cultural wellbeing of an Aboriginal person. This is why we need a new knowledge that combines Western and Aboriginal wisdoms, benefiting all Australians.

Among Indigenous peoples globally, strengths-based approaches have been found to decrease stigma (Choate & Badry, 2019; Petrenko & Kautz-Turnbull, 2021), build relationships (Flannigan et al., 2021) enhance cultural identity and connection (S. L. Hamilton, Maslen, Best, et al., 2020; Rogers, 2017), promote hope (Flannigan et al., 2021; S. L. Hamilton, Maslen, Best, et al., 2020), measure cognitive domains more accurately (Kully-Martens et al., 2022), increase resilience (Rogers et al., 2020) and support healthier coping for families (Shochet et al., 2019).

> *"...people with FASD have unique strengths and with appropriate support and intervention have been able to avoid the negative life trajectory and have stable and successful lives."*[6]

It is critically important to emphasise that a "strengths-based" approach is **not** simply listing the hobbies and interests of a person. A genuine strengths-based approach prioritises and privileges cognitive strengths and related achievements throughout the entire assessment process.

This section is about *how* to apply a strengths-based wellbeing approach in your practice that is grounded in strategies that enhance the physical, social, cultural, emotional and spiritual wellbeing of the Aboriginal person and family living with FASD.

Shared Decision-Making Model

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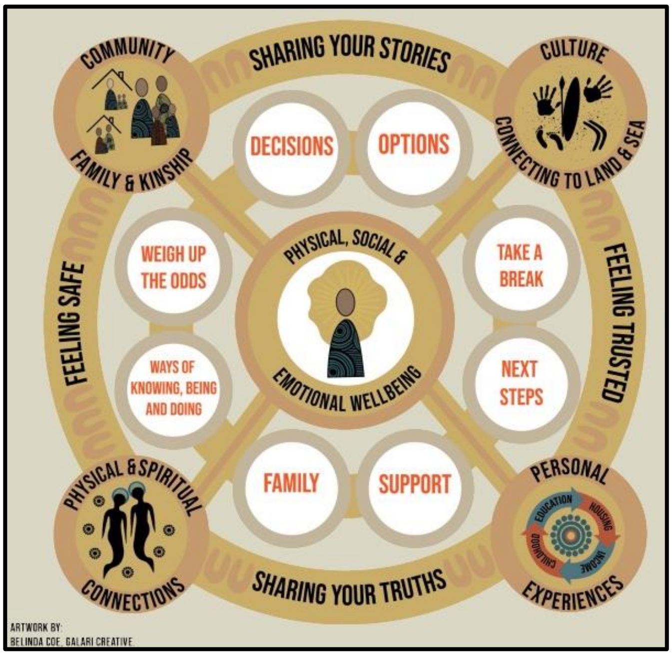
[6] p.55 Williams, R. D. (2018). *Understanding Fetal Alcohol Spectrum Disorder (FASD) through the Stories of Nyoongar Families and how can this Inform Policy and Service Delivery*. Curtin University.



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Finding Your Way: A shared decision-making model.
Artwork by: Belinda Coe, Galari Creative

The *Finding Your* Way shared decision-making model (Agency for Clinical Innovation, 2021) provides a practical tool for how to facilitate a holistic, two-way yarn where Aboriginal peoples and their health care professionals can collaborate and make decisions together. As the model here illustrates, physical, social, and emotional wellbeing is at the heart or the goal of this practice and surrounding this, is the scaffolding required to support this goal. The tool offers the prompts required to facilitate a yarn in a way that Aboriginal peoples can feel safe and trusted to make informed decisions. These decisions are based on each family's unique circumstances, values, and beliefs. Further information is described below about each step of the model and how it can be applied to the assessment process. (S. Hamilton, 2020)

The Finding your way model tells the story of an individual/family's journey. We all start at the beginning, but we choose different paths as we walk and understand the environment better. Below, the information is presented using the scaffolding needed for Aboriginal peoples to make health decisions and to guide you, as the practitioner, in supporting this holistic shared decision-making process in the assessment and diagnosis of FASD. Although the information is presented below sequentially, these yarns are circular as illustrated in the model, and will move you and the family forwards, backwards, or sideways depending on what is needed at the time. There is no standard, linear way to hold these holistic yarns, but it is important that they are led by the Aboriginal person or family in front of you. In this way, both you and your Aboriginal clients are finding your way to make informed decisions around FASD, ultimately strengthening the wellbeing of the person and family living with FASD.

> *"Diagnosis can be a label, or it can be a key that opens the door to understanding and opportunity to access the resources and supports required to manage the constellation of impairments that accompany a diagnosis of a neurodevelopmental disability."*[7]

This process can be applied in all sessions with individuals and families attending for assessment. Each area can shift dramatically from session to session, so it is important that the yarn continually revisits most areas each session. This demonstrates your respect for the living experiences of the family and that you are genuinely interested in listening and learning about their journey. In turn, you will be

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[7] p.89 Hamilton, S. (2020). *Yarning, Hearing, Understanding, Knowing: A qualitative study of the experiences of Fetal Alcohol Spectrum Disorder assessment and diagnosis for justice-involved youth and their care networks* [PhD Thesis, The University of Western Australia]. https://doi.org/10.26182/kt9z-tg36

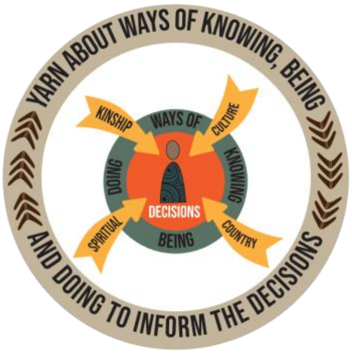
better equipped to understand the needs of the person and family and how best to support them.

