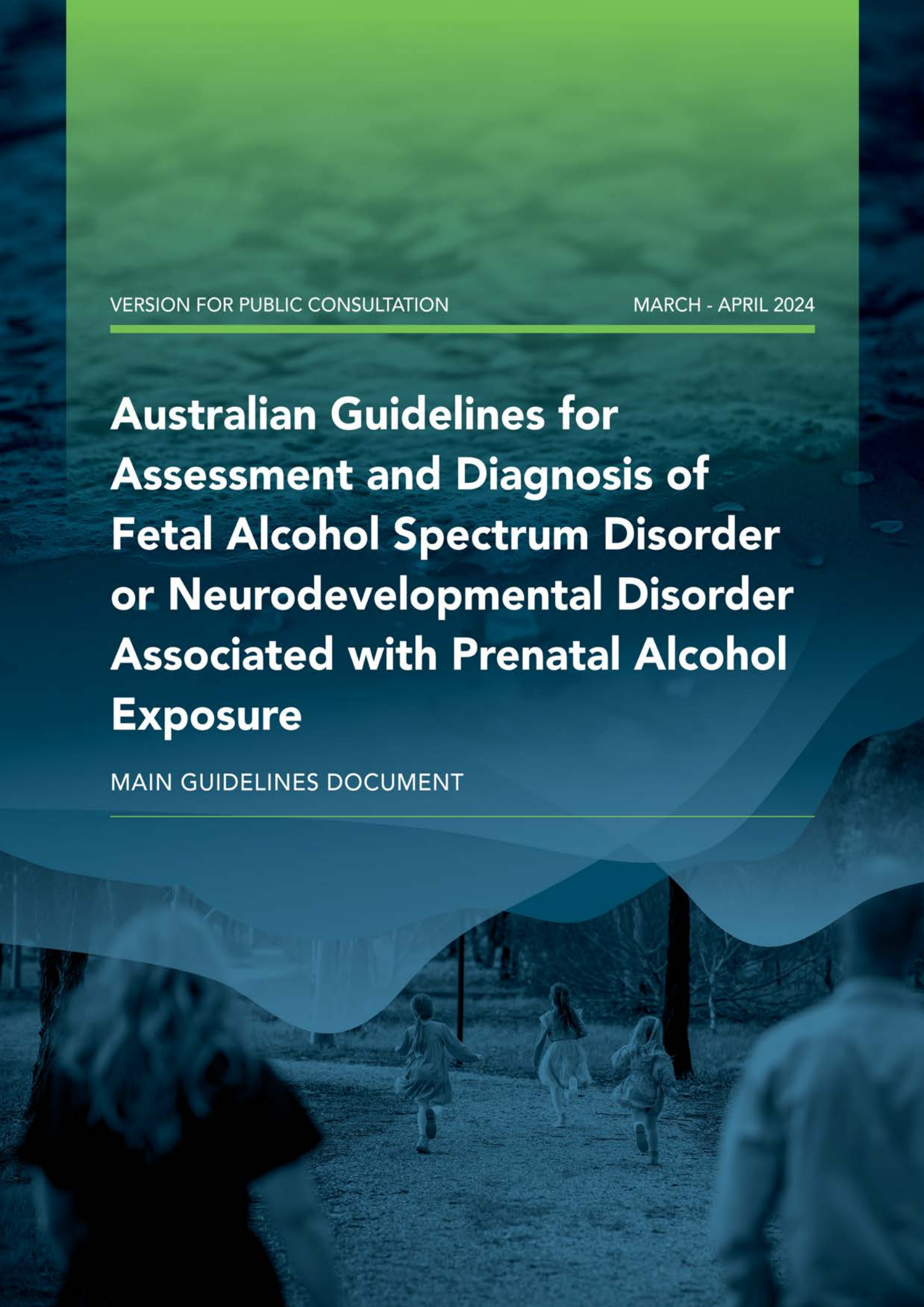
VERSION FOR PUBLIC CONSULTATION

MARCH - APRIL 2024

Australian Guidelines for Assessment and Diagnosis of Fetal Alcohol Spectrum Disorder or Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure

MAIN GUIDELINES DOCUMENT



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Disclaimer:	These guidelines are a general guide to best practice, to be applied subject to health professionals' judgement and values, and the circumstances and needs and preferences of the individual attending for assessment. These guidelines are designed to provide information to assist clinical decision making and the recommendations included are based on the best evidence available at the time. Practitioners can access appropriate professional development and supervision where required to support effective implementation.
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Artwork:	The 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 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 and knowledge qualities of water and the wise, vibrant, and flourishing colours of fresh vegetation. The design captures the continuity of culture and encompasses the whole support process to reflect that everything is supported through connections with culture.
Documentation access:	These guidelines and related documents can be found online at: website link TBA.

Acknowledgements

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See the Administrative and Technical Report for the full membership lists with affiliations included and details of group recruitment.

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Dedications

To the memory of an exceptional group of Australian trailblazing researchers and advocates who passed away during the development of the guidelines.

Dr and Aunty Janet Hammill AM trained as an intensive care nurse but gave it away in her fifties to undertake a Masters in Tropical Health and then a PhD in Medical Anthropology. Aunty Jan grew up in the Pilliga Scrub on a farm. Her country pragmatism and connection to Country never left her. She was a fearless Gomeroi woman and passionate advocate for individuals with FASD. She established the Collaboration for Alcohol Related Developmental Disorders (CARDD), which brought together people from a wide range of disciplines and helped kick start a program of FASD research at the University of Queensland that continues today. Aunty Jan was a dedicated educator, providing countless presentations across an extensive range of settings, nationally and internationally. Aunty Jan would demand and receive audiences with government ministers seemingly at will. She had a wicked sense of humour and a remarkable ability connect with people from all walks of life. Never shy of challenge, she set a world record for powerlifting in her 70s.

Dr Rochelle Watkins qualified as a physiotherapist and received her PhD in 1999. Since 2000 she drove many of the achievements of the Alcohol and Pregnancy and FASD Team at Telethon Kids Institute, Western Australia. She led foundational work developing the first Australian Guide to Diagnosis of FASD, was the architect of the acclaimed Banksia Hill study on FASD prevalence, and a senior analyst on the University of Sydney's 'Lililwan' FASD prevalence project in the Fitzroy Valley. She was a Chief Investigator and Assistant Director of the Telethon-University of Sydney NHMRC Centre of Research Excellence and a Board Director of the National Organisation for Fetal Alcohol Spectrum Disorders Australia (2012-2015) and Neurological Council of Western Australia (2010-2015). Rochelle was held in high regard by her collaborators and contributed to state and federal health, policy. She is remembered for her generosity to students, colleagues, and community.

Ms Heather Jones began work at the Telethon Kids Institute WA in the project team developing the first Australian Guide for FASD. In 2016 she was appointed Project Manager for the FASD Hub Australia, established by the University of Sydney. Under her stewardship the website officially launched on FASD Awareness Day 2017. It has since become a leading source for information on FASD nationally and internationally. Heather was respected throughout the FASD Community, forming deep connections with people and families living with FASD. She was equally at ease with government, researchers, and practitioners, and instrumental in developing education programs for police and magistrates across WA. Heather is remembered as a dedicated professional and champion of others, especially young and emerging researchers. She was the first recipient of an award created to recognise someone who shows extraordinary commitment to raising awareness and understanding of FASD – now named 'The Heather Jones Community Award' in her honour.

Dr Janet Payne began working at Telethon Kids Institute to establish the first birth defects register in Australia and the first research study on neural tube defects and folic acid. She coordinated the first national surveillance study of FAS through the Australian Paediatric Surveillance Unit in 2002 and managed the Telethon's Alcohol in Pregnancy Project from 2005. From 2006 she led a series of studies on Women's Knowledge, Attitudes and Practice regarding alcohol use in pregnancy and FASD. In 2007 she embarked on a PhD to develop and evaluate educational resources for health professionals. Her thesis had a strong focus on consumer and community involvement in research. She contributed to a screening-diagnostic instrument for FASD and data linkage studies on the impact of prenatal alcohol exposure on health, disability, education, and justice outcomes. Jan is remembered for her dedication, mentorship, humility, and kindness.

Foreword

On behalf of all contributors, I acknowledge the Traditional Owners of the many lands on which these guidelines were developed. I pay my deepest respects to Elders past, present and emerging. I would also like to acknowledge all people in Australia living with fetal alcohol spectrum disorder or neurodevelopmental disorder associated with prenatal alcohol exposure (FASD/ND-PAE). A central tenet throughout the development of these guidelines was maintaining respect and inclusivity of the diverse perspectives in the FASD/ND-PAE space. This has included prioritising evidence and the perspectives of people with lived and living experience of FASD/ND-PAE, and Aboriginal and Torres Strait Islander people. The messages from the Cultural Advisory and Lived Experience Groups provide further details regarding why this has been important, and I encourage you to read these to hear firsthand from the members of these Advisory Groups. We hope these guidelines respect and honour the experiences of those living with FASD/ND-PAE, their families and communities, and that these guidelines enhance assessment and diagnostic practices, reduce stigma, and improve the quality of life for all people living with FASD/ND-PAE in Australia.

We have worked extremely hard to undertake a rigorous evidence-based process, following the NHMRC's approach for development of guidelines in Australia. We believe this approach will provide practitioners with increased confidence and support in undertaking assessment and diagnosis of FASD/ND-PAE across a wide range of clinical contexts. We also hope the approach taken will enable continuous quality improvement of the diagnostic criteria and guidelines.

These guidelines would have not been possible without the hard work, support, and dedication of a large team. I sincerely thank all the members of our research team who have worked tirelessly to review and synthesise all the evidence. Big thanks to the members of our Guidelines Development Group, who have generously given of their time. I would like to say a special thanks to our Guidelines Development Group Chair, Professor Philippa Middleton, for keeping us on track, and our methodologist Professor Zac Munn, for his pragmatic advice. I am appreciative of all the members of Steering Committee and Advisory Groups – Lived Experience, Cultural, Clinical, and Research groups, who set the priorities and provided essential feedback. The countless hours you have all dedicated to this process demonstrates your passion for supporting individuals with FASD/ND-PAE and their families. I would like to also thank the Australian Department of Health for providing the funding to support the development of these guidelines and all the consortium members who were part of the funding application.

I am grateful for the special opportunity we had to collaborate with our Aotearoa New Zealand colleagues. Thank you to Dr Andi Crawford, Sarah Goldsbury, Ms Tania Henderson, Mr Haami Harmer, Dr Raewyn Mutch (The Aotearoa Project Team), Ms Jo Van Wyk, and all the members of the Steering Committee, Clinical, and Whānau Advisory Groups. I hope that the two-way knowledge sharing between our countries has strengthened approaches for both countries. I also hope our approach can provide an exemplar for how countries can collaborate, while taking account of the cultural context and implementation considerations specific to each country.

In summary, I would like to leave you with this quote, which I hope our Australian guidelines will embody: "diagnosis managed from a strengths and opportunities perspective can open doors of hope and possibility" (Choate & Badry, 2019, p.45).

Dr Natasha Reid
Senior Research Fellow & Clinical Psychologist
The University of Queensland, Faculty of Medicine, Child Health Research Centre

Message from the Cultural Advisory Group

These guidelines are written on a trail blazed by many Indigenous and non-Indigenous Australians and have intentionally embedded Indigenous perspectives to support best practice in Australia. This precedent acknowledges the negative legacies of colonialism while elevating the deep wisdom of Indigenous peoples for our collective hope and healing. As with all precedents, there is caution yet diligence about embedding Indigenous perspectives throughout guidelines focused on FASD/ND-PAE.

We acknowledge that many people may fear that including our Indigenous voices in guidelines such as these will serve to further stigmatise our community and reinforce beliefs that FASD/ND-PAE is an "Aboriginal problem". We all know that this could not be further from the truth, because where there is alcohol, there is the potential for FASD/ND-PAE.

We further appreciate that FASD/ND-PAE and awareness of FASD/ND-PAE is impacted and compounded by stigma for all communities. In this respect, our Indigenous worldview, and approaches towards FASD/ND-PAE are fundamental to addressing the invisible harms caused by stigma, particularly the lack of solutions, including early diagnosis and support.

The essential truth is that colonisation has been deeply unjust and unkind to Aboriginal and Torres Strait Islander peoples. The legacies of colonisation have laid the foundations for alcohol to have devastating impacts on our people and societies, both nationally and globally. We know this. But very rarely is this context understood when we are systemically excluded from systems, policies and guidelines that impact our people. Historically, colonisation drove segregation, assimilation and attempts to eradicate our culture. Today, fear of causing further harm to our people drives barriers to us accessing information, resources, and supports around alcohol harm and it is to the same end. Regardless of where fear stems from, whether it be good intentions or not, the outcome for our people is the same, exclusion and silencing. However, our people have profound resilience and we have not only endured but mobilised and continue to lead the way in healing from the impacts of FASD/ND-PAE.

Indigenous Australians have been resilient, global leaders in this space for decades with the pioneering work of our Elders, including the late Dr Janet Hammill AM, Dr Lorian Hayes, June Oscar AO, Maureen Carter, Emily Carter AM, and countless others. Our worldview is inherently strengths-based, healing-informed and culture-centred, which offers immeasurable benefits to Indigenous and non-Indigenous knowledges and practices. Our leadership is also based on our drive for urgent advocacy and the equitable access required to support our children, adolescents, and adults with FASD/ND-PAE. We invite you to walk alongside us and help us transform our current reality by decolonising practices and hopefully one day, systems.

These guidelines are about healing, hope, equity, and justice. We invite non-Indigenous practitioners to understand our history, perspectives, and strengths of our culture, if we are to create equitable access to assessment and diagnosis of FASD/ND-PAE and the healing that can accompany it. It is important that our ways of knowing, being and doing are not a side document for only those motivated to understand our people better. By embedding Indigenous ways throughout these guidelines, we aim to carry our voice to *all* non-Indigenous practitioners, regardless of whether, or not, they believe this knowledge is relevant to them. The realities are that Aboriginal and Torres Strait Islander peoples are overrepresented in justice and child protection systems and we know large numbers of these vulnerable populations are living with FASD/ND-PAE without access to diagnosis, accommodations, or individualised rehabilitation. If you are reading these guidelines, the chances that you will be providing an assessment to an Indigenous Australian, is high.

We assert that all guidelines should embed Aboriginal and Torres Strait Islander ways of knowing, being and doing to demonstrate a commitment to truth-telling and equity as an act of justice and respect for the original Custodians of Australia. The fact that this is unprecedented in Australia reflects the progressiveness and leadership of these guidelines. We appreciate that progress and change may be uncomfortable. We reiterate that the diligence applied to embed Indigenous ways of knowing, being and doing throughout these guidelines can seed immense benefit, healing, and hope for all people.

Throughout the guidelines we have interwoven our advice on how you can deliver a culturally responsive service to Indigenous Australians. You will note that much of this advice can be applied to non-Indigenous peoples and make assessment and diagnosis of FASD/ND-PAE more accessible to all cultures living in Australia. If you wish to deepen your learning journey to be inclusive of Indigenous worldviews on FASD/ND-PAE, please see the FASD Indigenous Framework that accompanies the main guidelines document.

We ask that you be bold and brave and re-read this letter when you feel whispers of doubt emerge. As Aboriginal leaders in FASD/ND-PAE and members of the Guidelines Cultural Advisory Group, we give you permission to be the change that sees our people have access to culturally responsive and healing informed FASD/ND-PAE knowledge, assessment, diagnosis, and support.

Message from the Lived Experience Advisory Group

In preparation

Summary of Actionable Statements

Actionable Statements Format

For clarity and consistency, the framework proposed by Lotfi et al. (2022) was used for developing and presenting the actionable statements (i.e., recommendations), with some adaptations for these guidelines. Notably, based on the results of the systematic review of lived experiences of the assessment and diagnostic process (Hayes et al., 2023), a novel type of actionable statement was developed, namely 'lived experience statements.' Each type of statement is identified and colour-coded in the document; this colour coding aligns with the Indigenous Framework artwork. Figure 1 provides an overview of the different types of actionable statements. See the Administrative and Technical Report for more information.