Family

Yarn about family and where the individual and family attending for assessment is from. Also share about where you and your family are from.

As a way of finding shared ground to build trust and to measure **belonging and connection** as well as **purpose and control** (as determined by sense of stability), it is important to identify intimate relationships, family networks and broader social relationships as a means of understanding the availability of culturally prescribed pathways that resonate with individuals and families. It is also important to share who you are (your truths and story) here to build connection and a safe space that invites the Aboriginal person and family to share their story.

When a family feels comfortable to share their story, it is important to recognise the knowledge, expertise and lived experience of FASD, especially as it relates to their individual child's needs and preferences. This helps to ensure families are 'co-therapists' in this shared decision-making process, which goes a long way in building trust and connection that is grounded in **dignity and respect.** Information gathered through yarning about family will also inform the feedback process and be included in the report.



Ways of Knowing, Being and Doing

Yarn about ways of knowing, being and doing to inform decisions that are based on a person's values and beliefs. This is underpinned by the notion that when the spirit is strong, you can make good health decisions.

The ways of knowing, being and doing will be unique to every Aboriginal person and family. The only way to find out the values, experience, beliefs, and preferences of the person/family sitting in front of you is to create a safe, trusted space, ask and then listen, deeply. You might yarn about:

- What is important to you? Why is it important?
- Do you participate in activities like language, art, singing, dancing, storytelling? Or would you like to?
- Are you connected to community in sport or employment?
- What do you know/believe about FASD and what feelings does this bring up?
- What do you know/believe about the assessment tools and approaches that allied health professionals use?
- What are your fears?
- What do you hope for?

Information collected from yarning about ways of knowing, being and doing will help across multiple areas of the assessment process. For example:

- Understanding appropriateness of assessment tools and approaches for each family.
- Understanding appropriateness of diagnosis for each family.
- Developing culturally responsive support recommendations that are individualised for each family.

Wellbeing Support

Yarn about what is happening for the individual and family, including social, emotional and wellbeing needs and supports during the assessment process.

Throughout the assessment process it is vital to be checking in and incorporating individual and family social, emotional and wellbeing needs. Strengthening the family as a dynamic source of support draws on the wellbeing dimensions of **holistic health**, **purpose and control** and **belonging and connection**. The available literature highlights that the wellbeing of Aboriginal peoples with FASD is strengthened when their **basic needs** are met- having a safe and secure place to go, and feeling supported, accepted and unconditionally loved (S. L. Hamilton, Maslen, Best, et al., 2020).

Having an understanding about the individual and family's social, emotional and wellbeing will also help to guide the structure of the assessment process to ensure quality and accurate information is gathered. To understand and strengthen the family's social, emotional and wellbeing you may begin by identifying the current needs and supports by:

- Yarning to assess the current level of formal and informal supports
- Addressing any immediate social, emotional and wellbeing needs for the individual and family that arise during the assessment process.
- Developing a collaborative plan for how to build supports as needed
- Collaboratively brokering, referring, and engaging with culturally responsive supports and services that strengthen family resources and address basic needs as part of the feedback and assessment follow-up process.

OPTIONS

Yarn about health needs, assessment options and the different supports available. This includes yarning about the benefits and risks of all these options. Ask questions, share knowledge and feelings about the potential assessment and support options.

Now that you have information about an individual's family and have an understanding about their values and needs, you are better equipped to have an informed discussion about the different assessment, diagnostic and support options. This includes providing information about the benefits and risks of the different options. Different options to yarn about could include:

- The use of Western allied health assessment tools used to measure a person's skills is often required to get access to Western health and education systems. Some tools might not provide a true reflection of an Aboriginal person's abilities. Discussion could occur about the risks and benefits, including whether more culturally appropriate tools could be chosen, or whether other methods of assessment would be more appropriate for the individual attending for assessment.

- The benefits and risks of a diagnosis of FASD. The benefits of a diagnosis may include helping an individual and family understand why a person is having the kinds of challenges they are and support them to access appropriate supports. At the same time, a FASD diagnosis can be experienced as shame by family and affect how they are perceived in their community. There may be times that it is more appropriate not to go ahead with an assessment or not provide a diagnosis of FASD based on what the family wants. Discussions should also consider what information is shared with the rest of the family.
- The impact of a FASD diagnosis on parents should also be considered- including those who are not the primary caregivers - as they, too, are affected. This will also require consideration of how the diagnosis will be communicated within the family and if the family would like support with this process.
- Accessing National Disability Insurance Scheme (NDIS) could provide a way for individuals/families to get support but there can be considerable stress or overwhelm in the application and review processes. Access to a support person to help the family with the process should be explored.