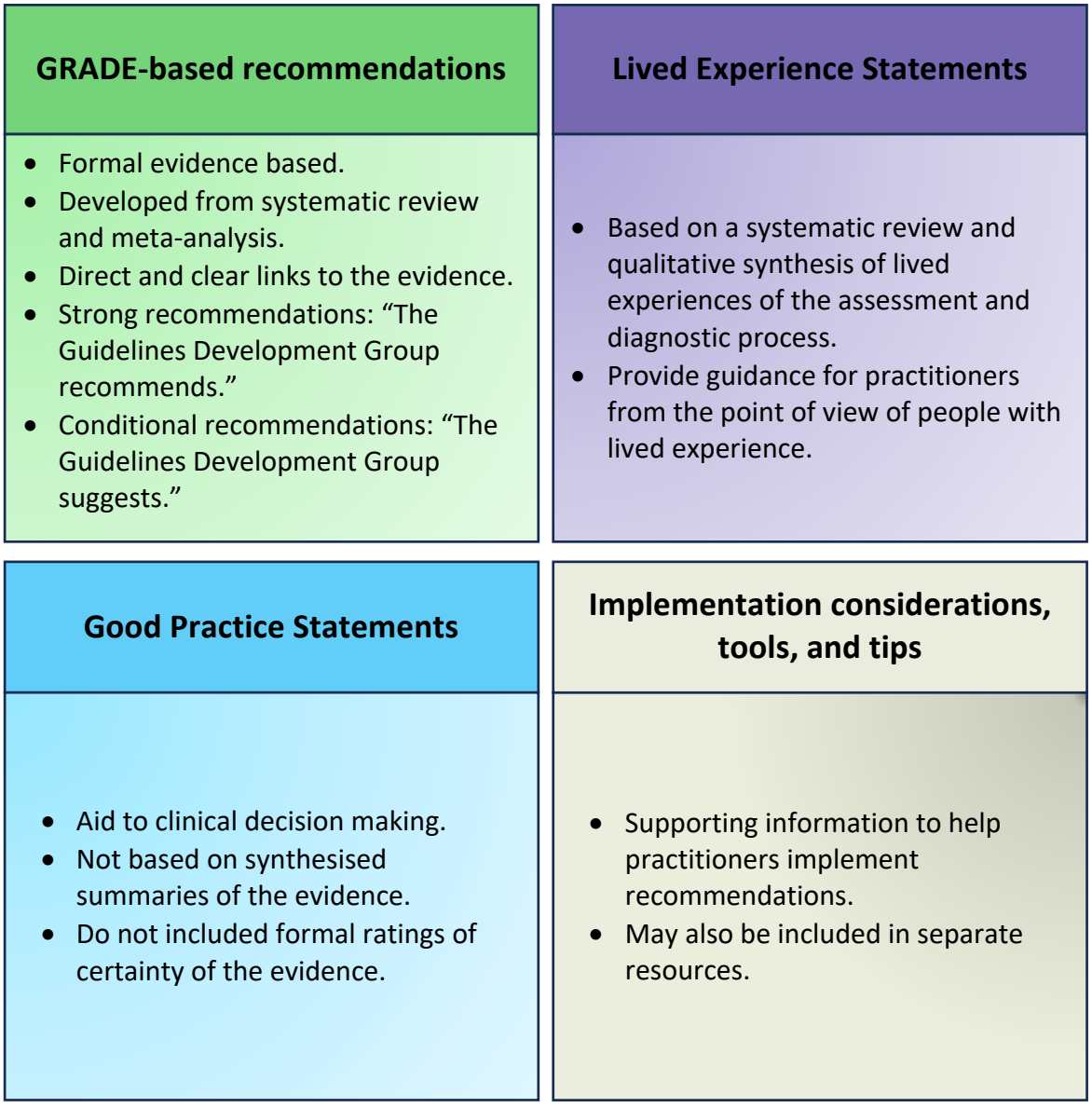


Figure 1. Summary of actionable statement types included in the guidelines.

Summary of Actionable Statements

Type	Statement
Clinical features included in the diagnostic criteria	
GRADE-based recommendation	The Guidelines Development Group suggests that birthweight corrected for gestational age according to the appropriate age- and sex-specific charts is included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Low to Moderate Certainty).
GRADE-based recommendation	The Guidelines Development Group suggests that birth length corrected for gestational age according to the appropriate age- and sex-specific charts is included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).
GRADE-based recommendation	The Guidelines Development Group suggests that postnatal weight according to the appropriate age- and sex-specific charts is included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).
GRADE-based recommendation	The Guidelines Development Group suggests that postnatal height according to the appropriate age- and sex-specific charts is included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).
GRADE-based recommendation	The Guidelines Development Group suggests that philtrum smoothness, vermilion thinness, and palpebral fissure length are included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).
GRADE-based recommendation	The Guidelines Development Group recommends against including minor dysmorphic features in the diagnostic criteria for FASD/ND-PAE (Strong Recommendation, Very Low to Low Certainty).
GRADE-based recommendation	The Guidelines Development Group suggests that head circumference corrected for gestational age according to the appropriate age- and sex-specific charts is included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).
GRADE-based recommendation	The Guidelines Development Group recommends against including structural brain abnormalities as observed on clinical imaging in the diagnostic criteria for FASD/ND/PAE (Strong Recommendation, Very Low Certainty).
GRADE-based recommendation	The Guidelines Development Group recommends against including neurological conditions of hearing and vision impairments, seizures, and cerebral palsy in the diagnostic criteria for FASD/ND/PAE (Strong Recommendation, Very Low Certainty).
GRADE-based recommendation	The Guidelines Development Group suggests that neurodevelopmental outcomes of communication, motor skills, general intellectual abilities, attention, memory, executive function, emotional and/or behavioural regulation, literacy and/or numeracy, and adaptive/social functioning are included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).
Assessment process	
Lived Experience Statement	Listen to and take seriously concerns raised by parents/caregivers about their child's development and behaviour in the context of prenatal alcohol exposure.
Lived Experience Statement	Provide or refer for assessment if a parent/caregiver is concerned about their child's development in the context of prenatal alcohol exposure.
Lived Experience Statement	To reduce barriers experienced by individuals and families, assessment can be provided across a range of settings. This includes, but is not limited to, specialist FASD/ND-PAE

	services, child development services, adolescent and adult private and public health services, primary care, mental health, disability, justice, and child protection services.
Lived Experience Statement	Provide non-judgemental and non-stigmatising support that acknowledges and respects the individual's and their parent/caregivers' experiences and concerns.
Good Practice Statement	If there is information suggesting heavy or very heavy (or potentially a moderate) level of PAE, including before pregnancy recognition, discuss assessment options and after obtaining informed consent provide assessment or support access to further assessment.
Good Practice Statement	If there is information documenting clinically significant neurodevelopmental impairments and/or distinctive facial features and confirmed or suspected PAE, discuss assessment options and after obtaining informed consent, provide assessment or support access to further assessment.
Prenatal alcohol exposure assessment	
Good Practice Statement	Sensitively and respectfully include discussions about alcohol use and potential risks as part of routine antenatal and postnatal care.
Good Practice Statement	Ask about alcohol use as part of routine pregnancy history taking, alongside other prenatal exposures and events (e.g., medications, tobacco, illicit drugs, infections, diet, exercise, stress, and pregnancy complications).
Good Practice Statement	To support accurate assessment of risk, assess PAE both before and after pregnancy recognition. Standardised screening tools, such as the AUDIT-C can be used.
Good Practice Statement	Explain what a standard drink of alcohol is (i.e., 10g of ethanol) before using the AUDIT-C, consider using resources such as the NHMRC Alcohol Guidelines for clarity. Practitioners can also gather the information and convert into standard drinks for the individual.
Good Practice Statement	Be mindful there are many factors that may have influenced alcohol use during pregnancy and collect information in a supportive, compassionate, and non-judgemental way.
Good Practice Statement	Recognise that individuals might face ongoing challenges with alcohol or other complex issues and provide appropriate support and referrals.
Good Practice Statement	Contact biological parents directly, if possible and appropriate to assess PAE. Otherwise, carefully review other sources of information (e.g., reliable observer reports, medical or legal records). **Note that a history of alcohol use without evidence of consumption during the index pregnancy is not sufficient to confirm exposure.**
Good Practice Statement	Consider that self-reports of PAE may be influenced by a range of factors. For example, the context in which information was collected (e.g., child protection settings) and the timing (e.g., during pregnancy and reported in antenatal records or later in the child's life). Practitioners may want to contact biological parents to check previously collected information.
Good Practice Statement	Sometimes there may be inconsistencies about PAE in available information. In instances when information was collected directly from the pregnant woman/person during an assessment, this information should be prioritised over other sources. Practitioners can document any inconsistencies and indicate that re-assessment could be considered should additional information arise.
Medical assessment	
Good Practice Statement	Practitioners should consider the appropriateness of all parts of the medical assessment for the individual and their family and ideally collaborate with individuals and families to make decisions about what the assessment will involve.

Good Practice Statement	When assessing facial features, use the University of Washington (UW) Lip-Philtrum Guide. Guide 1 Caucasian is recommended for less full lips and Guide 2 African American for fuller lips.
Good Practice Statement	When assessing facial features, use the Strömland et al. (1999) palpebral fissure norms. These norms are the best available for all Australians, covering birth to adulthood.
Good Practice Statement	Use the University of Washington facial analysis software to measure palpebral fissure length and/or take measurements by hand using a small, clear plastic ruler if you are not able to use the facial analysis software.
Good Practice Statement	Examine and document any other dysmorphic features of the face and the body and record any major birth defects of the central nervous, cardiac, renal, neurological, visual, auditory, and skeletal systems.
Good Practice Statement	Consider other syndromes or genetic conditions in which dysmorphic features can also be present. If unsure, refer to a clinical geneticist for review.
Good Practice Statement	With informed consent and assent, as clinically appropriate and in line with local health service guidelines, requests for a chromosome microarray (CMA) and DNA test for fragile X syndrome (FXS) may be made. These tests can be done using blood or buccal swabs. Refer to your local genetic health services for guidance if abnormalities are reported.
Good Practice Statement	Medical professionals can request additional tests as clinically indicated to understand current functioning and exclude other potential impacts on functioning, such as thyroid tests, vitamin B12, iron studies and imaging.
Good Practice Statement	Physical size can vary due to a wide range of demographic, maternal, placental, and fetal factors. Identifying what is atypical physical size should be based on a combination of medical assessment and consideration of individual risk factors, rather than relying exclusively on growth charts.
Good Practice Statement	Assess birth weight, length and head circumference of full-term infants using the WHO (2006) growth standards. Information may be available in the birth record or baby's personal health records (e.g., red, blue, or yellow books).
Good Practice Statement	Assess birth weight, length, and head circumference corrected for gestational age of preterm infants using the Fenton growth charts. This can be collected from the birth record or baby's personal health records (e.g., red, blue, or yellow books). Gestational age correction is completed until the baby is 24 months of age.
Good Practice Statement	For children up to 2 years of age, assess postnatal weight, height and head circumference using the WHO (2006) growth standards. For children over 2 years of age, follow local health service guidelines, as there is some variation across states and territories. For example, most jurisdictions use CDC growth charts. The Northern Territory adopted the WHO (2006) growth standards for all children.
Good Practice Statement	When available, review an individual's overall trajectory of weight-for-age, length/height-for-age and weight-for-length/height, or BMI-for-age (over 2 years) to understand how they are tracking.
Good Practice Statement	Consider other causes for individuals outside of height, weight and/or head circumference norms, and investigate appropriately.
Holistic developmental, functional, and wellbeing assessment	
Good Practice Statement	Take a holistic needs-based and family-centred approach to the assessment. This can involve considering strengths and challenges, functioning, environment, culture and supports. Gather this information in ways that work best for the individual and their family/support network.

Good Practice Statement	In taking a holistic approach, consider all the factors that individuals and families may be experiencing, and the potential influence on functioning, wellbeing, and participation.
Good Practice Statement	Collaborative goal setting and talking/yarning with individuals and their support network can help practitioners take a holistic approach to assessment. This allows for gathering personalised information about child and family strengths, interests, available resources, and future hopes and plans for both the individual and family.
Good Practice Statement	Each person attending for assessment should have a plan tailored to their specific developmental needs. This plan should consider current concerns, developmental age, history, past assessments, and other source documents (e.g., available medical and school records), ability to engage in an assessment, assessment adaptations and adjuncts including interpreters and any other relevant cultural and social factors. Assessment should include hearing and vision tests if these have not been done before.
Good Practice Statement	Depending on a person's presentation, it might be best to plan and recommend assessment across different timepoints to see if their challenges are persistent. These assessments can happen in various places, including primary health care, schools, and private practitioners, not just at specialist services.
Good Practice Statement	While it can be helpful to do a comprehensive assessment to understand developmental challenges, sometimes it may not be possible or appropriate. Practitioners should decide the neurodevelopmental domains to prioritise based on functioning and how much assessment is necessary to determine whether there are clinically significant impairments and if they meet criteria for diagnosis.
Good Practice Statement	It is important to understand the overlap of neurodevelopmental domains and influence of environmental factors. Interpreting assessment results requires looking at the whole picture or taking a gestalt approach, including considering how valid measures are for different groups of people and the range of prenatal and postnatal factors that can influence outcomes.
Good Practice Statement	It is useful to gather information from various sources and methods, such as naturalistic observation, assessing function, direct testing, and getting input from different observers (e.g., self-report, parents or other family members, teachers, work colleagues, support workers, treating professionals). This is important to overcome limitations of any single method.
Good Practice Statement	It is advantageous to assess neurodevelopmental domains concurrently. However, at practitioners' discretion, previous assessments may be used (e.g., in situations where impairment levels are unlikely to have changed, where there have been multiple previous assessments or current assessment is unable to be completed due to current significant behavioural challenges). The decision to retest an individual will depend on the context, referral question and the individual's needs.
Good Practice Statement	Assessment will naturally vary based on availability of resources. Where multi-disciplinary are not available or cannot be accessed, engagement with other services through a shared-care approach is suggested to support accessibility of assessment and diagnostic services.
Holistic formulation, feedback, and strengths-based pathways	
Good Practice Statement	Bring together information from the assessment to create an individualised holistic profile. This should summarise the key developmental factors. It is best if practitioners from different disciplines review this information.
Good Practice Statement	Consider all possible causes or conditions, including prenatal and postnatal factors, that might be influencing developmental outcomes.

Good Practice Statement	Consider, offer, and explain one or more diagnostic possibilities, summarising what is most likely, after considering what is less likely or unlikely, given the individual's presenting concerns and assessment findings.
Good Practice Statement	Practitioners should be aware of diagnostic overshadowing (i.e., where an individual's mental health concerns are attributed to the primary diagnosis rather than to a concurrent psychiatric condition) and provide diagnoses relevant in explaining an individual's presentation to facilitate targeted treatments and supports.
Good Practice Statement	Practitioners should consider how their own background, training and unconscious biases might influence their diagnostic decisions. For example, they may be overestimating what is attributable to trauma and underestimating what is attributable to alcohol or vice versa.
Lived Experience Statement	Understand that receiving a diagnosis can bring mixed emotions. Plan feedback and recommendations with this in mind.
Lived Experience Statement	Assessment results help understand behaviour. When communicating outcomes, provide specific information and examples clearly linking assessment results to observed or reported challenges in daily functioning to support understanding and insight.
Lived Experience Statement	Recognise both an individual's strengths and challenges to identify the most appropriate supports to enable positive outcomes post-assessment.
Lived Experience Statement	Be mindful that parents/caregivers and family members can have concerns regarding their child's future following diagnosis. Provide recommendations for specific local services that can provide emotional supports.
Lived Experience Statement	Tailor feedback sessions and reports to individual and family needs, including relevant social and cultural factors.
Lived Experience Statement	When writing reports, emphasise the individual's strengths and interests , while also addressing areas needing support.
Lived Experience Statement	When writing reports, prioritise recommendations that are important for the individual/family, and limit recommendations to those that are practical and achievable in their household and community.
Good Practice Statement	Involve individuals and families in diagnostic decisions. Individuals and family have the right to decide if diagnoses are appropriate for them, given their personal, social, and cultural context and beliefs. Sometimes, challenges can arise balancing the rights of the child and the rights of the parent/caregiver, but actively engaging and supporting all parties throughout the assessment can help to overcome these challenges.
Good Practice Statement	With consent, provide developmentally appropriate feedback to individuals attending for assessment, in coordination with parents/caregivers or other support people and tailored to their needs.
Good Practice Statement	Recognise that observed challenges might have multiple explanations and communicate this to individuals and families to enable effective supports.
Good Practice Statement	Include individuals and families in the development of report recommendations, respecting their preferences and needs, given their personal, social, and cultural context.

Summary of Changes

Summary of Changes from 2016 Guide to FASD Diagnosis

- **Embedding Aboriginal and Torres Strait Islander perspectives**

Through the valuable contributions of the Cultural Advisory Group these guidelines aim to support culturally responsive assessment practices and ultimately improve assessment and diagnostic approaches for all Australians.

- **Embedding lived and living experience perspectives.**

Through the valuable contributions of the Lived Experience Advisory Group and the findings of the systematic review and qualitative synthesis of lived experiences of the assessment process these guidelines aim to take into consideration the perspectives of people with lived and living experience to improve assessment and diagnostic practices.

- **Taking a lifespan approach to assessment and diagnosis**

Content and wording of these guidelines aims to support assessment and diagnosis across the lifespan.

- **Allowing for clinical judgement**

The Guidelines Development Group has worked hard to balance the level of guidance provided with a level of flexibility to allow clinicians to use their clinical judgement to enable person-centred assessment approaches across a wide range of clinical contexts. For example, this has included specific wording in the diagnostic criteria, and not providing a list of recommended standardised tools, but instead providing detailed information regarding assessment considerations in the neurodevelopmental domains.

- **Diagnostic terminology**

No consensus could be reached regarding diagnostic terminology (i.e., use of the term FASD or ND-PAE). The Guidelines Development Group has provided an opportunity for future open discussion and research to inform the next iteration of the diagnostic terminology. Specifically, future research should seek to understand the preferences of people with living experience of FASD/ND-PAE.

- **Structure of the diagnostic criteria**

A novel structure is put forward for the diagnostic criteria for FASD/ND-PAE. The aim of this structure is to capture the heterogeneous nature of FASD/ND-PAE. A hierarchical approach based on the evidence review is also included to allow consideration of a wide range of associated features and conditions, to support targeted supports and future research.

- **Prenatal alcohol exposure threshold for diagnosis**

A comprehensive review of the best available evidence was used to inform the development of a PAE threshold for diagnosis. In developing the wording of the PAE criterion and associated guidance the Guidelines Development Group aimed to balance the available evidence, the limitations of the evidence and consider how best to practically apply the evidence at an individual level.

- **Inclusion of neurodevelopmental domains.**

Neurodevelopmental domains were selected for inclusion based on the systematic review and meta-analyses of the best available evidence. Areas of neurodevelopment no longer included are social cognition, social communication/pragmatics, motor speech impairments, speech-sound impairments, seizures, hearing and vision impairments, cerebral palsy and structural brain abnormalities assessed via clinical imaging. Members of the Advisory Group requested review of the literature regarding sensory processing. There was limited evidence available, which did not support including sensory processing in the diagnostic criteria. Whilst omitted, these aspects of neurodevelopment can still be considered in the assessment and used to inform tailored supports.

- **Approach to determining presence of clinically significant neurodevelopmental impairments.**

For clinical cut offs to have meaning, evidence needs to be available to show there are differences in important life outcomes between people above or below a particular cut off. Given that this evidence is currently not available, information regarding the interpretation of standardised tests and how these scores are used to inform clinical decision making is currently based on expert guidance or 'best practices' that practitioners can consider.