The available research literature highlights the effectiveness of using visual resources when communicating assessment processes and FASD diagnosis to Aboriginal children and families (Hamilton, Maslen, Watkins, et al., 2020). Further, research has shown that children with FASD have demonstrate greater understanding and are able to showcase their abilities when visuals and visualisation strategies - such as the use of meaningfully connected information such as stories or metaphors-are are incorporated into assessments (Hamilton, Reibel, Maslen, et al., 2020).

	**WEIGH UP THE ODDS** Yarning about the possible benefits and risks. Compare options and weigh up the odds individual and for family and community.

The information collected during yarning will help the clinician and family to weigh up the benefits and risks for the family according to their values. Things that families may need help to weigh up:

- Do I want/need a referral for assessment?
- How could an assessment be helpful/harmful for me/my family/my child?
- Should I let the health professionals assess me/my child using Western assessment tools?
- Would a diagnosis of FASD or any other condition/s help me/my child?
- What supports do I need?
- Should I apply for NDIS?

Decisions

Yarning to bring it all together and either decide to act now if ready or wait.

It is important to provide the individual and their family with time to yarn about their decision(s), while also offering validation and support for whatever they choose to do. Although clinicians might have thoughts about what is the best decision, ultimately it is vital to respect the individual/family's decision as this is what is right for them at this point in time.

Yarn about the next steps, including how and what to do next and what might get in the way. Follow up later.

At the end of each session- and at the conclusion of the assessment process- it is valuable to provide space and opportunity for the individual or family to yarn and collaboratively plan the next steps that are right for them.

Advocacy

- Using your privilege and power—however small—to amplify the voices of those who are often unheard, or to advocate for support and help navigate complex systems alongside individuals and families, can create powerful ripples of healing. Even the smallest acts of advocacy can nurture hope, a sense of worthiness, and motivation.
- Many families will need your support beyond the assessment and diagnosis. Holistic health involves going above and beyond to enable Aboriginal families living with FASD to thrive. This may include:
  - Advocating for and building collaborative partnerships with accessible services that help strengthen culture and identity while providing regular opportunities to participate in social and cultural activities.
  - Facilitating access to and providing support in navigating complex non-Indigenous systems such as NDIS and schools.
  - Providing additional social, emotional and wellbeing supports for Aboriginal peoples on your waiting lists for neurodevelopmental assessments and finding ways in which to make these assessments affordable.
  - Identifying accessible ways in which to collaborate with caregivers and provide emotional and practical supports.
- If you would like to advocate at a broader level, the Royal Commission into Disability released a series of recommendations in June 2023 to improve service availability and accessibility for Aboriginal and Tores Strait Islander peoples with a disability: https://disability.royalcommission.gov.au/publications/options-improve-service-availability-and-accessibility-first-nations-people-disability

- Even without FASD or a disability, Aboriginal peoples are subject to significant negative messaging and ongoing stigma. This stigma is often internalised if there is not a strong voice to counteract these experiences across the lifespan - especially in the developmental years. Advocating for an Aboriginal person or family not only builds profound trust but also provides the opportunity to transform lives. Your advocacy can literally change the trajectory of an Aboriginal person's life.

> *"…For Aboriginal peoples, the escalation to child removal and justice is significantly sharper than for non-Aboriginal peoples"*
>
> Dr Michael Doyle
> Bardi academic

What do Aboriginal communities need to **know, be** and **do** to access culturally responsive assessments?

Alcohol use among Aboriginal peoples can only be understood within the social and historical context of colonisation, dispossession of land and culture, and economic exclusion. While colonialism and dispossession are not the cause of all harmful alcohol use among Aboriginal peoples, observed drinking patterns are a response to Australia's history and the current social conditions that have arisen from it. This is a shared story and experience for all Indigenous peoples across the world. The intergenerational and ongoing trauma combined with a history of exclusion from education, health and jobs has created fertile grounds for cycles of poverty, feelings of helplessness and harmful alcohol use across the lifespan, including during pregnancy.

There has been a scarcity of Aboriginal authors publishing in matters of FASD. Although there is a hopeful and changing horizon around this, much of the rich information provided below has been informed by Aboriginal Knowledge Holders in the FASD space. They have generously and graciously shared their wisdom, in the spirit of finding pathways that bring intergenerational healing and change for Aboriginal peoples throughout Australia.

The following information unfolds the shifts that Aboriginal peoples need to make, at a local level, in their communities' ways of knowing, being and doing to access culturally responsive FASD knowledge, resources, assessments, diagnosis and support services.

WAYS OF KNOWING

Unveiling FASD

Consistent with the limited awareness and knowledge of FASD in general Australian society, some Aboriginal peoples are not aware of FASD, and this is due to a multitude of factors. Culturally, many communities do not necessarily see "dis" ability, many communities see "different" abilities (June Riemer, Cultural Advisory Group, 2022). This is expanded upon further below.

Historically, the abovementioned intergenerational cycles are compounded by the entrenched shame, guilt, and stigma from colonisation and this is salient across all areas of health, including alcohol use during pregnancy. For some Aboriginal peoples, to acknowledge the existence of FASD is to reinforce toxic stereotypes and invites fear, further racism, and even deeper shame, guilt, and stigma among Aboriginal families. Naturally, this has a silencing effect on Aboriginal peoples, so there remains many untold stories of alcohol use during pregnancy. The lack of records of alcohol use during pregnancy combined with a lack of awareness around FASD behaviours allows FASD to hide in the shadows of communities and silently exacerbate cycles of trauma, grief, and loss.

The impact of FASD awareness within families is essential to nurturing and protecting children with FASD. It is also key to building supportive wrap-around healing-informed pathways to loosen the grip that colonisation continues to have on some families. This must begin with a sensitive and respectful 'unveiling' of the existence of FASD in the local community. You will notice that all the "ways of knowing" strategies used to unveil FASD draw on Aboriginal culture and therefore, are grounded in the strength, sovereignty, resilience, and healing qualities that our culture inherently yields.

> *"The silent story of FASD within all our families has been there for many years, waiting to be recognised and understood by society. Family narratives of FASD must be told to bring forward hope, reforms and a new era of awareness to replace what is too often described as "despair and hopelessness" by families caring for children adolescents with FASD".*
>
> *Dr Robyn Williams Noongar academic.*

Role of History

- It is important to unveil and connect the role of history and how it continues to play out for our people on both personal and collective levels. While Aboriginal peoples are aware of colonisation and the accompanying oppression and dispossession, understanding *how* colonisation continues to impact us individually, as a family and as a community is a different understanding.
- Not all Aboriginal peoples have the privilege of time and capacity to reflect and truly understand how history manifests in their lives. Without awareness, there can be no change, nor can we hold compassion for ourselves to undermine the guilt and shame we may carry as a result of racist narratives that we are saturated in, unconscious behaviours or the various coping strategies used. The way in which we unveil the FASD story must be grounded in a healing-informed and strengths-based lens, highlighting what has kept us strong and what will continue to strengthen our wellbeing. Here, we draw on the Fabric of Wellbeing model to identify what makes each of us

strong and how can we use this knowledge to inform what we need to build on to heal the scars of colonisation.

> *"The ritual of being intoxicated due to the consumption of alcohol is not the custom of Aboriginal people. It has nothing to do with Aboriginal culture and everything to do with the hopelessness of being immersed in cycles of intergenerational boredom, learned behaviours, power struggles, crisis, vulnerability, abuse, trauma, poverty, grief and loss. We have children that wake up and drink their parents' alcohol because they are hungry and need something to fill their bellies. Their parents did the same and their parents before that. Here, cycles of loneliness and being alone begin and our children become desperate for connection. This desperation creates gangs of lonely, hungry, isolated, traumatised children with FASD that have been starved of love and all the other basic needs. The only thing these kids are focused on is survival and that leads to a life of crime. That is not a choice, there is no freedom or self-determination in these situations."*
>
> *Dr/Aunty Lorian Hayes, Iningai and Bidjera FASD academic.*

Community story-based yarn

- When unveiling FASD in an Aboriginal community, it is important to prioritise listening to stories and experiences, which may not necessarily be about FASD. In many communities, it will be more appropriate during the initial engagement and yarns to avoid mentioning 'FASD' unless you are invited specifically to yarn about FASD. Alternative introductory titles for these yarns might be 'alcohol/grog and pregnancy' or 'healing from alcohol/grog harms'.
- Drawing on Dr/Aunty Lorian's grassroots knowledge and experience, when invited into a community to yarn about alcohol and pregnancy, you may begin by sharing your story, being critically mindful of the privilege and power you hold in this space. Your story may prompt others to share theirs or you may have to ask a particular question around what the priorities in the community are. From this space, Dr/Aunty Lorian yarns with those present, and draws on the principles of a problem-based learning approach (Hayes, 2019). This approach allows community members to share their stories and lived experiences of alcohol and discuss what they believe are the important issues in their community. As experts on their own lives, these stories help community members draw their own connections and conclusions which inevitably unveils the link between alcohol use in pregnancy and adverse experiences the community are having.

- Holding space for such a yarn—in a way that the involved Aboriginal community deems safe and meaningful—relies on the identity, authority, and reputation of the facilitator, as well as their ability to follow culturally appropriate protocols and processes. Facilitators must approach this role with gentle vulnerability, letting go of predetermined goals related to time, data, and place. Above all, these yarns must be conducted with deep sensitivity and a strong commitment to confidentiality. As Dr/Aunty Lorian reminds us, "…confidentiality itself is something that needs to be demonstrated rather than simply promised" (P.61, Hayes, 2019).
- Such a space inevitably generates a rich two-way unveiling, where both the facilitator and community members share and learn from each other:
    - when community understandings and their beliefs around FASD are realised, it mobilises the community's intuitive response to protect, nurture and support members living with FASD.
    - facilitators gain insights into community understandings, attitudes and beliefs as well as what kind of language is used locally. They also learn about the needs, dynamics, influences and opportunities within the community.
- Such information can reveal powerful and meaningful metaphors, stories, key messages, communication pathways, and innovative visual resources. These approaches support the translation of FASD knowledge in ways that best resonate with that particular community.