Comprehensive information and practitioner templates are provided to support practitioners in taking a holistic or 'gestalt' approach to the neurodevelopmental assessment and formulation to support more detailed considerations of the interplay between neurodevelopmental domains and potential impacts of co-occurring conditions, exposures, and experiences.

- **Conceptualisation of the affect regulation domain**

Based on the findings of the evidence review this domain has been re-conceptualised to focus on the emotional and/or behavioural regulation symptoms. Detailed assessment considerations are provided to support practitioners in applying this domain in practice.

- **Terminology of the cognition, language, and academic achievement domains**

Based on feedback from Advisory Group members slight amendments were made to the terminology used to describe some of the neurodevelopmental domains to better reflect current practices and/or target the specific aim of the neurodevelopmental assessment process.

Introduction

Introduction

Clinical practice guidelines establish standards of care backed by scientific evidence to optimise service provision. Importantly, guidelines can enhance practitioner and client decision making through translating complex research findings into recommendations that are relevant at an individual level, rather than presenting a one size fits all approach. High-quality guidelines are based on systematic reviews of the evidence and have a transparent process for development, interpretation of the evidence and decision making by experts, people with lived experience, and end users (NHMRC, 2018).

Fetal alcohol spectrum disorder (FASD), alternatively termed neurodevelopmental disorder associated with prenatal alcohol exposure (ND-PAE), is a significant public health issue that necessitates the development of high-quality guidelines to optimise service provision. The critical importance of FASD/ND-PAE is emphasised in the Australian Government's National FASD Strategic Action Plan (2018-2028):

> *"The Plan recognises that with early and accurate diagnosis and early, individualised interventions for children and adults who have FASD, along with appropriate support for parents and carers, the quality-of-life outcomes for individuals with FASD and their families can be substantially improved"* (p. 4).

In 2016, the first Australian Guide for the diagnosis of FASD was published (Bower & Elliott, 2016). The guidance was based on the Canadian Guidelines for the diagnosis of FASD (Cook et al., 2016) and included elements of the University of Washington 4-Digit Diagnostic Code (Astley, 2004). Since publication of the 2016 Guide, Australia has seen an increase in awareness and provision of assessment and diagnostic services. This has been supported by funding for some state-based diagnostic services, a National FASD Register and FASD Hub website, and additional funding for NOFASD Australia.

In 2020, The Australian Department of Health provided funding to revise and update the 2016 Guide. The development process has been undertaken in line with the National Health and Medical Research Council (2020) procedures and requirements.

Rationale for the current approach

A key consideration in the development of the current guidelines was that, internationally, there is no unified diagnostic criteria for FASD/ND-PAE. Given the complex and varied nature of presentations, different research groups have prioritised different clinical features and implemented various diagnostic terms to describe FASD/ND-PAE. However, lack of consistency and standardisation complicates research and diagnostic processes, negatively impacting individuals and families. Thus, there is need for a more structured approach that is based on systematic reviews of the evidence, and that integrates relevant person-level factors (i.e., patient/client values, needs and preferences, and cultural context) into an aetiological based diagnostic framework.

The current guidelines put forward an approach to advancing diagnostic criteria for FASD/ND-PAE based on GRADE, a framework for developing and presenting evidence to guide clinical practice recommendations (GRADE Working Group, 2013). By using a GRADE-based approach to develop the diagnostic criteria, these guidelines aim to provide a summary of the best available evidence and the structured approach used to interpret the evidence and develop recommendations.

Diagnostic terminology

Internationally, there are numerous diagnostic terminologies used to describe FASD/ND-PAE. All consultative groups discussed the potential advantages and disadvantages of different diagnostic terminologies. Ultimately there was no consensus, with some stakeholders preferring the term ND-PAE or similar, and others preferring the term of FASD. There was a diverse representation of stakeholder types providing these differing perspectives. The Guidelines Development Group did not want the diagnostic terminology adopted to be a barrier to individuals accessing services. Thus, it was decided that a flexible approach to terminology was the best way to move forward at this time. The diagnostic criteria are described in such a way that all the relevant features of the condition can be documented for each individual attending for assessment, regardless of the diagnostic nomenclature. Practitioners are encouraged to use shared decision making with individuals attending for assessment and their families, carers or significant others and decide together what terminology is most appropriate.

Public health messages about prenatal alcohol exposure versus diagnosis of FASD/ND-PAE

It is critical to consider that there is a substantial amount of literature investigating the potential impacts of prenatal alcohol exposure (PAE) that has not been examined as part of the evidence review for these guidelines. For example, there is literature relating to how PAE can impact the health of the pregnant woman or person (e.g., mental health, nutrition, absorption of nutrients), how PAE can influence the structure and function of the placenta, the potential adverse pregnancy outcomes that can be associated with PAE (e.g., miscarriage, stillbirth, preterm delivery), and a wide range of outcomes that have not been examined (e.g., experimental study designs, functional MRI and physiological outcomes). It is **not the role of these guidelines to provide public health messages regarding PAE**. Rather, the aim of the evidence review was to support practitioners in deciding at what level of PAE to consider a potential diagnosis of FASD/ND-PAE. We refer interested readers to the Australian Guidelines to Reduce Health Risks from Drinking Alcohol (2020) for information on public health guidelines pertaining to alcohol use and pregnancy.

Challenges and opportunities in developing the current guidelines.

There were a range of challenges discussed and many extended beyond the FASD/ND-PAE field. Engaging in open discourse and transparently sharing these challenges can foster the generation of new ideas and opportunities for collaboration and future research initiatives. A summary of some of the challenges and opportunities discussed are reported here.

- In developing the diagnostic criteria and actionable statements (i.e., recommendations) the Guidelines Development Group aimed to balance the level of detail and structure that practitioners need, with the flexibility to support implementation of the guidelines at the individual client level. The need for clinical judgement and appropriate clinical supervision specific to one's discipline and setting has been highlighted to support practice.
- The importance of balancing potential risks of both under- and over-diagnosis of FASD/ND-PAE was discussed. The need for the diagnostic criteria and actionable statements to support accurate diagnosis and to be accessible to practitioners in different disciplines and settings were key considerations in the development process.
- The current review took place in the context of a lack of defined and structured approaches to evidence-based development of diagnostic criteria. This includes many conditions listed in the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental

Disorders (DSM-5-TR). Researchers (e.g., First, 2017; Kendler & Solomon, 2016) have highlighted that the DSM has not consistently used systematic reviews to inform decision making. Consequently, the comprehensive evidence review, and structured, transparent, evidence-based decision-making processes applied in the development of these diagnostic criteria represent the highest standard for such undertakings and provide an exemplar for improving diagnostic criteria beyond the FASD/ND-PAE field.

- Members of the Clinical Advisory Groups and Guidelines Development Group highlighted current challenges associated with applying diagnoses under the DSM–5-TR neurodevelopmental domain. Specifically, the neurodevelopmental domain does not easily accommodate co-occurring neurodevelopmental conditions or the impact of adverse childhood experiences (ACEs) and other postnatal adversities. Suggestions were discussed regarding how future DSM revisions could consider conditions such as "Neurodevelopmental disorder associated with early life adversity" and "ADHD associated with prenatal alcohol exposure," to help practitioners differentiate between conditions with different associations or aetiologies, which, in turn, may lead to more specific support pathways. Notably, this approach aligns with the recommendations of CATALISE, an international consensus effort that defines criteria and terminology for language impairments (Bishop et al., 2017). CATALISE emphasizes that grouping all children with language impairments, irrespective of their causes and support requirements, is counterproductive. Instead, the recommended diagnosis is "Language disorder associated with X," where X represents the specific differentiating biomedical condition (Bishop et al., 2017).
- All diagnoses face the challenge of what has been referred to as the ‘line drawing problem’ (Schwartz, 2007). This refers to the understanding that all functioning occurs on a continuous spectrum, and that difficulties arise when trying to apply an arbitrary, binary cut-off (i.e., disease vs. no disease). To the Guidelines Development Group’s knowledge, there is no evidence that links an increased risk of adverse life outcomes to a specific clinical cut off for any of the FASD/ND-PAE diagnostic features. This is also the case when applying clinical cut offs for many other neurodevelopmental and medical conditions. Therefore, it needs to be acknowledged that clinical cut-offs are applied for diagnostic and pragmatic purposes, and although they are informed by research evidence, they remain arbitrary. Further research is required to understand the meaningfulness and utility of clinical cut-offs in the Australian context.

Overall Objectives

These guidelines aim to support practitioners in undertaking assessments across the lifespan, when one possible outcome may be a diagnosis of FASD/ND-PAE. This document provides actionable statements based on information collected from multiple sources. These include:

- Rigorous review of the best available evidence regarding associations between PAE and diagnostic outcomes.
- Information collected from people with living experience of FASD/ND-PAE.
- Information collected from Aboriginal and Māori people with FASD/ND-PAE knowledge and expertise.
- Information collected from practitioners and researchers with knowledge and expertise regarding assessment and diagnosis of FASD/ND-PAE.

Target Users

The primary target users of these guidelines are Australian health practitioners (henceforth referred to as practitioners) undertaking assessments of infants, children, adolescents, and adults, that may result in an FASD/ND-PAE diagnosis.

Secondary users of these guidelines may include:

- Individuals who have challenges that may be explained by a diagnosis of FASD/ND-PAE and want to understand the assessment process.
- Family members/support networks of individuals with suspected FASD/ND-PAE who want to understand the assessment process.
- Health, education, child protection, disability and justice/police professionals who work with individuals presenting with challenges that may be explained by a diagnosis of FASD/ND-PAE and want to understand the assessment process and ensure appropriate supports are provided.
- Government and non-government service providers who want to understand how to develop referral pathways to assessment and support services.
- Training providers, including tertiary institutions and health professional associations, to inform professional development, and educational resources to enhance the capability of their professions to work with FASD/ND-PAE.
- Policy makers across health, education, child protection, disability, and justice/police settings, who could align their practices and procedures to support best practice service provision and resource allocation for individuals with suspected or confirmed FASD/ND-PAE.
- National and international researchers who may use the results of the evidence review and identified research gaps to inform clinical guidelines or directions for future research.

Please note the Guidelines Development Group aimed take an inclusive approach to be relevant to a variety of practitioners (e.g., midwives, paediatricians, allied health, and general practitioners) working across a range of settings (i.e., health, justice/police, child protection and education). However, processes and practices differ across contexts and minor variations may be required to suit each of these professional groups and settings. For example, in the context of assessments within custodial settings for the purposes of youth or adult court matters. The terminology of ‘where possible’ has been incorporated in some instances to reflect that flexibility may be required in implementation of some of the actionable statements.

Stakeholder Inclusion

Collaborating with stakeholders has been critical to development of these guidelines. Extensive time was committed to stakeholder inclusion to include a wide range of views in a meaningful way. This is supported by research that shows stakeholder involvement leads to increased uptake and implementation of guidelines (NHMRC, 2018). Stakeholders are defined as any person who may be impacted by the guidelines. To maximise collaboration and inclusion three groups were established: the *Project Steering Committee*, *Advisory Groups* and *Guidelines Development Group*. The Administrative and Technical Report provides detailed information regarding the selection and membership of each of these groups. In brief:

The **Project Steering Committee** was comprised of representatives of each of the organisations who were part of the consortium awarded funding to develop the guidelines.

Four **Advisory Groups** including:

1. *Clinical* – practitioners from a wide range of areas, including psychology, social work, occupational therapy, speech pathology, physiotherapy, and medicine. This included representatives from professional associations where applicable and available.
2. *Research* – researchers and academics working in the FASD/ND-PAE field and the wider PAE and alcohol fields.
3. *Cultural* – Aboriginal and Māori peoples working in community, clinical or research positions in the FASD/ND-PAE field or in relevant professional associations. No Torres Strait Islander representation could be identified during this project.
4. *Lived Experience* – adults with FASD/ND-PAE, parents and caregivers of children, adolescents, and adults with FASD/ND-PAE.

The **Guidelines Development Group** was comprised of practitioners, researchers, cultural and lived experience members. The Guidelines Development Group was chaired by Professor Philippa Middleton and included Professor Zachary Munn as the Guideline Methodology consultant.

Guidelines Development Process

Three key components informed the review and development process: (1) review of existing guidelines; (2) evidence review; and (3) Advisory Group input. The Administrative and Technical Report provides detailed information. In brief:

Review of current guidelines: A comprehensive review of all current FASD/ND-PAE diagnostic guidelines was undertaken. This involved extracting both the content and reasoning behind clinical decision making, including the evidence cited in these publications.

Evidence review: In consultation with the Steering Committee, and with consideration of NHMRC requirements, four key research questions were selected to guide the evidence review.

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

Advisory Group input: Advisory Groups provided detailed input and feedback. This included attending Advisory Group meetings, completing a priority-setting survey (Hayes et al., 2022), co-design of the Australian FASD Indigenous Framework (Hewlett et al., 2023), and comprehensive feedback on draft diagnostic criteria and guidelines documents.

Foundational Considerations

"Another way to address the difficulties with current diagnostic and nosological systems is to approach the problem with multiple conceptual frameworks and methodologies."

JENSON ET AL. 2015 P. 13

"Substance use during pregnancy is a highly contested space, and is often associated with trauma histories; thus, highlighting the need for an intersectional approach that recognises the influences of gender, poverty, race, class and housing."

BAGLEY & BADRY 2016 P. 10

Foundational Considerations

These guidelines aim to be transtheoretical by bringing together multiple inter-professional approaches. The conceptual approaches underpinning the guidelines include the Indigenous Framework developed by the Cultural Advisory Group, human rights principles, the International Classification of Functioning, Disability and Health (ICF) Framework (World Health Organization, 2001), shared decision-making principles, developmental psychopathology perspectives and risk/disease models (Figure 2).

Combining these perspectives is needed as FASD/ND-PAE is more than a medical diagnosis, it is a social condition influenced a range of social determinants of health, or as aptly described by Abel (1995), FASD/ND-PAE "is not an equal opportunity birth defect." Alcohol use does not occur in a vacuum, it relates to individual, family, and societal determinants. For example, living in a society that is accepting of heavy drinking, coming from a family of heavy drinkers, and having a partner who drinks are all factors found to increase risk of FASD/ND-PAE (May et al., 2011). Additionally, alcohol exposure does not occur in isolation, but is influenced by a wide range of complex factors, including prenatal nutrition, metabolic rates, genetic differences, and biochemical and inflammatory responses to alcohol, which can all exacerbate or ameliorate the effects of the exposure. These foundational considerations aim to support practitioners in taking a wider lens in the assessment and diagnosis of FASD/ND-PAE.

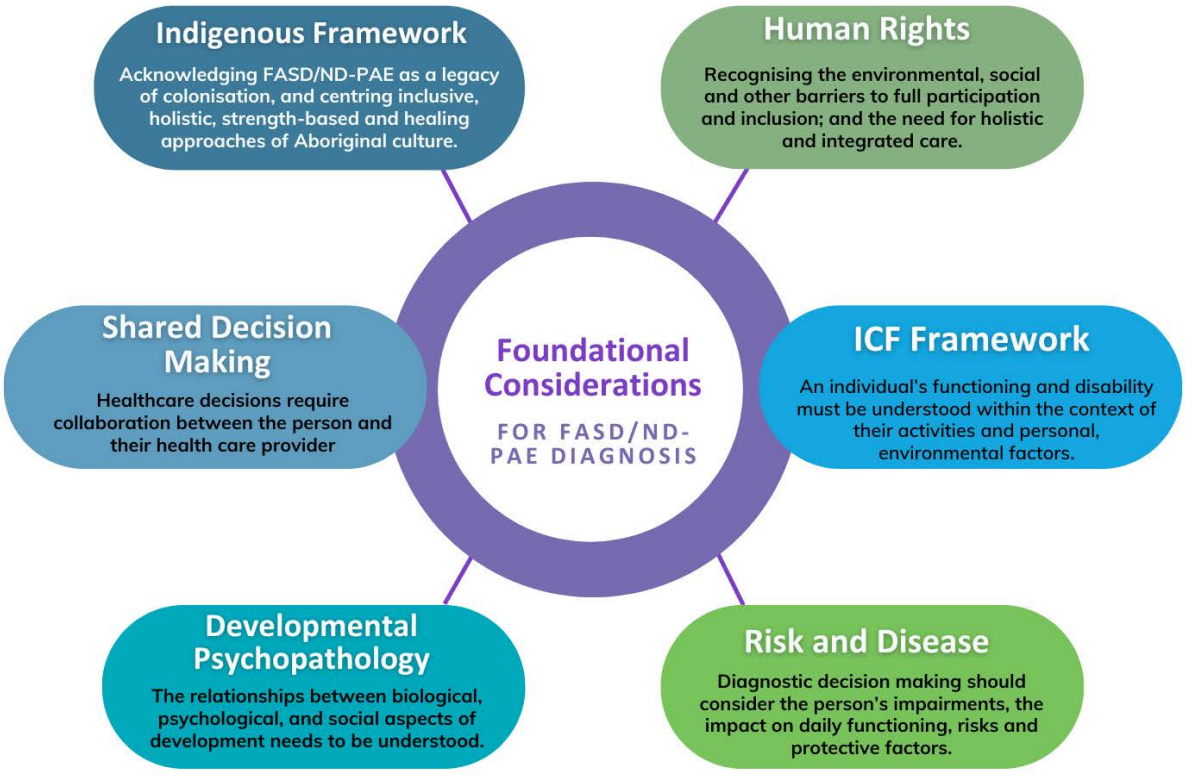


Figure 2. Overview of the conceptual frameworks underpinning the guidelines

Indigenous Framework

In the spirit of genuine reconciliation, truth-telling and justice, a fundamental driver of the guidelines is to facilitate equitable access to culturally responsive, strength-based, and healing-informed assessment and diagnostic services among Aboriginal and Torres Strait Islander peoples. To achieve this, Aboriginal voices were prioritised and valued to uphold Aboriginal sovereignty and ensure the development of these guidelines were underpinned by Aboriginal ways of knowing, being and doing. Although efforts were made, the Project team could not find a Torres Strait Islander person to speak on the issue of FASD/ND-PAE. Thus, in the spirit of respect, honesty and transparency, the current version of the Indigenous Framework speaks only from Aboriginal perspectives.

Australia was built on violent foundations that saw countless and brutal massacres of Aboriginal and Torres Strait Islander peoples. This caused destruction to kinships, knowledges, culture, Country, and spirit of Aboriginal and Torres Strait Islander peoples. Aboriginal and Torres Strait Islander peoples were denied access to education, quality food, employment, and health services. The practice of paying Aboriginal and Torres Strait Islander peoples in alcohol in some regions and tobacco exacerbated these inequities. Aboriginal and Torres Strait Islander children have been forcibly separated from their families and communities since European occupation began. However, it was the assimilation policies that imposed arguably the most violent systematic removal of children from their homes with the ultimate goal to eliminate Aboriginal and Torres Strait Islander culture from Australian society. These Aboriginal and Torres Strait Islander children became known as the 'Stolen Generations'. The unspeakable and accumulated trauma and loss was two-fold; Aboriginal and Torres Strait Islander communities were robbed of their children with little hope of finding them again and the stolen children were often placed in institutions and subjected to ongoing and multiple abuses. The broken spirit of many Aboriginal and Torres Strait Islander peoples gave rise to cycles of intergenerational trauma, poverty, and hopelessness, on which liquor outlets have opportunistically capitalised. The ongoing systemic racism experienced by Aboriginal and Torres Strait Islander peoples has compounded these issues and led to an entrenched and deep fear and mistrust of the Western system and services, especially in child protection services. Legacies of colonisation remain in the fabric of the Australian systems and manifest in a myriad of social, health and economic barriers and inequities experienced by Aboriginal and Torres Strait Islander peoples today.

Informed and led by a Cultural Advisory Group of Aboriginal leaders in the FASD/ND-PAE space, the FASD Australian Indigenous Framework was developed (Hewlett et al., 2023). 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 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 and knowledge qualities of water and the wise, vibrant, and flourishing colours of fresh vegetation. The design captures the continuity of culture and encompasses the whole support process to reflect that everything is supported through connections with culture (Figure 3; Table 1). The colours from the artwork have been incorporated throughout the documents.

The Framework summarises the shifts non-Aboriginal practitioners and Aboriginal peoples need to make in their respective ways of knowing, being and doing, to facilitate access to FASD/ND-

PAE knowledge, services, and support among Aboriginal peoples (Figure 4). The Framework presents an opportunity for all Australians to walk alongside each other, in solidarity, to heal the impacts of FASD/ND-PAE on the Australian community. This is achieved through drawing on the wisdoms of Western health approaches and therapeutic models and the wisdoms of strengths-based Aboriginal approaches that are grounded in holistic and integrated support, to create a new knowledge and practice that offers immense benefit to the quality of assessment and support for all Australians living with neurodiversity. The application of the Indigenous Framework supports understanding of the strengths, needs and context of all people attending for assessment. If the inclusive and holistic approaches of Aboriginal culture is genuinely drawn upon and applied, everyone is included, and everyone benefits.

See the Indigenous Framework document and associated publication (Hewlett et al., 2023) for more detailed information regarding the development, content, and implementation suggestions regarding the Australian Indigenous FASD Framework.

Figure 3. FASD Indigenous Framework visual design

Table 1. Description of the visual elements in the Indigenous Framework visual design.

	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 translating knowledge and navigating the Western biomedical system to ensure 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 blending information with grass roots culture.
	Clinical services and specialists

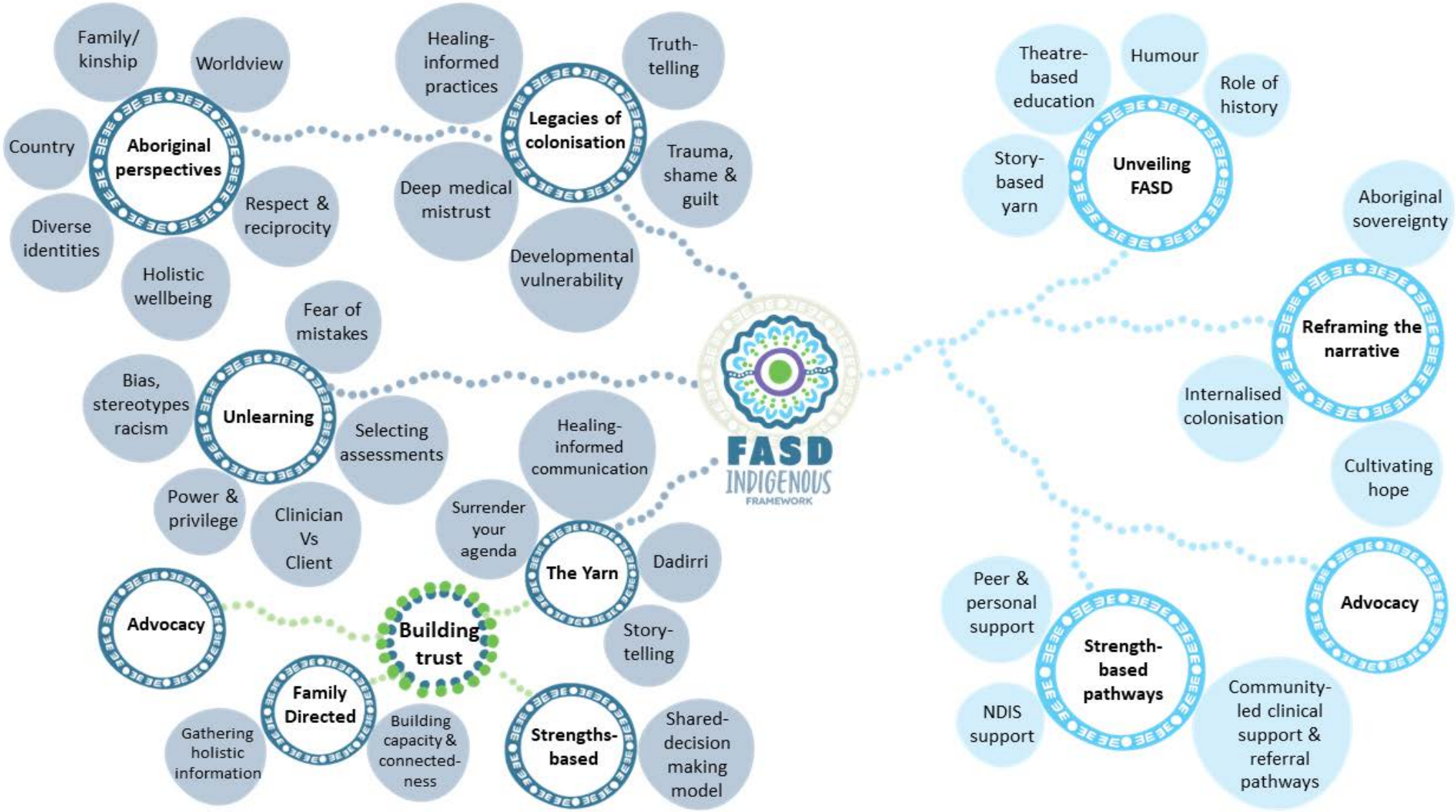


Figure 4. The FASD Indigenous Framework. The dark blue represents what practitioners need to know, be and do to deliver culturally responsive and healing-informed FASD/ND-PAE knowledge, services, and support, to Aboriginal peoples. The light blue represents what Aboriginal communities at a grass roots level need to know, be and do to access FASD/ND-PAE knowledge, services, and support.

Human Rights Conventions

Australia is a signatory to the United Nations (UN) Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations, 2006), the UN Convention on the Rights of the Child (UNCRC; United Nations, 1989) and the prioritized equity principles embedded in the Declaration of the Rights of Indigenous Peoples (UNDRIP; United Nations, 2007). These conventions and the Leave No One Behind Principle (LNOB; United Nations, 2017) each provide critical recommendations to be incorporated in the design and delivery of assessment and diagnostic services. Notably, to align with a human rights model of disability an individual's impairments should not be the only considerations in an assessment (Waddington & Priestley, 2021). Assessments should also explore the social determinants of health and strengths, wellbeing, environmental and personal factors, and the support requirements of persons with disabilities. This also aligns with recent research in the field of FASD/ND-PAE, highlighting the importance of holistic and integrated care approaches to enable targeted and meaningful supports (e.g., Himmelreich et al., 2020; Masotti et al., 2015; Pei et al., 2021; Reid et al., 2021).

Integration of a human rights models in the current guidelines include:

- Involving individuals with FASD/ND-PAE, parents/caregivers and relevant advocacy organisations in the development process.
- Promoting and supporting active participation in the assessment process by individuals and their family members, and acknowledgement of individuals and family members as experts based on their own experiences.
- Advocating for a holistic assessment process that encompasses the strengths and impairments of an individual, relevant functional, environmental, and cultural factors, in addition to an individual's support needs.
- Ensuring that informed consent is obtained prior to assessment and diagnosis of FASD/ND-PAE.

International Classification of Functioning, Disability and Health Framework (ICF)

One approach that can support holistic assessments aligned with human rights models is the International Classification of Functioning, Disability and Health Framework (ICF; World Health Organization, 2001). The ICF framework conceptualises a person's level of functioning as a dynamic process resulting from the interaction between a person's physical condition, environment, and personal factors (Figure 5).

In Australia, the National Disability Insurance Scheme (NDIS) aims to comply with Australia's obligations under the CRPD. The NDIS outlines a framework for assessment that is aligned with the ICF.

Definitions of the ICF components

The key components of the ICF include:

Body Functions: physiological and psychological functions of the body systems, such as mental functions, sensory perception and pain, functions of the digestive, metabolic, and endocrine systems.

Body Structures: anatomical parts of the body, such as organs and limbs and their components.

Impairments: problems in body function or structure, such as significant deviation or loss.

Activity: execution of a task or action by an individual, such as how they eat their lunch, complete work or school related activities, sport, or other recreational activities.

Participation: involvement in a life situation, such as spending time with friends or family.

Environmental Factors: the physical, social, attitudinal, and environment context in which people live and conduct their lives, such as family, work, cultural beliefs.

Personal Factors: gender, age, coping styles, social/cultural background, education, past and current experiences, character, and any other factors that could influence how disability is experienced by an individual.

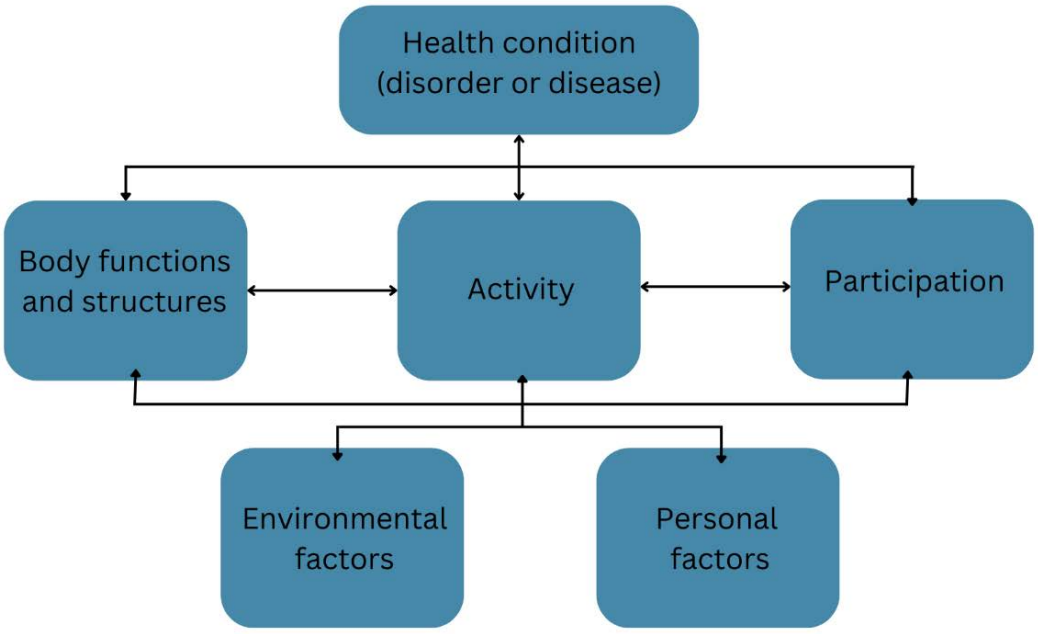


Figure 5. Interactions between components of the International Classification of Function Framework
Source: WHO 2001: 18.

Implementation considerations: ICF informed templates	Practitioners can integrate the ICF components into their assessment process. The background history taking, and case formulation templates provided in Appendix D includes some ICF components.

Shared Decision-Making

Shared decision making is an approach that can support assessment and diagnostic practices and is aligned with human rights models. This *"involves discussion and collaboration between the consumer and their healthcare provider. It is about bringing together the consumers' values, goals, and preferences with the best available evidence about benefits, risks, and uncertainties in treatment, in order to reach the most appropriate healthcare decisions for that person" (*Shared decision making resources for practitioners | Australian Commission on Safety and Quality in Health Care, 2023).

Consistent with the practice of 'yarning' used in Aboriginal communities, shared decision-making enables two-way communication and brings a range of benefits regarding cultural safety and improved understanding for practitioners, individuals attending for assessment, and their families. This leads to trusting, respectful relationships where individuals, families and communities can feel comfortable to ask questions, make informed decisions and express their views and preferences.

Integration of shared decision-making principles in the guidelines includes the following, where possible:

- Facilitating discussion and informed consent and assent (1) before a referral for further assessment is provided and (2) before commencement of an assessment. Where relevant, including interpreters to support individuals and families where English is a second/additional language. Please note, that information about consent is provided as a guide to a practitioner's ethical, rather than legal obligations.
- Enabling active involvement and collaboration with individuals, parents/caregivers, and/or family members, as part of the assessment. For example, this could include, but is not limited to, shared decision-making about the types of assessments, the use and availability of professional interpreters, and the approach to completing assessments (e.g., location, and structure of assessment sessions).
- Supporting discussion and collaboration with individuals, parent/caregivers, and/or family members, as part of the feedback process. For example, this could include, but is not limited to, shared decision making regarding diagnosis, use of diagnostic terms, personalised goal setting, sharing of information with other agencies, planning and prioritising of support needs and application to NDIS where appropriate.
- Facilitating shared decision-making (e.g., supported decision-making), when the person has difficulty with communication (e.g., hearing impairment, language disorder, use of augmentative and alternative communication devices to communicate or intellectual disability). Advocacy for involving allied health professionals to identify the necessary resources required to assist people in shared decision making.

Implementation considerations: shared decision-making information and resources

Link to further general information: Shared decision making: an overview

'*Finding your way'* is a shared decision-making model created with, and for, Aboriginal and Torres Strait Islander people, through the NSW Agency for Clinical Innovation.

Learn more about the model here: https://aci.health.nsw.gov.au/shared-decision-making and the assessment process section in this document and in the FASD Indigenous Framework, where application of this model is discussed in further detail.

Developmental Psychopathology

> *"Developmental psychopathology is an evolving interdisciplinary scientific field that seeks to elucidate the interplay among the biological, psychological, and social-contextual aspects of normal and abnormal development across the life span"* (Cicchetti & Toth, 2009; p. 16).

Developmental psychopathology has been applied to the study of FASD/ND-PAE to help understand and support the self-regulatory challenges of individuals with FASD/ND-PAE (Reid & Petrenko, 2018). Developmental psychopathology provides a means to bridge fields of study to *"aid in the discovery of important new truths"* (Cicchetti, 1990; p. 20).

In the context of FASD/ND-PAE this approach could assist with bringing together areas of teratology; developmental origins of health and disease (DoHaD); epigenetics; intergenerational trauma; and early life adversities. Each of these scientific fields is crucial to understanding development across the lifespan. Yet, despite their importance, these areas of understanding have largely evolved independently. It is critical for researchers and practitioners to take a more holistic approach to understanding development. As such, these guidelines encourage practitioners to apply a wide lens to understanding the possible explanations for an individual's presentation.

Risk and Disease

To determine whether an individual has a disease, disorder, or condition, it has been suggested (e.g., Daly, 2022; Walker & Rogers, 2018) that practitioners should consider:

- **Dysfunction:** defined at the basic level to be the failure of a body system or organ to follow its medically established function (Walker & Rogers, 2018). In the disability field, this is commonly referred to as the *impairments* that a person experiences.
- **Harms:** refer to how the impairments that a person experiences impacts their life. Terminology in the disability field that is more commonly used is *functional impact*s. This may include the impact of harms on a person's daily living activities independence, social activities, wellbeing, and health.
- **Risk**: refers to the probability of an impairment as well as harm. Daly (2022) states that: *"Risk factors are not themselves the determinants of dysfunction, but rather elements of schemes (among an array of schemes—both internal and environmental), that condition well-ordered or disordered function of the whole organism"* (p. 476). For example, PAE and neurodevelopmental impairments; smoking and lung cancer, high blood pressure and stroke. Risk is therefore not predetermined, and in line with First Nations perspectives, ICF, and developmental psychopathology, risk factors, impairments and functional impacts are modulated by the environment. Consequently, risk also requires us to consider **protective factors**, which can include a wide range of social, cultural, and biological factors.

Each of these components has been taken into consideration in the development of the diagnostic criteria and further information is provided to support practitioners in reflecting on these elements in their decision making.

Assessment Principles and Diagnostic Criteria

"I didn't label my child. My child got a diagnosis so that he can get the help that he needs."

BIOLOGICAL MOTHER AND ADVISORY GROUP MEMBER

"Diagnosis has allowed me to shift the blame and sadness of my perceived shortcomings and redefine them with a new appreciation of what I have overcome and what I have managed to achieve despite them."