> "For Aboriginal peoples, story and story-telling commenced at the beginning. Stories are embodied acts of intertextualised, transgenerational law and life spoken across and through time and place. In and of the everyday and every time, stories – whether those that told of our origin or of our being now – all carry meaning: a theorised understanding that communicates the world." [8]

Humour

- Intergenerational trauma is often discussed, but its ugly siblings – stigma, shame, and guilt – are rarely addressed. These elements have insidiously infiltrated all areas of Aboriginal health, serving as colossal barriers to prevention and equitable access to services for Aboriginal peoples.
- The extreme negativity and deficit narratives used at a societal level have generated a fear of those with FASD, which is underpinned by a belief that "children who were damaged had the potential to become adults who could be dangerous in society" (p.34, Williams, 2018). The FASD narrative, combined with the entrenched racist and dysfunctional portrayals of what it is to be "Aboriginal," has created fertile grounds for prolific levels of stigma

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[8] p.8 Phillips, L., Bunda, T. and Quintero, E. (2018). *Research through, with and as Storying,* London, Routledge.

and shame for Aboriginal peoples especially. Consequently, conversations about FASD become unspeakable across individual, family, community, organisational, and policy levels. For Aboriginal peoples- many of whom already live with profound levels of shame and fear- the mere mention of FASD can be deeply triggering and can intensify distress when not done in a healing-informed, strengths-based and culturally grounded way. If FASD remains unspoken, it cannot be unveiled and therefore, the necessary supports, resources and funding will not be allocated, exacerbating cycles of unhealed trauma, grief, loss, stigma, and shame.

- Aboriginal culture offers many powerful antidotes to stigma, shame and guilt. One of the most understated of these is Aboriginal humour and its incredible role in our coping, resilience, and healing (Duncan, 2014).
- Humour is an effective way to increase awareness and knowledge of FASD and undermine stigma using a strengths-based and healing-informed approach.

Theatre-based education

- When translating FASD knowledge to build the capacity of the Aboriginal Health workforce and community members, Dr Robyn Williams has drawn on humour and storytelling (Williams, 2018). Robyn developed FASD education using a narrative therapy approach, titled “Yarning with cheeky FASD”.
- Narrative therapy complements the richness of storytelling in Aboriginal cultures. “Yarning with cheeky FASD” encourages participants to bring their personality, and to act younger than their age. This involves people acting out the “cheeky FASD” character and demonstrate some of the behaviours that people with FASD may experience, but in a light-hearted way. Given that FASD training content can be confronting, role play provides participants with some light relief, while consolidating their learning about FASD.
- Using this theatre-based, narrative therapy approach externalises FASD for the audience, allowing them to meet FASD as a visual character in a non-confrontational way. This approach unveiled FASD in a healing-informed, strengths-based and culturally grounded way.

Reframing the Narrative

Developing our knowing in FASD will unveil its existence in our local community. However, this knowledge alone will not build the skills necessary to bring about meaningful change. It is important to understand who we are – our ways of **being** - and to compassionately explore what drives our behaviours, while recognising and building on the strengths and skills we already hold. All Aboriginal peoples possess incredible sovereignty, skills, and wisdom inherent in our ancient cultural bloodlines. However, if we have internalised colonisation, we may need to help to reframe our personal and collective narratives.

> *"We need to take back our narratives. We lead the way in FASD research and knowledge translation, not because FASD in an "Aboriginal problem" but rather because our cultural ways are powerful, strengths-based and holistic. When the narrative lacks our Aboriginal voice and ownership, deficit discourses that focus on Aboriginal shame and blame emerge and this plays out at a grass roots level for our people. We are sovereign people and these narratives belong to us."*
>
> Dr Robyn Williams, Noongar academic.

Addressing internalised colonisation

- Richard Frankland describes internalised colonisation as "*the organised, harmful behaviours that we do to each other collectively as part of an oppressed group: within our families; within our organisations and; within our communities. When we are consistently oppressed, we live with great fear and great anger, and we often turn on those who are closest to us*" (P. 8, Australian Human Rights Commission, 2011).

> *"If people are brainwashed to think they're inferior then there is a collapse and people begin to act in negative ways and this is served up as proof of 'inferiority'. This gets handed down to our kids who hear it all around. [We] need to remember how great we were and go forward from a position of strength.*[9]

- All human beings respond to stress through our central nervous system—an automatic system designed to protect us from harm. It prepares our bodies to quickly react to threats through fight, flight, or freeze responses. This survival response is essential in life-threatening situations, such as fighting off a dingo, fleeing from a box jellyfish, or freezing in the presence of a snake.

- However, modern-day harms—such as racism—can also activate and keep this survival system switched on, because the threat is ongoing. This constant activation can continue to trigger fight, flight, or freeze responses, even when physical danger isn't present.

- The harm of your own people attacking your identity and the hopelessness that comes from living in a world that does not value your culture or worth can create a toxic environment for Aboriginal communities. This environment can lead to engaging in behaviours that erode the very things that bring wellness, strength and healing belonging, connection and positive cultural identity. It is important that we all, as Aboriginal people, to listen deeply to our spirit to understand how shame and guilt impact on our lives and what coping behaviours we may automatically use to soothe these emotions. This allows us to reflect on whether these coping strategies are ultimately helping or harming us.