ADULT WITH FASD AND ADVISORY GROUP MEMBER

Assessment Principles

The following *Assessment Principles* are provided to support practitioners in applying the diagnostic criteria in practice:

- For individuals who already have a diagnosis of FASD made using previous criteria, re-assessment is not required, unless clinically indicated.
- PAE can result in a wide range of whole-body outcomes from subtle to severe. In making a diagnosis of FASD/ND-PAE we are aiming to identify individuals who are experiencing pervasive, persistent, and clinically significant impairments that impact daily functioning, where it is determined that PAE has contributed to these outcomes.
- Assessment should include input from health professionals across multiple disciplines. In applying this principle, practitioners should be mindful of the overarching principles of value-based health care and person-centred care. Both of these approaches respectfully place the individual, their carer(s) and support people, at the centre of care through fostering trust and mutual respect and by providing education and support so that they can actively engage in making decisions about tailoring care to their needs.
- There is no formally agreed definition of impairment within, or between, health disciplines. As such, differences in functional performance and/or physical features evidenced by indices such as percentile ranks, should not be used in isolation. Clinical judgement informed by the relevant available information is essential to determine the best explanations for an individual's neurodevelopmental or physical differences, and in turn, whether their presentation meets criteria for a diagnosis of FASD/ND-PAE.
- Assessment should follow a 'developmentally informed approach'; whereby different assessment approaches are applied across developmental stages to provide the most appropriate assessment, given an individual's presentation.
- Assessment and diagnosis of FASD/ND-PAE can and should take place across the lifespan. Individual attributes that may manifest as barriers to equitable inclusion may only become evident with age. Review should occur periodically when clinically indicated, but in the context of the supports being put in place and the potential impacts of major life transitions on functioning.
- In providing a diagnosis of FASD/ND-PAE practitioners are making the determination that an individual is impacted by a life-long condition. This means that impairments are not transient or due to changes in current circumstances or enduring environmental adversity. However, practitioners also need to take into consideration how an individual may change over time due to life experiences and opportunities, and formal supports or the lack thereof, as well as changing expectations across different life stages and contexts.
- Practitioners are encouraged to seek relevant discipline-specific professional development and clinical supervision, preferably from those with specific FASD/ND-PAE expertise to support them in undertaking assessment and diagnosis in their specific settings, whilst also being mindful of professional and ethical guidelines.

Diagnostic Criteria

Diagnostic criteria aim to inform practitioners of the symptoms and signs usually required to ensure accurate diagnosis of a health condition, while also allowing a degree of flexibility to accommodate natural variances in presentation and clinical decision-making (WHO, 2004). As such, the following criteria do not form strict rules for diagnosis, but rather provide evidence-based guidance to inform the assessment, diagnostic reasoning, and case formulation.

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

Terminology

As noted in the Introduction section, at this time no consensus could be reached regarding diagnostic terminology. The Guidelines Development Group did not want terminology to be a barrier to individuals accessing services. Thus, it was decided that a flexible approach was the best way to move forward, with the option to use FASD or ND-PAE. Practitioners are encouraged to use shared decision-making with individuals attending for assessment and their families, carers, or significant others, to determine their preference for the terminology used in describing the individual's diagnosis and with whom the diagnosis is shared.

There are also a range of differences in terminologies applied both within and between disciplines and across different clinical settings regarding a variety of aspects of the assessment process. For example, the terminology of 'clinically significant impairments' has been used in the diagnostic criteria, however practitioners may prefer to use wording of 'severe impairments' or other relevant discipline specific terms. The terminology of standardised tests has been used, but practitioners may prefer wording such as standardised measures, validated tests, or measures. Please note that diagnostic criteria and supporting information is not meant to be prescriptive, but to provide guidance and support for practitioners.

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

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

Fetal Alcohol Spectrum Disorder (FASD), alternatively, Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure (ND-PAE)

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

A. Evidence of prenatal alcohol exposure (confirmed by point 1 **or** 2)
   1. Evidence consistent with heavy or very heavy prenatal alcohol exposure (PAE) at any time during gestation, including prior to pregnancy recognition. Practitioners could consider moderate PAE depending on the strength of concurrent evidence. See the additional information section for further details.

      Confirmation of PAE may be obtained from any of the following sources: self-report of alcohol use in pregnancy, and/or collateral reports from individuals who directly observed the prenatal alcohol use, and/or information obtained from medical or other records.

   2. In the absence of a confirmed history of PAE, the presence of the three sentinel facial features (i.e., short palpebral fissures, thin upper lip, and smooth philtrum) may be considered sufficient to meet Criterion A, following the exclusion of other causes.

B. Presence of pervasive neurodevelopmental impairments.

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

   Clinically significant impairment is defined through points 1 **and** 2:

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

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

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

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

   Note:

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

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

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

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

Specify if the following physical features are present:

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

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

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

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

At risk of FASD/ND-PAE: In situations where PAE is confirmed and concerns are identified, but an assessment process cannot be completed, or available assessment is insufficient to determine if pervasive and clinically significant impairments exist, individuals may be considered 'at risk of FASD/ND-PAE' with follow-up and reassessment recommended as clinically indicated. Practitioners should specify why the 'at risk' designation has been used. This designation should not be used where diagnosis is not possible due to lack of resources.

Additional Information

Structure of the diagnostic criteria and 'associated with' section.

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

Criterion A: Prenatal alcohol exposure (PAE)

PAE is a key factor in differentiating FASD/ND-PAE from other conditions. Practitioners need to have reliable evidence of PAE at levels that have the potential for adverse outcomes relating to the diagnostic features.

Criterion A has been specifically worded to align with the findings from the evidence review, whereby heavy and very heavy PAE was more consistently found to be associated with adverse diagnostic outcomes. The available evidence was uncertain regarding the potential impacts of moderate PAE. However, there are some key limitations that need to be considered when using this evidence in practice at an individual level:

- The review was unable to control for, or compare, different timings or patterns of exposure (e.g., chronic exposure, exposure only prior to pregnancy recognition, first

trimester only exposure, or binge exposure). This was due to the variability in definitions, reporting, and the number of studies available assessing the same outcomes at the same PAE level. It is possible that a lower level of PAE at a critical period of gestation could result in adverse outcomes and practitioners need to have flexibility and use clinical judgement to take this into consideration.

- Whilst adjusted outcomes were used where possible, the review was often unable to control for, or compare, different individual prenatal parental and child factors, which may exacerbate or ameliorate impacts of PAE (e.g., prenatal nutrition, metabolic rates, genetic differences, biochemical and inflammatory responses to alcohol).
- Whilst adjusted outcomes were used where possible, the review was often unable to control for or compare different individual postnatal parental and child factors, which may exacerbate or ameliorate impacts of PAE (e.g., postnatal environments and events, postnatal nutrition).

As per the assessment principles section, the PAE criterion A1 **should not be rigidly applied in isolation**. Practitioners need to take into consideration the timing, duration (i.e., the number of weeks the exposure occurred) and the pattern of the exposure (i.e., less frequent but larger quantities of alcohol, versus more frequent exposure at lower levels or varying patterns between pre- and post-recognition of pregnancy). A binge exposure pattern may fall into moderate, heavy, or very heavy exposure categories, depending on how many drinks were consumed during one or more binge occasions per week. Rather, the available evidence should be used to inform clinical decision making as part of an individual's case formulation.

In practice, precise information regarding the number of drinks per week and the pattern of consumption may not be available. For example, the biological parents may not be available to interview, or the biological parents may not be able to recall specific details. However, other information is commonly available that is consistent with a heavy level of exposure. For example, self-reported information, witness reports or available records that documented episodes of intoxication during the pregnancy. In such instances, after considering the reliability of the information at hand (i.e., including the nature of the relationship between biological parent/s and witness reports), practitioners may exercise informed clinical reasoning about the PAE risk based on the best available information. Practitioners are encouraged to engage in case discussion to support clinical decision making.

Overall, practitioners should use their clinical judgement to determine, based on the best available PAE history, the likely level of risk of the exposure in the context of the individual's presentation, and the likelihood that PAE has played a significant role in an individual's presentation (Figure 6). As described in the Foundational Conditions section, practitioners are encouraged to remember that whilst PAE is a risk for neurodevelopmental impairments, risks are not predetermined.

See the prenatal alcohol exposure assessment section for a range of good practice statements and implementation considerations to further support applying Criterion A in practice.

Also see section below on facial features to support implementation of Criterion A2.

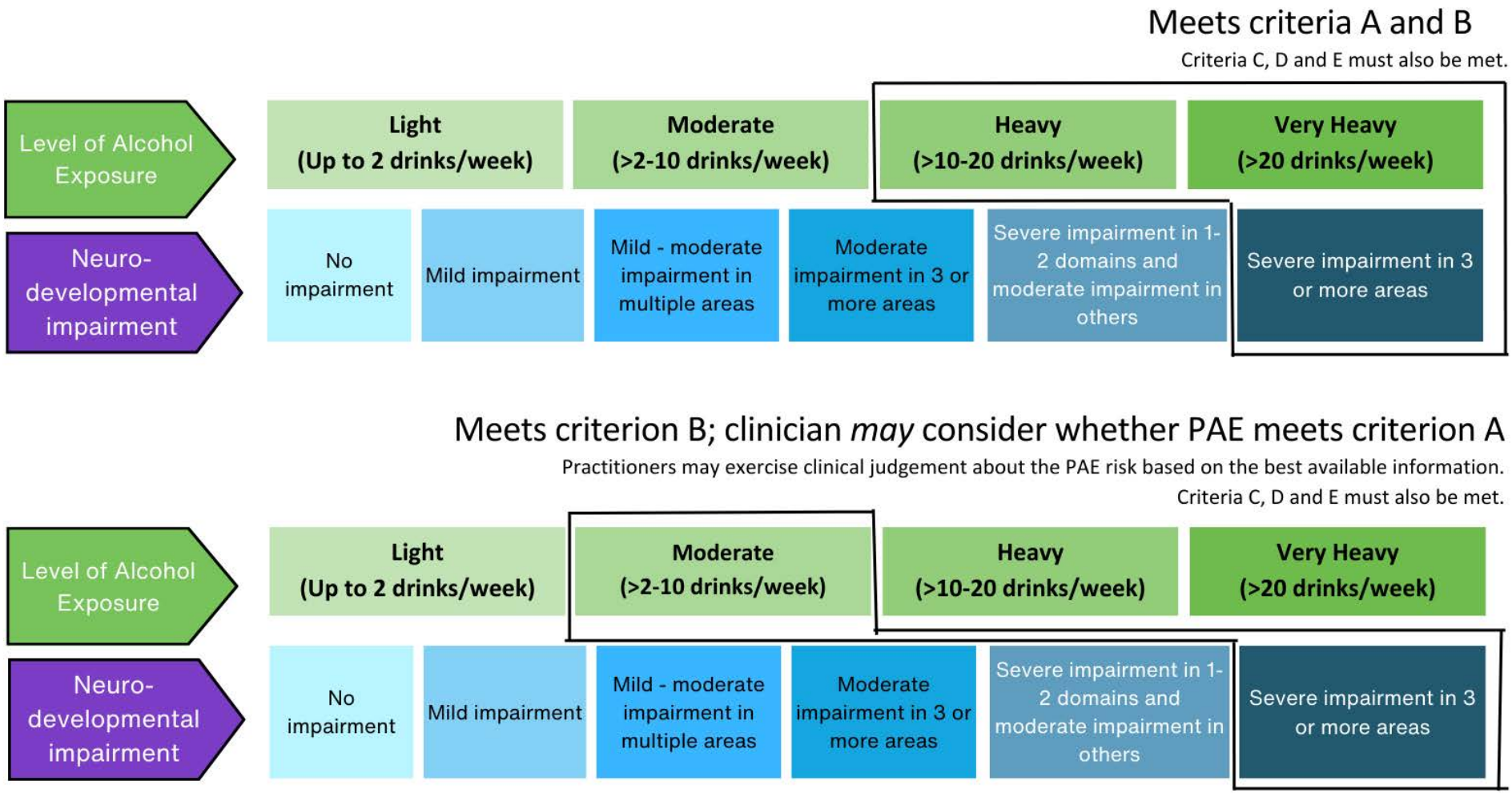


Figure 6. Visual to support application of prenatal alcohol exposure evidence in practice

Considerations from the evidence review

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

An extensive evidence review was undertaken. To allow appropriate comparison across the diagnostic outcomes available evidence was quantified according to the grams of ethanol exposure per week and grouped into different levels of exposure (Table 2).

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

Table 2. Definitions of PAE levels per week used in the evidence review. ***Note.*** *these definitions are not intended as rigid cut offs in practice but rather provided as information to inform clinical decision making.*

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

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

See the Technical Report of the systematic review of the components of the diagnostic criteria and associated Supplemental Files for the full results.

Criterion B: Presence of pervasive neurodevelopmental impairments

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

To provide evidence of the pervasive nature of the impairments, there needs to be evidence that an individual's daily functioning is negatively impacted in *three or more*

neurodevelopmental domains. The Guidelines Development Group have retained the three or more domains on the premise that the impact of PAE needs to be demonstrated across multiple areas of functioning. It is recognised that further research is needed to empirically validate this judgement.

As per Criterion E, practitioners need to consider all other possible factors that could better explain or contribute to the neurodevelopmental impairments. Practitioners need to be cognisant that having three or more neurodevelopmental domains with clinically significant impairments is not specific to FASD/ND-PAE and can apply to a wide range of other neurodevelopmental conditions. Thus, while the neurodevelopmental domains included can be impacted by PAE, they are not discriminatory for PAE. As discussed earlier in risk and disease section, PAE is a risk for neurodevelopmental impairments, it is not predetermined. Practitioners may also need to consider a higher threshold for pervasive impairments in the presence of multiple comorbidities and that a range of psychiatric conditions can cause (often transient) impairments.

Considerations from the evidence review

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

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

Determining the clinical significance of neurodevelopmental impairments in practice

Practitioners are required to use all the information collected as part of the assessment to decide if clinically significant impairments are present. Noting that, single test scores should not be used to establish impairments in multiple neurodevelopmental domains.

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

Percentiles are a simple metric for conveying test information in the context of best available population norms. However, as has been described previously (Crawford et al., 2009) there are numerous challenges of which practitioners should be aware. Appendix B provides a brief overview of some key considerations. Given the complexity in interpreting test scores, it is important that practitioners follow established conventions for instruments used in the assessment, when reporting an individual's performance. More generally, practitioners may

benefit from considerations suggested by Guilmette et al. (2020) when determining impairment (see Appendix B for an overview).

Guilmette et al. (2020) proposed the following (Table 3) for characterising levels of performance on tests that have normally distributed scores. Test scores in the exceptionally low score range and the below average score range could be considered as being significantly below the normative level. While useful, practitioners are reminded to consider the characterisation of performance on the tests they use in line with established best practices for each test.

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

It is important to note that most normative studies of standardised tools do not include Australia's culturally diverse population. Therefore, these recommendations should be applied with caution for individuals from different cultures to the population on whom the tests were normed.

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

Table 3. Test score labels based on standard scores and percentiles for tests with normal distributions taken from Guilmette et. al (2020)

Standard score	Percentile	Score label
≥130	≥98	Exceptionally high score
120–129	91–97	Above average score
110–119	75–90	High average score
90–109	25–74	Average score
80–89	9–24	Low average score
70–79	2–8	Below average score
<70	<2	Exceptionally low score

Note. These scores do not necessarily hold for tests that have non-normal score distributions and these categories may vary by a few or several standard scores (or percentiles) depending on the nature of a measure's distribution of scores. It is recommended that practitioners consult the test manuals for all measures that they use, to ensure that the correct naming convention is used to describe a test's score.

Assessing neurodevelopmental domains in practice

An overview of the neurodevelopmental domains and specific considerations for assessment are provided in Table 4. FASD/ND-PAE is a complex and multifaceted condition that is best assessed and diagnosed via an interprofessional framework. As such, practitioners are encouraged to engage in a collaborative approach to formulating individual cases (e.g., through case conferencing), to bring their relevant scope of practice to the assessment

process, and access clinical supervision to support application of the diagnostic criteria. Different practitioners in a multidisciplinary setting should not simply contribute their assessment findings without consideration of all domains, in consultation with their team.

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

As noted in Criterion B, standardised tests are preferred. However, it is acknowledged that there may be some circumstances where this is not appropriate. Some examples include *(note – non limiting list)*: individuals who are extremely low functioning, where standardised tests would not likely produce valid results due to the presentation, and may negatively impact well-being; situations where practitioners in consultation with the individual or their family decide that the use of standardised tests are not culturally and linguistically appropriate; or when assessment of a domain or use of a tool is not appropriate given the person's history, such as academic testing of a child who has not been in the education context for many years.

A summary of specific assessment considerations for practitioners are provided in Table 4. However, there are a wide range of standard clinical practices practitioners may apply (e.g., considering impacts of motor skills on measures that include motor requirements, considering performance validity). Practitioners are encouraged to access relevant discipline specific resources and supervision as required.

Specific examples of standardised tools are not provided, as practitioners should apply their discipline specific knowledge and clinical judgement to determine the most appropriate approaches for the individual attending for assessment, the clinical context, and the limits of their own professional expertise. Feedback gathered during the review process indicated that the list of example standardised tools included in the 2016 Guide was sometimes being applied rigidly, which could negatively impact on providing person-centred and culturally responsive assessments.

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

See the assessment process and the holistic developmental, functional and wellbeing assessment sections for further guidance.

Assessment of infants and young children

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

Internationally, diagnostic criteria differ regarding whether microcephaly alone meets criteria for brain impairment. Astley (2013) documented that the combined presence of the three facial features and microcephaly was predictive of later significant impairments. However, concerns have been raised by Clinical Advisory Group members regarding the diagnosis of FASD/ND-PAE in young children based on facial features and microcephaly alone, due to lack of local tools and norms for assessment of facial features, (2) inter-rater reliability issues in assessing facial features reported in clinical practice, (3) the potential lack of concordance between microcephaly and functional neurodevelopmental outcomes, and (4) current lack of Australian research in this area. Practitioners are encouraged to be mindful of these concerns and collaborate with families to make diagnostic decisions.

Consideration of co-occurring conditions

Diagnoses of co-occurring conditions (e.g., ADHD, ASD, anxiety, depression) have not been included in the neurodevelopmental domain table (Table 4). Feedback from the Clinical Advisory Group indicated that the inclusion of these as part of the domain table may unintentionally lead to a 'tick box' approach to diagnosis. Pre-existing diagnoses can provide helpful information regarding current functioning and should be considered when reviewing the available evidence. Practitioners are encouraged to consider an individual's functioning in each of the neurodevelopmental domains based on all the available information and decide if they believe there are clinically significant impairments. Further, as per the co-occurring conditions section listed below the diagnostic criteria, practitioners should provide diagnoses of relevant conditions to support comprehensive understanding of an individual's presentation.

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

Table 4. Overview of neurodevelopmental domains: definitions and specific assessment considerations

Domain	Definition	Specific assessment considerations
Communication (Language skills)	Communication is how we receive and convey ideas, thoughts, and feelings to other people. Language skills refers to the words, syntax, morphology, and pragmatics we understand and use to communicate in oral, sign, and written forms. The domain focuses on language as a developmental process with which PAE can interfere. Although language skill development is sensitive to a range of factors (including other exposures, absence of modelling, hearing difficulties) it can also be disrupted idiopathically. Currently there is no clear phenotype for disordered language skills in the presence of PAE. Therefore, the domain should be assessed in keeping with best practice recommendations. There is currently limited evidence that other communication disorders (e.g., motor-speech, speech sound, pragmatic/social communication, and voice disorders) are associated with or attributable to PAE. Therefore, such communication disorders will not solely contribute to a FASD/ND-PAE diagnosis but are important to the overall clinical profile and treatment of a client and should be characterised and documented in reports, with recommendations made as appropriate.	Impairment is present in this domain if the individual's language skills are found to be *disordered*. Assessment should be according to principles of best practice (Bishop et al., 2016; Bishop et al., 2017), specifically it should: • Consider that disordered language skills are heterogenous and a thorough assessment should examine the principal dimensions of language: o Syntax/morphosyntax o Word finding and semantic knowledge o Discourse/narrative o Phonology (where indicated and considered linguistic in origin, though phonology should not solely contribute to meeting the criteria) o Verbal learning/memory (if best attributable to communication skills than memory abilities) • Functional language skills should also be considered as part of the assessment (e.g., how the person performs in everyday meaningful tasks). • For assessment with Aboriginal and Torres Strait Islander peoples and other culturally and linguistically diverse individuals, relevant Practice Guidelines produced by Speech Pathology Australia can be used to guide practice. • Evaluate the prognostic indicators for poor outcomes resulting from disordered language skills. • If an individual meets criteria for FASD/ND-PAE and disordered language is identified, the appropriate diagnosis relating to language disorder is 'Language Disorder associated with FASD/ND-PAE' (as per Statement 6; Bishop et al., 2017).

		Diagnostic terminology should not distinguish between 'expressive' and 'receptive' diagnostic subtypes as these are not categories that are considered stable over time (Bishop et al., 2017).
Motor skills	Motor skills include general motor abilities, areas of fine motor, gross motor, graphomotor (handwriting) skills and/or visual motor integration.	• Assessment of more than one aspect of motor skills is recommended to provide an understanding of strengths and challenges in this domain. • Assessment could commence with understanding the area of functional motor concern. A dynamic performance analysis can be undertaken to understand where the breakdown in performance is occurring and help select the most appropriate standardised test or additional functional assessments required. • Assessment should consider performance on standardised tests as well as within a functional context (e.g., handwriting within the classroom, gross motor skills moving around a playground). • Gross motor impairment may not be detected without a comprehensive assessment of gross motor skills. • There is a need to establish that an impairment in visual motor integration is due to a motor deficit and not a visual spatial deficit. • Graphomotor tasks require learned skills and need to be assessed in relation to opportunity and only after access to relevant intervention. • Other causes of motor challenges, such as dysfunction of the vestibular system, executive function, musculoskeletal system, or peripheral nervous system should be considered.
	Practitioners should apply generally accepted models of intelligence, which is often defined to	• Impairment in this domain may be established through deficits in an underlying general factor of intelligence ('*g*' e.g., full-

General intellectual abilities (Cognition)	include the capacity for abstraction, to solve problems, and acquire new skills. As there are multiple models and definitions in current usage, practitioners are recommended to consider the implications of the model they select and maintain their knowledge of this area.	scale intellectual quotient) or one or more major subdomains that load on this factor according to established models of intelligence. Examples include Verbal Comprehension, Visual Spatial Index (visual perception), Fluid Reasoning, Working Memory, and Processing Speed constructs as defined in the Wechsler paradigm or broad and narrow constructs as defined by the Cattell-Horn-Carroll Model. • If available records indicate a person's presentation is consistent with significant impairments in intellectual abilities this could be indicative of neurodevelopmental impairments across multiple domains. We encourage practitioners to take this into consideration when planning the assessment approach. • Assessment may be limited to nonverbal measures, where appropriate. • Practitioners should consider the impact of any language impairments (or if English is not the dominant language) on measures that include verbal instructions or responses. • Practitioners are advised that while discrepancy analysis forms a critical part of interpreting test scores in co-normed test batteries, discrepancies in test scores are not sufficient in and of themselves to demonstrate impairment. • Working memory could be included in either this domain *or* the attention or executive functioning domains depending on whether the scores are considered more strongly associated with performance on tests of general intellectual functioning or with the individual's attention and executive functioning performance.

Attention	There are many models of attention, however a commonly used framework is to conceptualise attention as having the following components: • Selective attention (i.e., focusing on a particular stimulus); • Sustained attention (i.e., attending for longer periods of time with resistance to distractions); • Distractibility (i.e., susceptibility to distractions). Attention refers to both auditory and visual modalities. The available evidence for the impact of PAE did not demonstrate differences between auditory and visual attention. Therefore, it is advisable to assess attention using the method most appropriate to the individual.	• Depending on the individual's presentation during the assessment of attention and their performance on language skills, memory, and executive function assessment, more basic attentional processes (i.e., visual scanning, immediate attention span) could be considered as part of the attention domain while more complex attention processes (e.g., inhibition, dividing, shifting/switching) could be considered as contributing to other domains (i.e., executive functioning, communication, memory, literacy/numeracy) as appropriate. • Challenges with visual scanning could indicate problems with oculomotor control and this could be further explored if clinically indicated. • Consider the potential impact of prescribed medications (e.g., stimulants), level of engagement/rapport, and whether formal testing was conducted in a quiet room without distractions.
Memory	Memory includes the ability to encode, store and retrieve information. It has traditionally been conceptualised as including declarative (explicit) and procedural memory. Explicit memory may be further subdivided by modality (verbal, visual) or by the type of information stored, including episodic memory (personal events and experiences) and semantic memory (factual information; Mujawar et al., 2021). The available evidence for the impact of PAE on memory did not include procedural/implicit memory tasks or separate the impact of PAE on different stages of memory (encoding, storage, retrieval). However, the foundation of a sound	• Memory may be assessed through performance on free recall, cued recall (immediate, delayed) and recognition tasks. • Consider the interplay between attention, language skills, intelligence, executive functioning, anxiety, and memory; and based on test performance determine the best explanation for impairments. • Consider memory abilities across settings (including but not limited to home, education, work, and community), to accurately represent any deficits and their functional impacts. • It may be appropriate to assess prospective memory (i.e., remembering to perform a specific action in the future, at a particular time, or in response to a specific event) to assist in understanding an individual's day-to-day functional memory problems. However, practitioners should consider the multi-

	memory assessment requires these capabilities be assessed to provide a comprehensive understanding of an individual's memory challenges, to identify memory disorders, and to inform targeted supports.	dimensional nature of this ability including impacts of executive function (e.g., Ji et al., 2021; Martin et al., 2003).
Executive Function (EF)	There is no universally accepted conceptualisation of EF. EFs are traditionally defined as higher-order cognitive functions including initiation, inhibition, mental flexibility, novel problem solving, planning, emotion regulation, and self-awareness, all of which are needed for adaptive goal-directed functioning (Sira & Mateer, 2014). Among the many conceptualisations of EF that practitioners may find helpful for characterising the individual and differentiating functions within domains is the distinction between *hot* (i.e., reward or affect-related, high emotional arousal during decision-making) versus *cold* (i.e., purely cognitive, no affective component) domains of EFs. There are many abilities that fall under the *cold EF* umbrella; however, core skills are better assessed by formal tests and include (and are not limited to): response inhibition (e.g., inhibitory control), cognitive flexibility, updating (i.e., self-monitoring, working memory), shifting (i.e., switching flexibly between tasks or mental states), planning and problem-solving. *Hot* EFs, can include processing of information related to reward, emotion, and motivation, and can be	• Capabilities and deficiencies in EF are best captured through a combination of standardised behavioural tests, domain specific questionnaires and semi-structured interviews. • Consideration should be given to performance of EFs across settings (including but not limited to home, educational settings, work, and social engagement), to accurately represent any deficits and their functional impacts. • Individuals with severely impaired EFs may have limited insight into their difficulties and may not be able to accurately represent their level of functioning. In such instances, convergent information from a reliable informant should be sought (e.g., via informant questionnaires). • For older children, adolescents, and adults, EFs are generally considered as multi-factorial, and include different inter-related and inter-dependent skills that act within an integrated top-down control system. • For young children some research has indicated that EFs could be considered as a unitary concept that only differentiates as children age (i.e., distinct EF abilities have not developed yet). There is discrepancy in available research regarding the specific ages at which differentiated EF skills emerge (e.g., can vary from 6 to 12 years depending on study methodologies). Clinical judgement is required to determine if multi-

	better assessed via clinical history, questionnaires, or direct observation (Salehinejad et al., 2021).	component assessment of EF skills is beneficial, based on an individual's presentation. • Depending on assessment results, emotion driven (reward, arousal, affective based) EFs may be considered under the behavioural regulation domain.
Emotional and/or behavioural regulation	Emotional and/or behavioural dysregulation could include significant difficulties with any of the following: • mood (internalising symptoms such as depression or anxiety, negative affect) • emotional regulation (e.g., irritability, low frustration tolerance, mood lability, suicide threats, where this is not the direct impact of another aetiology). • behavioural regulation (externalising behaviours could include rule-breaking behaviour [e.g., confabulation, taking things that belong to others], oppositional/non-compliant, behavioural outbursts, and reactive aggression).	• The frequency, intensity, severity, and duration of the behaviour must be disproportionate and/or inappropriate for the context and developmental age of the individual. • The behaviour must be persistent over time and across contexts, though may present differently due to the nature of specific contexts; and the behaviour must not only occur in response to specific life circumstances and/or current substance use. When required, re-assessment can be recommended to determine whether behaviours are persistent. • Consider the individual's history to identify the best explanation for the current presentation (e.g., family history, postnatal exposures, and adverse childhood experiences). Parental substance use may be associated with an increased genetic and environmental risk for emotional and behavioural regulation problems. • Consider whether the individual has had access to evidence-based treatments and how well they have responded. • Involvement with the justice system should not be used as direct evidence of significant impairment in this domain as a variety of criminogenic factors could lead to involvement with the justice system that are not related to an individual's impairments.

		• Emotional/behavioural regulation impairments should only be considered diagnostically when there is sound evidence to suggest they are due to the direct effects of PAE or secondary effects of the disabilities that have arisen from PAE
Literacy and/or Numeracy	Literacy refers to reading, writing, and spelling skills and numeracy refers to mathematics skills.	• This domain should only be considered towards a diagnosis when individuals have had access to appropriate engagement in formal education and remediation in the learning environment, in a language in which the individual is fluent and when the person has not significantly benefitted from attempts at remediation. • Consideration must also be given to an individual's educational placement (e.g., mainstream, educational support class, special school) and opportunities (e.g., remote location, multi-lingual setting, new immigrant) and the type and level of supports provided. • It is possible that impairments in literacy and/or numeracy could be a direct consequence of PAE or a functional consequence of the combined impacts of impairments in other neurodevelopmental domains (e.g., intellectual abilities, communication, attention, memory, executive function). As such, clinicians must carefully consider whether literacy and/or numeracy deficits independently contribute to the person's neurodevelopmental profile when formulating against the diagnostic criteria. o For example, if significant attention impairments are identified it is recommended, they are treated before retesting to determine if impairments in literacy and/or numeracy are also present.

Adaptive/social functioning	Effective adaptive and social functioning requires a collection of learned skills that enable people to function in their daily lives in accordance with cultural and societal expectations. This can include understanding concepts of money and time, activities of daily living (personal care), occupational skills, safety, health care, travel/transportation, schedules/routines, interpersonal skills (e.g., quality of peer relations and challenges in social interactions), social responsibility, gullibility, naivety, suggestibility, or social problem solving.	• Consider any formal and informal supports the person may be receiving and how this may influence ratings of their adaptive/social functioning. • Consider different expectations and skills required at different developmental stages. • Consider the level of exposure to different adaptive and social opportunities and differences that can exist across different communities (e.g., urban vs rural and remote settings). • Consider direct functional assessments of adaptive and social skills, as well as informant rating scales. • Consider the functional impacts of language skills and pragmatic language skills on social functioning and social problem-solving abilities.

Neurodevelopmental domains: evidence for inclusion

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

Wherever possible, adjusted outcomes were used that incorporated consideration of confounding variables. However, the available neurodevelopmental evidence did not often include adjusted outcomes. As such, the available evidence often did not exclude the impact of other factors that may influence neurodevelopmental outcomes. To provide additional examination of the evidence, a summary of the studies that included regression analyses was undertaken (results provided in the Technical Report of the Systematic Review of Diagnostic Components). Overall, the pattern of results was generally consistent, whereby after controlling for confounding variables, results remained significant only at higher levels of PAE.

Extensive feedback was received from the Clinical Advisory Groups and discussions undertaken in the Guidelines Development Group regarding the conceptualisation of the neurodevelopmental domains. The complex interplay between neurodevelopmental domains was thoroughly discussed. This included that some domains can be considered as more primary impairments (e.g., intellectual abilities, memory, attention) and some domains may be considered as more secondary impairments (e.g., academic, adaptive, social). Detailed information is provided in Table 4 to support practitioners in considering the complex interplay between neurodevelopmental domains in the formulation process.

Creating higher order groupings of the domains (e.g., as per the proposed DSM-5 criteria) was considered and discussed. However, it was decided this would introduce another arbitrary element to the diagnostic criteria, which would not currently be evidence based and may lead to the exclusion of certain presentations from this type of grouping system. **It was determined at this stage that it is better for practitioners to undertake these conceptualisations at the individual case formulation level.** Future research is required to explore different conceptualisations of the neurodevelopmental domains.

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

Criterion C: The neurodevelopmental impairments necessitate significant supports.

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

Criterion D: Onset of neurodevelopmental impairments in development

The Guidelines Development Group want to ensure that this criterion does not impact on adults accessing assessment and diagnosis. This criterion should not be interpreted to mean that specific assessment results are required from the early developmental period for diagnosis of adults. Rather, that the overall pattern of available evidence indicates impairments were present in the developmental period and therefore, that impairments are not a decline in abilities or due to specific life circumstances or events. Information from previous assessments can be used as support for Criterion D if available.

Specifier: Sentinel facial features

Inclusion of three sentinel facial features

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

Palpebral fissures

Short palpebral fissures are defined at ≤ 3rd percentile (i.e., ≤ 2 SD). There was limited evidence available and comparison across different percentile cut offs was not possible. The Guidelines Development Group also took into consideration current implementation factors, whereby most practitioners in Australia currently use the University of Washington facial

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

Due to the small number of studies and lack of reporting of the normative charts used in the available research, the evidence review was not able to examine the impacts of different palpebral fissure reference values on diagnostic outcomes. There was also limited research that had undertaken comparisons between available palpebral fissure normative charts. In a retrospective comparison of U.S FASD clinical data, Astley Hemmingway et al. (2019) observed that switching to the Clarren charts from 6 years of age resulted in an artificial decrease in short palpebral fissures. In the only Australian study to examine this, Tsang et al. (2017) found that the Strömland et al. (1999) norms were the best fit from the norms available for a sample of Aboriginal children from one Australian community. Overall, there is very limited research in general, but also specifically in the Australian context regarding the assessment of facial features. This is an area that needs to be addressed in future research. **Based on the very limited evidence available, the Strömland palpebral charts are recommended for use across the lifespan.**

Lip and philtrum

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

See the medical assessment section of this document for further good practice statements to support facial features assessment in practice.

Assessment of facial features for individuals from culturally diverse backgrounds

Concerns were raised regarding the lack of local norms and lip/philtrum guides for the assessment of people from diverse ethnic backgrounds in Australia, including Aboriginal and Torres Strait Islander peoples (e.g., as documented in Hayes et al., 2022). Future research is urgently required to develop local norms and tools relevant to the Australian context to improve the assessment of facial features. The Cultural Advisory Group recommend practitioners use shared decision-making with individuals and families attending for assessment to provide information about the limitations of current approaches to facial features assessment available in Australia. Individuals can still be assessed and diagnosed with FASD/ND-PAE without assessment of facial features. The wording of Criterion A.2 that facial features "may be considered sufficient" is to reflect that inclusion of facial features in

Criterion A is not a requirement for diagnosis if not deemed appropriate, following consultation with individuals and families.

Specifiers: Head circumference and physical size restrictions

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

See the medical assessment section of this document for further good practice statements to support physical size assessment in practice.