[Alcohol] helps to escape stress and/or emotional pain. Both young adult men and women reported drinking alcohol to 'drown out the pain,' and to help them 'forget things, numb pain and depression, and to make memories go away.' Other adults suggested that they use alcohol as a tool to 'get away from things in their lives.'[10]

- Healing from internalised colonisation requires, an awareness of its existence before exploring what kind of the coping strategies will serve to release or *externalise* the accumulative impacts of colonisation (i.e., so it does not remain *internalised*). For human beings, releasing this stress can only be achieved through our fight, flight or freeze systems.

- Whichever system is used will be unique to each person and what works for them. For example, some people may need to release by one or a combination of:
  - **Fight** – harnessing this response in a productive way by focusing it on advocacy and changing policies and practices.
  - **Flight** – moving something inside yourself through counselling or moving physically and putting distance between yourself and the immediate harm.
  - **Freeze** - to just be still and express the pain through Dadirri, storytelling, dance, yarn, weaving or art.

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[9] p.7 Gorringe, S., Ross, J. and Fforde, C. (2011). *Will the Real Aborigine Please Stand Up': Strategies for breaking the stereotypes and changing the conversation,* AIATSIS Research Discussion Paper 28.

[10] p.8 Gonzales, K. L., Jacob, M. M., Mercier, A., Heater, H., Nall Goes Behind, L., Joseph, J., & Kuerschner, S. (2021). An indigenous framework of the cycle of fetal alcohol spectrum disorder risk and prevention across the generations: Historical trauma, harm and healing. *Ethnicity & Health*, *26* (2), 280–298.

- As we learn to reframe the narratives imprinted on us by oppression, we open the opportunity to reframe our own lives and those of the families and communities we live in. There is much healing and hope to be found when we are given the opportunity, privilege, and space to understand ourselves. Every person deserves this, regardless of their journey.

Cultivating hope

- Fundamental to Aboriginal wellbeing is having **purpose and control** in our lives, and the belief, opportunity, and hope that accompanies this thread of wellbeing. Reframing the narrative for *all* young Aboriginal peoples but especially those living with FASD, involves embedding hope about what is possible and achievable.
- For people living with FASD, it is essential to identify and nurture each individual's strengths—and to use those strengths as a foundation for building self-understanding, confidence, and practical life skills. These skills can support basic needs such as employment, financial independence, and stable housing. In Western Australia, Aboriginal youth with FASD have expressed aspirations such as becoming Indigenous rangers, working with their hands to build things, or starting small businesses to sell their art or photography (S. L. Hamilton, Maslen, Best, et al., 2020). These dreams—and many others—are not only valid but entirely achievable. As a community, we must recognise this potential and work collectively to create and support meaningful pathways and opportunities.
- It is worth noting again, that the Aboriginal worldview is inherently strengths-based and the concept of "disability" is an introduced Western way of thinking. Aboriginal peoples understand community members according to different abilities, as determined by how a child participates in community. What is considered "**dis-ability**" in Western ways may be seen as **"diff-ability"** in Aboriginal ways. This perspective is critically important when cultivating hope in someone living with FASD. If any human being believes they *are* the problem, that they are somehow 'broken' or fundamentally flawed, hopelessness can occur because of the intrinsic belief that nothing can help them.
- Fo By building the capacity of community to understand how to cultivate hope and create local, supportive, and strengths-based pathways, we can support Aboriginal peoples and their families to live well with FASD.

> *"He has problems, **he is not the problem**. We must be part of the solutions for him"*
>
> *~Detention Centre Educator*[11]

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[11] p.144 Hamilton, Reibel, T., Watkins, R., Mutch, R. C., Kippin, N. R., Freeman, J., Passmore, H. M., Safe, B., O'Donnell, M., & Bower, C. (2019). 'He Has Problems; He Is Not the Problem. . .' A Qualitative Study of Non-Custodial Staff Providing Services for Young Offenders Assessed for Foetal Alcohol Spectrum Disorder in an Australian Youth Detention Centre. *Youth Justice*, *19*(2), 137–157.

Drawing on Aboriginal Sovereignty

- Building the capacity of our community to support each other is about having sovereignty over our storylines and narratives. To achieve this, it's important that communities understand their rights and know how to confidently advocate for the right to have access and be able to make informed decisions about anything impacting on their lives.
- It's important that you and your family know that it is entirely your choice whether to proceed with any type of assessment for your child or yourself. If you or your child take part in an assessment—such as for FASD, Autism, or ADHD—you are not required to accept a diagnosis if it doesn't feel right or helpful for you. You have the right to accept or decline a diagnosis, and it is the practitioner's responsibility to clearly explain both the potential benefits and challenges of any decision. You also have the right to ask questions and decide how to use the information you receive.
- The *Finding Your Way* shared decision-making tool (see page 36) is designed to help community members feel confident in knowing what kinds of questions to ask, and what kind of yarn to have with a practitioner. If the practitioner you're working with is not open to using the *Finding Your Way* tool, you are within your rights to find another practitioner. Keep seeking support until you receive the respect and care you deserve—because accessing the right help and diagnosis can be "the catalyst for change and quality of life" (Williams, 2018, p. 1).