Other associated features

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

Reasoning regarding structural brain abnormalities

Based on a review of the best available evidence, PAE can be associated with a range of structural brain abnormalities. However, research documenting these abnormalities is predominately based on advanced quantitative MRI findings. Available data from routine clinical MRI (i.e., qualitative radiological MRI) do not currently provide diagnostic utility. Therefore, at this stage, if abnormal imaging results are available, it is recommended these are recorded as an associated feature. This approach supports documentation and consideration of available results in the assessment but does not include these results as part of the neurodevelopmental domains, based on the available evidence.

Reasoning regarding other neurological conditions

A review of the best available evidence indicated there was insufficient evidence to understand the association between PAE and neurological conditions of hearing and vision impairment, seizures, and cerebral palsy. Therefore, at this stage it is recommended that these neurological conditions be recorded as associated features. Some of the Clinical Advisory Group members also highlighted that the genetic basis of seizures is an emerging area of research. This approach supports recording and consideration of neurological conditions in the assessment process but does not include these conditions as part of the neurodevelopmental domains, based on the available evidence.

At risk of FASD/ND-PAE

Feedback gathered from the Clinical Advisory Groups indicated that the 'at risk' designation had been a helpful option for practitioners to have available. Specifically, it was discussed how this option can support access to early supports and encourage review when children are older to determine if a diagnosis is appropriate. In Australia, access to early intervention does not require a diagnosis, but rather presence of developmental delay. Therefore, an 'at-risk' designation in these cases should not impact access to supports including NDIS. Rather, it would allow for more time and careful consideration of whether a lifelong diagnosis would be appropriate. However, it was noted that consideration of repeat standardised testing should be made by an appropriately qualified practitioner, not a NDIS coordinator who may lack appropriate qualifications to make these clinical decisions.

Notably, concerns were raised by members of the Advisory Groups that the 'at risk' designation can sometimes be inappropriately applied, and this can lead to inequities for individuals and families, for example, across different settings where resources and clinical capacity differ. Practitioners are encouraged to use shared-care approaches to support additional assessment and diagnostic pathways in low resource settings and access professional development and clinical supervision as required.

Summary of GRADE-based recommendations for the diagnostic criteria

GRADE-based recommendation	The Guidelines Development Group suggests that birthweight corrected for gestational age according to the appropriate age- and sex-specific charts is included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Low to Moderate Certainty).
GRADE-based recommendation	The Guidelines Development Group suggests that birth length corrected for gestational age according to the appropriate age- and sex-specific charts is included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).
GRADE-based recommendation	The Guidelines Development Group suggests that postnatal weight according to the appropriate age- and sex-specific charts is included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).
GRADE-based recommendation	The Guidelines Development Group suggests that postnatal height according to the appropriate age- and sex-specific charts is included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).
GRADE-based recommendation	The Guidelines Development Group suggests that philtrum smoothness, vermilion thinness, and palpebral fissure length are

	included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).
GRADE-based recommendation	The Guidelines Development Group recommends against including minor dysmorphic features in the diagnostic criteria for FASD/ND-PAE (Strong Recommendation, Very Low to Low Certainty).
GRADE-based recommendation	The Guidelines Development Group suggests that head circumference corrected for gestational age according to the appropriate age- and sex-specific charts is included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).
GRADE-based recommendation	The Guidelines Development Group recommends against including structural brain abnormalities as observed on clinical imaging in the diagnostic criteria for FASD/ND/PAE (Strong Recommendation, Very Low Certainty).
GRADE-based recommendation	The Guidelines Development Group recommends against including neurological conditions of vision and hearing impairment, seizures, and cerebral palsy in the diagnostic criteria for FASD/ND/PAE (Strong Recommendation, Very Low Certainty).
GRADE-based recommendation	The Guidelines Development Group suggests that neurodevelopmental outcomes of communication, motor skills, general intellectual abilities, attention, memory, executive function, emotional/behavioural regulation, literacy and/numeracy skills and adaptive/social functioning are included in the diagnostic criteria for FASD/ND-PAE (Conditional Recommendation, Very Low to Low Certainty).

Summary of Areas of Major Debate

Whilst the Guidelines Development Group reached consensus on each of these areas, a summary of the areas of major debate is provided for transparency and to inform future revisions of the guidelines.

- **PAE threshold**

There was wide variability in views in the Guidelines Development Group, spanning from not wanting to include a PAE threshold to including a threshold of heavy and very heavy exposure. Given this was an area where evidence was available to inform decision making, the final decision was to align the wording of Criterion A with the available evidence, while being mindful of the limitations of the evidence and the practicalities of taking a body of evidence and applying this in practice at an individual level.

- **Structure of the neurodevelopmental domains**

There was extensive discussion regarding the neurodevelopmental domains. Many members of the group would like to move to a different conceptualisation of the domains that could better consider the complex interplay. There was also discussion regarding whether the adaptive/social domain should be included as a domain, as this is the functional impact of the impairments of the other domains. Ultimately, it was decided that minimising changes was an important consideration due to the lack of current research to inform this decision.

- **Clinical cut-off for neurodevelopmental domains**

Some members of the Guidelines Development Group did not want changes to the recommendation regarding the clinical cut-off for neurodevelopment. This decision was informed by best practice approaches to assessment based on the available literature and expertise of the practitioners in the Guidelines Development Group and feedback from the Clinical Advisory Group.

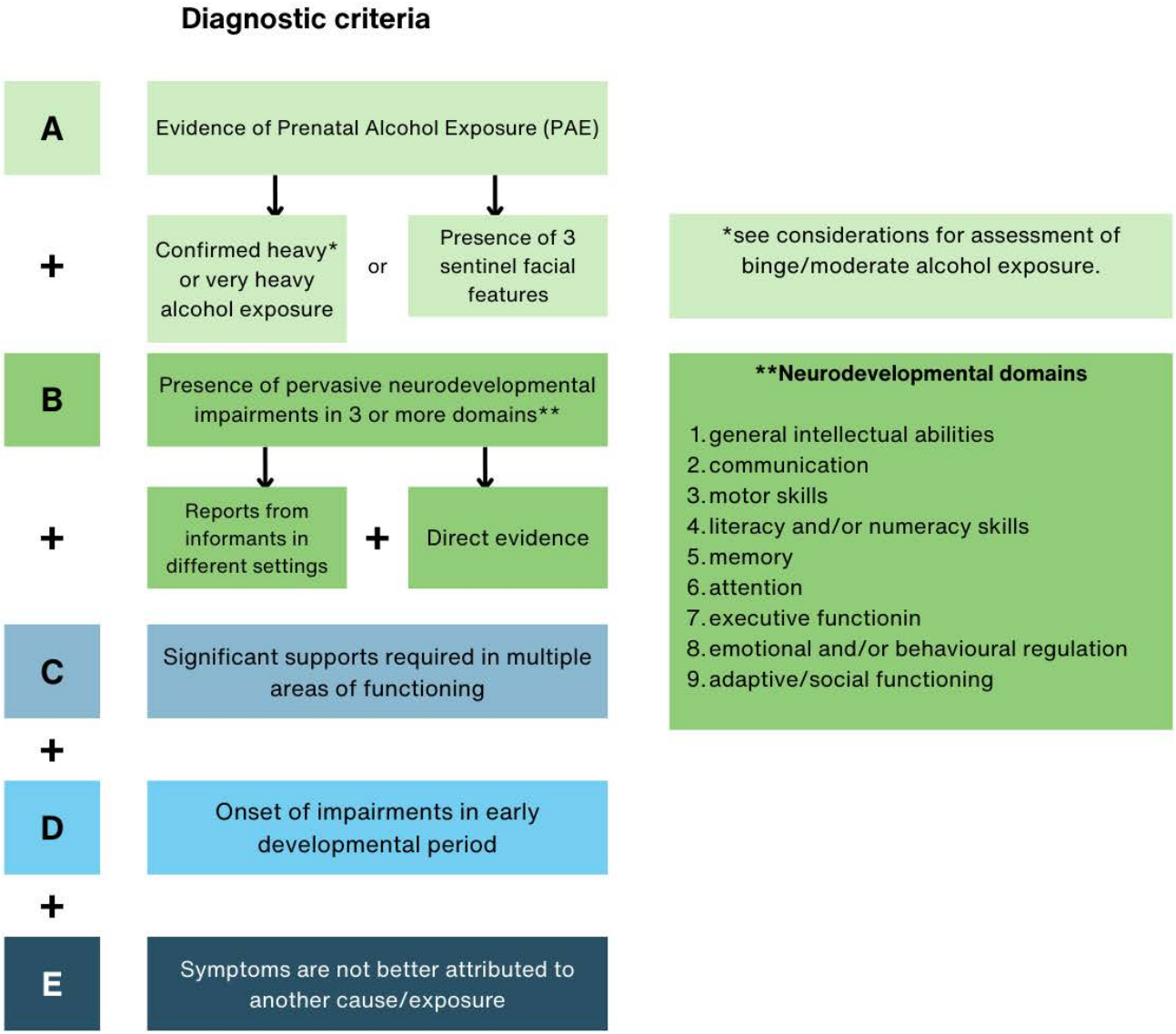
- **Structure of the specifiers**

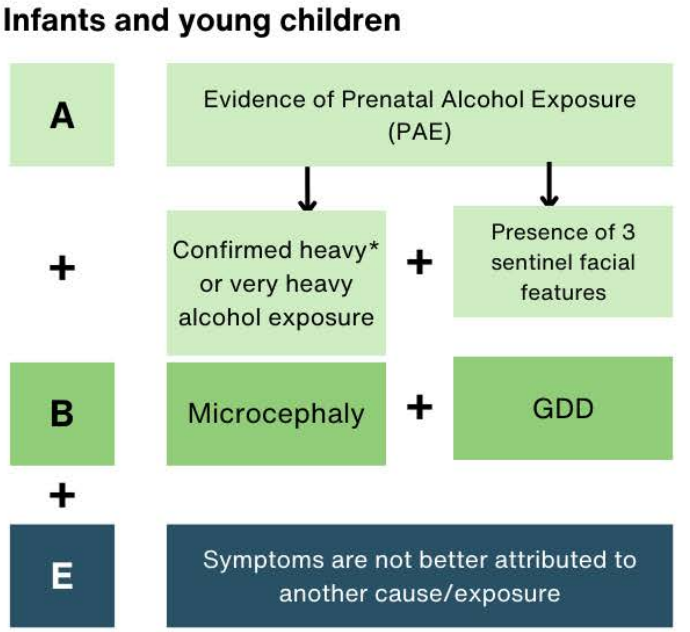
Some members of the Guidelines Development Group viewed the inclusion of the physical features as specifiers as minimising the importance of these features. These concerns were weighed up in the context of the diagnostic structure being able to support more detailed documentation of physical features, enabling more comprehensive understanding of the heterogeneity of FASD/ND-PAE presentations and facilitating future research on the physical features. Additionally, this structure could support simplification of diagnostic nomenclature (i.e., one diagnostic term that can capture all the potential neurodevelopmental and physical features), once there is future consensus on diagnostic terminology.

- **Diagnosis of young children with microcephaly and three sentinel facial features**

There were different views on approaches to diagnosis of young children with microcephaly and three sentinel facial features. Some practitioners would prefer to provide an ‘at risk’ designation and undertake follow-up assessment to make further diagnosis, whilst others were comfortable with making diagnosis based on microcephaly and three sentinel facial features. There was limited evidence available to inform decision making. Concerns regarding possible inequities for families who may not be able to access re-assessment and potential benefits of early diagnosis were taken into consideration in retaining this in the diagnostic criteria. However, wording of ‘may be sufficient’ has been used to provide flexibility for practitioners to use shared decision making with families to inform diagnostic decision making.

Visual overview of the diagnostic criteria





*Ideally PAE evidence is available however, presence of 3 sentinel facial features may be considered sufficient to meet criterion A.

Assessment Process

"My whole life experience has been clarified by the results of this assessment. I now know why I've struggled so deeply. Only once the difficulties were identified, could support be put in place and only with that support could my life change."

ADULT WITH FASD AND ADVISORY GROUP MEMBER

"The assessment process could be considered as a journey. You may provide a parent or caregiver with information about prenatal alcohol exposure, but they are not ready. But one day they are ready, and they come back to see you. Or they may never be ready to take that journey and as health professionals we need to be understanding and accepting of this. At the end of the day, it can be a conftronting process and it needs to be the family's choice."

CLINCIAN AND ADVISORY GROUP MEMBER

Assessment Process

The following lived experience statements were developed from the systematic review and qualitative synthesis of lived experiences of the assessment and diagnostic process (Hayes et al., 2023; Technical Report):

Lived experience statement	Listen to and take seriously concerns raised by parents/caregivers about their child's development and behaviour in the context of prenatal alcohol exposure.
Lived experience statement	Provide or refer for assessment if a parent/caregiver is concerned about their child's development in the context of prenatal alcohol exposure.
Lived experience statement	To reduce barriers experienced by individuals and families, assessment can be provided across a range of settings. This includes, but is not limited to, specialist services, child development services, adolescent and adult private and public health services, primary care, mental health, disability, justice, and child protection services.
Lived experience statement	Provide non-judgemental and non-stigmatising support that acknowledges and respects the individual's and their parent/caregivers' experiences and concerns.

Consistent with evidence from the systematic review of lived experiences of the assessment and diagnostic process (Hayes et al., 2023), the scoping review of resources and models of care (Kent et al., 2023), input gathered from the priority setting survey (Hayes et al., 2022) and Advisory Groups and Guidelines Development Group meetings, an assessment process is presented that could be completed either in one setting where available (i.e., multidisciplinary clinic) or across multiple different settings (Figure 7).

The assessment process aims to encourage all practitioners, no matter the setting or discipline, to contribute where they can. Table 5 provides a brief overview of what and who may be involved in each part of the assessment.

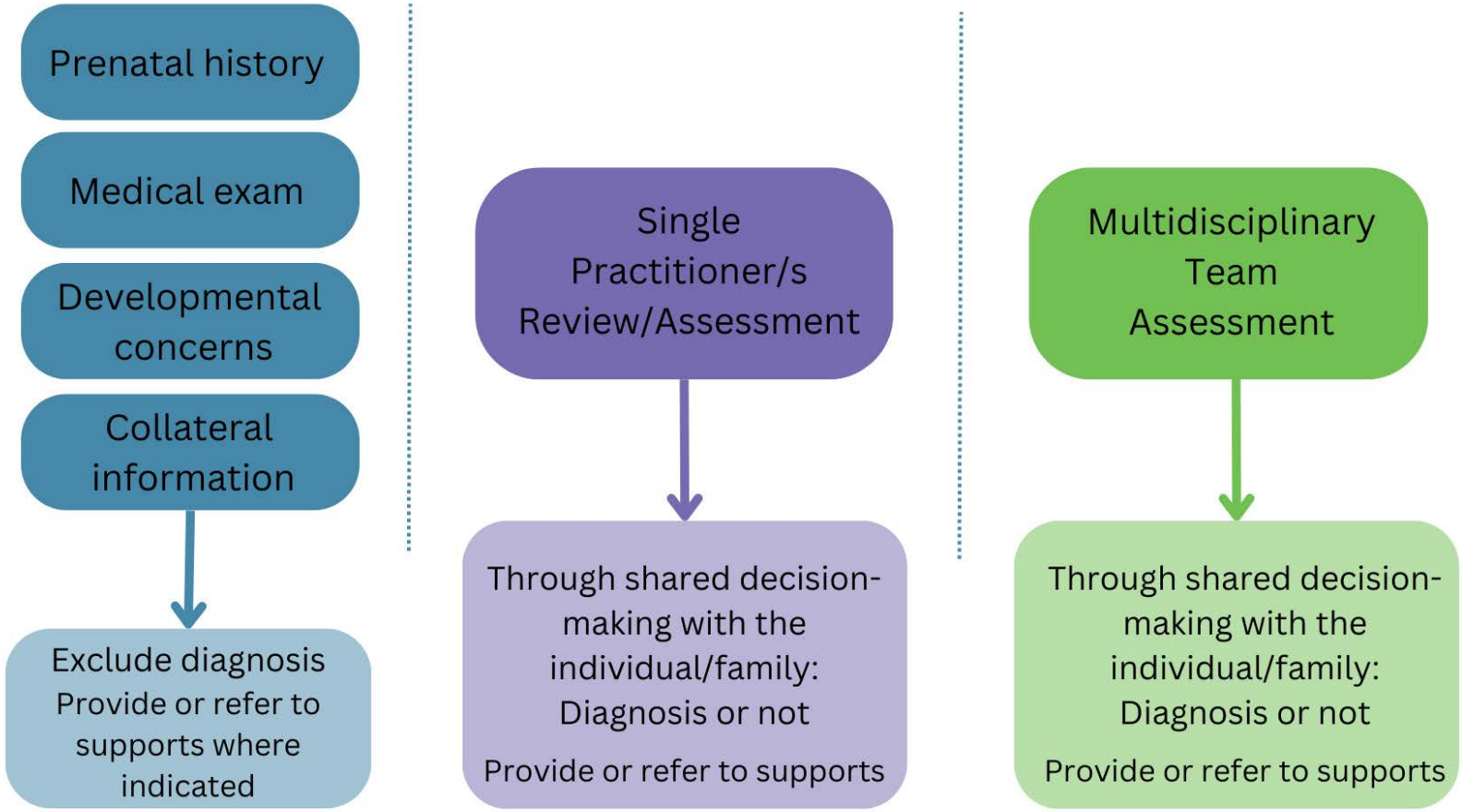


Figure 7. Overview of the assessment

Table 5. Brief details of what and who may be involved in each part of the assessment.