Strengths-based pathways

Once FASD has been unveiled and the narratives and storylines reframed, Aboriginal communities will be better equipped to identify, advocate for, and build strengths-based pathways to FASD knowledge, resources, services, assessments and supports that resonate with the local community. Past and present experiences tell us that the only way to achieve successful and equitable access is to demand it and continue demanding for it until such time as someone listens. Your voice is important and invaluable to bringing about change. Never forget that you are the expert on your life, and if you believe that your client, child or someone in your family needs help, keep going until you get it. It can be a lonely journey, but by looking after your own wellbeing by building your sense of belonging and connection with the supports listed below, you will find your own strengths-based pathway to gently hold you, or the family you are supporting, on this journey.

> *"I would be saying jump up and down as loud as you can for the child.... Stay strong in your instincts, trust yourself, and ask for help, and especially with medical professionals, if at first you don't have success try a different doctor; don't stay with a doctor if you are not happy. Find someone who is actually going to help you and your child."* [12]

Building community-led clinical support and local referral pathways

Different pathways may be more appropriate for different communities, depending on which organisations are trusted locally. These pathways need to be developed at the community level and aligned with the capacity of the local workforce. Achieving this requires strong, trusted relationships across sectors—and a shared commitment to working together in solidarity. If you do not have local assessment

[12] p.2 Williams, R. D. (2018). *Understanding Fetal Alcohol Spectrum Disorder (FASD) through the Stories of Nyoongar Families and how can this Inform Policy and Service Delivery*. Curtin University.

and diagnostic service providers in your area here are some suggestions that could support your community in developing these:

- **Connect with established FASD clinics to explore opportunities for support in setting up local services.** You can find service providers listed on the FASD Australia Hub website or contact the NOFASD Hotline for help identifying services that may be able to offer guidance and support.
- **Reach out to your local Aboriginal Community Controlled Health Organisation (ACCHO)** and let them know you're seeking access to FASD assessment and diagnosis in your area. A growing number of ACCHOs are beginning to offer these services, and your interest can help guide local service planning.
- **Speak with your local child development service** to express your interest in accessing FASD assessment and diagnosis locally. Your voice matters and can help create momentum for service development in your community.
- **Engage with your local GP and other primary health care providers** and let them know you would value their involvement in the assessment process. They can play an important role in supporting diagnosis, care coordination, and follow-up.
- **Engage with local practitioners and encourage collaboration across different settings.** The assessment process doesn't need to happen in one location. For example, some components can be completed at school by guidance officers, or by therapists you're already connected with. These practitioners can work together with other clinicians to bring all the information together in a coordinated way.
- **Consider starting or joining a local community action group or family support network.** Many people have created local groups (e.g., the QLD FASD Support Group on Facebook) to connect with others, share experiences, and support one another in building culturally safe and locally relevant pathways to assessment and diagnosis.
- **Promote access to FASD diagnostic training programs**—such as the UWA short courses, graduate programs, or the Gold Coast Child Development Program. These can help build the skills and knowledge of local staff, including Aboriginal Health Practitioners and Workers, to strengthen local diagnostic capacity.

National Disability Insurance Scheme (NDIS) Support

A diagnosis of FASD can support access to the NDIS. The types of supports that can be funded depend on the individual's specific needs. To apply, supporting documentation is required, which may include:

- **Reports from health professionals** (such as a speech pathologist, occupational therapist, or psychologist) that confirm a diagnosis of FASD and describe how it impacts day-to-day life. These reports help explain how the disability affects the person at home, at school or work, and in the community.
- **A functional assessment** by an occupational therapist, which shows how much support the person needs to do the things others their age is typically able to do. These assessments help determine how many hours or types of support may be required.

How to apply for NDIS:

- The process begins by completing the Access Request Form, which can be found here NDIS Access Request Form
- As part of the application, a **health professional** will need to complete the **Supporting Information Form**. This could be done by someone who completed the FASD assessment or another professional currently working with you or your child.
- After submitting the application, the next step is a **Planning Meeting**. At this meeting, you'll be asked to set goals for the person receiving support. It can be helpful to have already discussed and written down some goals with health professionals or support workers beforehand. Goal setting can feel overwhelming in the moment, so preparing ahead of time is strongly encouraged. Preparing for your Planning Meeting

Getting help with the process

The NDIS application and planning process can be challenging to navigate, and it's **completely okay to ask for help**. People who can assist include:

- **Aboriginal Community Controlled Health Services (ACCHOs)** – Many have Aboriginal Disability Liaison Officers who can support you through every step of the NDIS journey, including applications and reviews.
- **The health professionals** who completed the FASD assessment – have a yarn with them to see how they can support you or who they recommend.

- NDIS Early Childhood Partners – For children under 9 years old: Early Childhood Approach – NDIS
- NDIS Local Area Coordinators (LACs) – For children and young people aged 9 and above: LAC Partners in the Community
- Other professionals who may be able to help:
    - Therapists already working with your family
    - Student welfare coordinators
    - Community health workers
    - Kinship care organisations
    - Disability advocacy organisations

A Note for Families

Talking about what your child "can't do" or "finds difficult" can be emotionally hard. It may feel like their strengths and uniqueness are being overlooked in favour of focusing on deficits. You have the right to decide how much to share and with whom.

Try to see this part of the process as a **necessary step**—a bumpy road that helps identify your child's needs to get the support they deserve. Once the application or review is complete, you can return to focusing on your child's many strengths, and how new supports are helping them thrive.

Other challenges in the process can include:	**Some ways to manage this might be**
Needing access to a computer to download or complete forms online.	Forward emails to a trusted support person or provider helping you with the process, so nothing gets missed.
Receiving emails requesting more information.	Ask for face-to-face or phone meetings if anything is unclear. Do not Hesitate to ask for help from the support people around you.
Not being sure what is being asked or how to respond.	It is okay to ask for clarification or support – you're not expected to understand everything on your own. Feel free to ask your support person to help you write down what you want to say

	before a meeting, so you cover everything. IYou do not have to attend meetings alone- bring a family or a trusted support person. you don't have to. Family or support people can also attend any NDIS meetings with you.
Attending meetings usually over the phone.	If meetings are held by phone, ask for a written summary afterward so nothing is missed.

The benefits of accessing NDIS

Even though the NDIS process can be tough to navigate, it can provide significant supports. Some of the services that may be funded include:

- **Therapies** to build life, communication, and sensory skills
- **Respite** for caregivers to have a break and recharge
- **Daily living support** to build independence (e.g., shopping, public transport, learning to drive), including access to a support worker or health professionals.
- **Support for parents and carers** to learn strategies that work for their child
- **Assistive technology or equipment** can be accessed through NDIS
- **Employment supports**, including help with job matching, workplace accommodations, and training (More info here)
- **Cultural connection supports**, such as engaging Aboriginal organisations or workers for mentoring, social activities, or on-Country programs

Visit First Peoples Disability Network (FPDN) for culturally safe information and support—run by and for First Peoples with lived experience of disability.

NDIS and level of FASD education

Many professionals and support workers do not have knowledge or training about FASD. NDIS funding can also be used for training support people (and professionals working with you) to better understand FASD.

Understanding how the NDIS decides what supports are funded is key. Supports must be considered "**reasonable and necessary**," and NDIS considers what is already available through family, school, or community. Learn more here

Managing NDIS Plans

There are three main ways to manage your NDIS plan:

- **NDIA-managed**: The NDIA handles all payments. You must use providers registered with NDIS.
- **Plan-managed**: A plan manager is funded by NDIS to pay for services and help with admin. This gives more flexibility—you can use both registered and unregistered providers (e.g., artists, community members).
- **Self-managed**: Full control but more responsibility. You manage all payments, paperwork, and find your own services.
  More on funding options here

Peer and Personal Support

Support from people who understand FASD can make a big difference. Many parents and caregivers have started local support groups—like the QLD FASD Support Group on Facebook. If none exist nearby, connect with trusted local services to explore creating your own.

Advocacy

Most of the 'doing' in local Aboriginal communities is focused on advocacy and building our communities capacity to advocate effectively and strategically. What is advocated for may differ according to each community and the resources available. Below are systemic advocacies to introduce, influence and secure positive and sustainable change in Aboriginal communities across Australia. Systemic advocacy in FASD may include:

- **Culturally connected services:** Advocate for **local community supports** around FASD that strengthen connections, identity, culture and resilience
- **NDIS supported cultural activities at a local level:** There is an indisputable demand for services that focus on enhancing culture and identity, which in turn, strengthens connection, resilience, and wellbeing whether you are living with FASD or not. Such activities may include Elder yarns, on Country programs, weaving, art or dance. There is an opportunity for Aboriginal organisations to become NDIS providers and establish programs that strengthen culture and offer daily activities, social connection and skill development for NDIS participants.

https://csialtd.com.au/becoming-a-ndis-service-provider-for-aboriginal-and-torres-strait-islander-peoples/

- **Increased and ongoing funding to the Aboriginal community-controlled disability services sector** – the sector needs to be developed and supported before it can be expected to thrive in an open market (https://absec.org.au/disability-support/). This means increased and ongoing funding to the community-controlled sector and supporting Aboriginal disability workforce development such as yilabara.orga.ua/aboriginal-disability-services/
- **Roadmaps to accessing NDIS** – providing practical guides for community to access and navigate NDIS support is key to the whole family living well with FASD. Educating community on NDIS so that they confidently know what they are entitled to will increase resilience and motivation to continue demanding support until it is received.
- **FASD interpreters, liaisons or advocates** – having a trusted person to translate FASD in ways that Aboriginal families can meaningfully use information and strategies is key to accessing FASD diagnosis and support. A vast amount of money is invested in court supports and liaisons for Aboriginal children and youth, which is important but by this stage, it is often too late, and many will tragically remain on justice pathways. If we invested in interpreters, liaisons or advocates earlier to better understand the challenges experienced by those living with FASD, we would inevitably avoid the current overincarceration of Aboriginal children with disabilities.

"We don't want our kids knowing the language of the court and these systems. We want our kids knowing their languages, and the language of community and strength"

Dr Sharynne Hamilton
Ngunnawal academic

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