Assessment component	What may be involved	Practitioners who may be involved
Prenatal history	Detailed history taking including all prenatal exposures and events and pregnancy complications and risk factors.	A wide variety of practitioners across a range of different settings (e.g., hospital, primary health care, public and private practitioners) can collect this information including, but not limited to: Midwives, Child Health Nurses, General Practitioners, Aboriginal Health Workers/Practitioners, Medical Specialists, and all Allied Health disciplines. In settings where there are multiple practitioner available, the team be flexible and consider who has an established trusting relationship with the biological parents.
Medical exam	Comprehensive physical examination and detailed medical, family, and social history.	Different parts of this process may be completed across different appointments and settings depending on complexity, client's age, and service availability. Different medical practitioners may complete some or all parts, depending on their scope of practice. Medical practitioners could include General Practitioners, Nurse Practitioners, Aboriginal Health Workers/Practitioners, Paediatricians, Psychiatrists, Neurologists, Geneticists.
Developmental concerns	Can include information collected from parents/caregivers and other key informants, information collected through interviews, direct observations, screening tools and/or direct/indirect assessments.	A wide variety of practitioners across a range of settings (e.g., hospital, primary health care, public and private practitioners, education) collect this information including: Midwives, Child Health Nurses, Aboriginal Health Workers/Practitioners, General Practitioners, Medical Specialists, all Allied Health disciplines. The context and practitioner will inform the approach to collecting information and the types of screening and/or assessment tools that may be used.

		Depending on need and service availability, this may or may not include use of standardised tools. At this stage, available information can be used to indicate if further assessment is required (i.e., if there are no developmental concerns currently, then no further assessment is required).
Collateral information	Collecting a range of information from the individual presenting for assessment, their parents/caregivers, other family, school/work, community, and any other people relevant to understanding a person's functioning, participation, and environment.	All practitioners can support the collection of collateral information.
Single practitioner review/ assessment	A practitioner or practitioners collaborating across settings (e.g., education, health, child protection, justice) can review available information and determine if/what assessments may be required to consider FASD/ND-PAE as one possible diagnostic outcome.	The contributions of individual practitioners to the assessment process are determined by their individual training and level of expertise, alongside their discipline specific scope of practice requirements.
Multidisciplinary team assessment	In some settings multidisciplinary teams are available that can undertake all the assessments in one location.	Composition of multidisciplinary teams vary across different settings. Team members may include social work, educational specialists, psychology, physiotherapy, occupational therapy, speech pathology, cultural consultants and different medical professionals depending on an individual's age and service availability (e.g., paediatrician, nurse practitioner, psychiatrist, neurologist).

Implementation considerations: practitioner training and qualifications	The FASD Hub Australia contains a list of training resources and currently available professional development/training programs in Australia to support practitioners with accessing further education and training.
Implementation considerations: cultural responsiveness	Culturally responsive care is different for every individual and family. Practitioners should not make assumptions about the type of care a person would prefer because they are Aboriginal, Torres Strait Islander or culturally and linguistically diverse. *"There are many Aboriginal families that are comfortable to use western biomedical systems and in fact, work really well and engage best that way. And then we have families that definitely do not, and they need more cultural supports and safety. It's all on a spectrum"* (Aboriginal Health Practitioner). See the Australian Indigenous FASD Framework for detailed suggestions regarding how practitioners can reflect and adjust their practice to provide culturally responsive assessments.
Implementation considerations: Interpreting services	Where appropriate, for individuals and families where English is a second/additional language, it is critical, and a requirement for the national health and safety guidelines that interpreting services are available (https://www.safetyandquality.gov.au/standards/nsqhs-standards). For further supports and information see: https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard/health-literacy/action-208 https://culturaldiversityhealth.org.au/wp-content/uploads/2018/02/Outcomes-document-NSQHS-Standards-2-ed..pdf https://www.niaa.gov.au/sites/default/files/publications/pili-fact-sheet-1.pdf
Implementation considerations: Medicare Benefits Scheme (MBS) Items	Assessment for FASD/ND-PAE can be undertaken using the MBS items for complex neurodevelopmental disorders, introduced 1 March 2023. For more details see https://www.servicesaustralia.gov.au/medicare-items-for-complex-neurodevelopmental-disorders-and-eligible-disabilities

Informed Consent and Assent in the Assessment Process

Inclusion of this section was based on information gathered from the members of the Advisory Groups (e.g., Hayes et al., 2022) who had witnessed situations where referrals had been made for assessments or assessments had been commenced without appropriate informed consent.

> *"Ensuring informed consent is properly obtained is a legal, ethical and professional requirement on the part of all treating health professionals and supports person-centred care"* ~Australian Commission on Safety and Quality in Health Care.

Informed consent is a person's decision, given voluntarily, to agree to a healthcare service that is provided: Following the provision of accurate and relevant information and with adequate knowledge and understanding of the benefits and risks of the proposed service. https://www.safetyandquality.gov.au/our-work/partnering-consumers/informed-consent

Informed assent provides individuals without competence (e.g., children and individuals deemed to not have cognitive abilities to provide informed consent) *'developmentally appropriate involvement in decision making'* (Joffe, 2003). This involves providing information so that individuals will know what will happen and letting them have a say and be listened to regarding their preferences (Spriggs, 2023).

The following good practice statements (GPS) have been prepared using available research and feedback from Advisory Groups:

GPS	If there is information suggesting heavy or very heavy (or potentially a moderate) level of PAE, including before pregnancy recognition, discuss assessment options and after obtaining informed consent provide assessment or support access to further assessment.
GPS	If there is information documenting clinically significant neurodevelopmental impairments and/or distinctive facial features and confirmed or suspected PAE, discuss assessment options and after obtaining informed consent, provide assessment or support access to further assessment.

Implementation considerations: FASD Indigenous Framework and Informed Consent	In line with the FASD Indigenous Framework, the informed consent and assent process must provide information in a way that can be meaningfully understood. It is also critical that the person and/or family feels comfortable and safe during this process. This requires respectful communication that is two-way and avoids using medical jargon. Two-way communication involves listening with genuine respect and interest to what another person shares, verbally and nonverbally, to increase understanding and share meaningfully.

	Two-way communication is an exchange where participants' knowledges are equally valued. To support a culturally comfortable and safe environment practitioners can incorporate information (including in other languages and with interpreter support where needed) and visual resources to explain: • what the referral/assessment is for • what the assessment process generally involves • what the potential outcomes and follow-up from the assessment can involve • the potential benefits and risks. The informed consent process should be inclusive of appropriate family/support people (i.e., recognising everyone's unique kinship and familial system), with the goal of ensuring that all people have genuine control over decisions about their healthcare. This can only be achieved if the person and their family have been supported to make a truly informed choice about whether an assessment is something they want.
Implementation considerations: Informed consent and assent in different clinical situations	Different approaches to informed consent and assent may be required depending on assessment situations. For example, where the referral question is about the possibility of FASD/ND-PAE informed consent and assent specific to FASD/ND-PAE can be completed from the outset. Whereas circumstances where information about PAE emerges later in the assessment process (i.e., is not the basis of the referral) would benefit from including an additional informed consent and assent process.

Integration of Shared Decision-Making into the Assessment Process

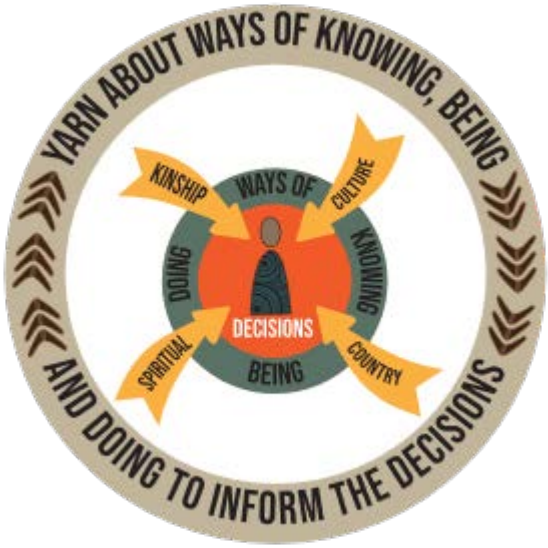
It is recommended that the diagnostic criteria be implemented in the context of a dynamic and interactional, social-contextual, shared decision-making approach. Using this approach, clinical reasoning, and collaboration with the individual and/or family is used to consider the probability of risk, an individual's strengths, impairments and functional capacities, and the individual/family's perspective regarding disability and diagnosis. This allows determination of if/when diagnosis is applicable/appropriate for each individual presenting for assessment.

The application of the Finding Your Way Shared decision-making framework (Agency for Clinical Innovation) has the potential to benefit all Australians. The Finding Your Way model supports a process through which relationships are central and everyone is connected and involved in the process. Application of this model may need to be adapted to suit the needs of practitioners in different settings (e.g., justice context). Each of the steps of the model are provided with examples of how this could be applied in the FASD/ND-PAE context.

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 your truths and stories here to build connection and a safe space that invites the Aboriginal person and family to share their truths. When a family feels comfortable to share their truths, it is important to recognise the knowledge, expertise and lived experience of FASD/ND-PAE, 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 everyone. 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?
- What does culture mean to you?
- Do you participate in or have access to cultural activities like language, art, singing, dancing, storytelling, ceremonies, hunting? Would you like to?
- Are you connected to community in sport or employment?
- What do you know/believe about FASD/ND-PAE and what feelings does this bring up?
- What do you know/believe about the assessment tools 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 (e.g., neurodevelopmental, and physical assessments) and processes 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 check in and incorporate 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** (Garvey et al., 2021). For example, the available literature emphasised the importance of ensuring Aboriginal peoples with FASD felt their wellbeing was strengthened in particularly when their **basic needs** of feeling supported, accepted loved unconditionally, secure with a safe place (Kully-Martens et al., 2022) was met.

Having an understanding about the individual and family's social and emotional 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 social,

emotional and wellbeing you may begin by identifying the current needs and supports by (Reid et al., 2022):

- 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 these supports as needed.
- Collaboratively brokering, referring, and engaging with culturally responsive supports 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 it allows you to have an informed discussion about the different assessment, diagnostic and support options including providing information about the benefits and risks of the different options. Different options to yarn about could include, but are not limited to:

- The way the assessment process is structured e.g., block scheduling assessment days could get the assessment completed faster, could be more convenient for families having to travel to appointments versus scheduling shorter assessment appointments across more days may take longer to get the assessment process completed but may be more manageable for individuals/families.
- The use of Western allied health assessment tools could help people get access to western health and education systems, but the risk is that these tools may not be a true reflection of an Aboriginal person's abilities.
- The use of U.S tools for assessment of facial features. There are currently no Australian tools for the assessment of facial features. You can decide if you want these tools to be included or if you would prefer this is not part of your/your child's assessment.
- Having a diagnosis of FASD/ND-PAE could have benefits in helping an individual and family understand about why a person is having the challenges in their life that they are experiencing, but there could also be harms experienced. For example, a risk

could be the shame that the family feels and how they are perceived in their community.

- Accessing NDIS could provide a way for individuals/families to get support, but a risk could be the stress or overwhelm that they may experience in the application and review processes.

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, et al., 2020). Further, research has shown that children with FASD have increased understanding and are able to better demonstrate their abilities when visuals and visualisation (i.e., the use of meaningfully connected information such as stories or metaphors) are employed during an assessment (Hamilton, Reibel, et al., 2020).

WEIGH UP THE ODDS

Yarning about the possible benefits and risks. Compare options and weigh up the odds for the individual and for family and community.

Depending on the information collected during the yarning about knowing, being and doing will help the practitioner and family to weigh up the benefits and risks here that are informed by the family's values. Things that families may need help to weight up:

- Do I want/need a referral for assessment?
- How could an assessment be helpful/harmful for me/my child?
- Should I let the health professionals assess me/my child using western and/or international tools?
- Would a diagnosis of FASD/ND-PAE 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.

Providing the individual and family with time to yarn about their decision/s and providing validation and support for what they decide to do. Although practitioners might have thoughts about what is the best decision, ultimately it is important to respect the individual/family's decision as this is what is right for them now.

NEXT STEPS

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 end of the assessment process providing the opportunity for the individual/family to yarn and collaboratively plan what the next steps are.

Prenatal Alcohol Exposure Assessment

"When it comes to FASD, the best defence is a really strong offence. Women need to be aware of the possibility of FASD as early as possible in order to prepare and avoid incorrect or missed diagnosis."

BIOLOGICAL MOTHER AND ADVISORY GROUP MEMBER

"Imagine waking up everyday to the challenges of FASD, but no one knows you're experiencing them. Not only does no one know, but YOU don't know. Informed health professionals accurately assessing for prenatal alcohol exposure will change lives."

ADULT WITH FASD AND ADVISORY GROUP MEMBER

Prenatal Alcohol Exposure (PAE) Assessment

The following good practice statements (GPS) have been prepared to support collection of PAE information, informed by available evidence and input from the Advisory Groups.

GPS	Sensitively and respectfully include discussions about alcohol use and potential risks as part of routine antenatal and postnatal care.
GPS	Ask about alcohol use as part of routine pregnancy history taking, alongside other prenatal exposures and events (e.g., medications, tobacco, illicit drugs, infections, diet, exercise, stress, and pregnancy complications).
GPS	To support accurate assessment of risk, assess PAE both before and after pregnancy recognition. Standardised screening tools, such as the AUDIT-C can be used to assess alcohol intake.
GPS	Explain what a standard drink of alcohol is (i.e., 10g of ethanol) before using the AUDIT-C, consider using resources such as the NHMRC Alcohol Guidelines for clarity. Practitioners can also gather the information and convert into standard drinks for the individual.
GPS	Be mindful there are many factors that may have influenced alcohol use during pregnancy and collect information in a supportive, compassionate, and non-judgemental way.
GPS	Recognise that individuals might face ongoing challenges with alcohol or other complex issues and provide appropriate support and referrals.
GPS	Contact biological parents directly, if possible and appropriate to assess PAE. Otherwise, carefully review other sources of information (e.g., reliable observer reports, medical or legal records). **Note that a history of alcohol use without evidence of consumption during the index pregnancy is not sufficient to confirm exposure.**
GPS	Consider that self-reports of PAE may be influenced by a range of factors. For example, the context in which information was collected (e.g., child protection settings) and the timing (e.g., during pregnancy and reported in antenatal records or later in the child's life). Practitioners may want to contact biological parents to check previously collected information.
GPS	Sometimes there may be inconsistencies about PAE in available information. In instances when information was collected directly from the pregnant woman/person during an assessment, this information should be prioritised over other sources. Practitioners can document any inconsistencies and indicate that re-assessment could be considered should additional information arise.

Implementation considerations: transfer of information from the pregnancy record to the child's record	To support early identification of prenatal factors that can influence developmental outcomes, information that could affect longer term health outcomes for children can be transferred from the pregnancy record to the child's health record. This information should be kept to the minimum required to support the wellbeing of the child and no personal or identifying information of the parents should be included. The Advisory Groups reported that transfer of information from the pregnancy record was occurring systematically in Western Australia, through the Midwives Notification System (Mutch et al., 2015) https://ww2.health.wa.gov.au/Articles/J_M/Midwives-Notification-System and Victoria where information from the Birthing Outcomes system was reportedly automatically copied from the maternal discharge to the newborn discharge. During the guidelines development process, a procedure was established in Queensland to support the automatic transfer of a minimum amount of prenatal information through the integrated electronic medical record.
Implementation considerations: bias in the assessment process	PAE can adversely impact people across all groups in our society. Members of the Advisory Groups noted that it is important for people to be aware that PAE is *"everyone's business and everyone's responsibility."* Practitioners need to be mindful of bias in the referral and assessment process and be careful to not make assumptions about the likelihood of PAE or FASD/ND-PAE based on an individual's demographic features. Members of the Lived Experience Advisory Group described experiences where they were not asked about PAE due to practitioners assuming they *"knew not to drink"* based on their sociodemographic features. Members of the Clinical Advisory Group reported concerns regarding inappropriate referrals for assessments that were based on an individual's sociodemographic background, rather than accurate information being collected about PAE.
Implementation considerations: AUDIT-C pre- and post-pregnancy recognition	An associated practitioner resource in Appendix E provides an overview of the Alcohol Use Disorders Identification Test-Consumption (AUDIT-C) tool structured to collect information pre- and post-pregnancy recognition.

Implementation considerations: electronic referral systems	Some states/territories have, or are establishing, electronic referral systems (e.g., between primary and tertiary health services). These systems are designed to provide practitioners with up-to-date evidence-based assessment, management, and referral information in an easy to access web format. Where these electronic referral systems are available there is sometimes information included regarding FASD/ND-PAE (as reported by the Advisory Groups). Where available, we suggest that information about FASD/ND-PAE and descriptions of the local pathways can be uploaded to HealthPathways or other available electronic referral systems to support provision of up-to-date information to primary health care professionals and facilitate streamlined assessment processes.
Implementation considerations: child protection settings	Challenges with gathering prenatal history for children in out-of-home care was discussed as a major barrier to assessment across Advisory Groups. To support collection of accurate PAE information the following implementation considerations are provided: • Information about PAE should be documented alongside other relevant prenatal factors (e.g., other drug exposures, domestic violence, family medical history). • As part of training and practice resources for child protection staff, include information on the accurate collection and documentation of PAE and local referral pathways. • PAE is not a reason for a child to be placed into out-of-home care. There can be many reasons why PAE occurs, including exposure that occurred before a woman/person knew they were pregnant, pre-existing alcohol use disorder or drinking to cope with domestic violence or other traumatic circumstances. Pregnant women/people need to feel safe to discuss concerns and seek help for themselves and their children without the fear of their children being removed. • Information about plans for assessment, diagnostic outcomes, and recommendations should be incorporated into a child's health management plan and this information be provided to foster and kinship carers. • Information and an example template developed by the Gold Coast Child Development Service is provided to support accurate collection of prenatal and postnatal history.
Implementation considerations: justice settings	Challenges with collecting prenatal history were also noted in the Advisory Groups for individuals involved with the justice system, including collecting this information through court-ordered assessments within restricted timeframes. Notably, the United Nations Convention on the Rights of the Child (UNCRC) General Comment No. 24 states: *"Children with developmental delays or neurodevelopmental disorders or*

disabilities (for example, autism spectrum disorder, fetal alcohol spectrum disorders, or acquired brain injuries) should not be in the child justice system at all, even if they have reached the minimum age of criminal responsibility. If not automatically excluded, such children should be individually assessed." Whilst the UNCRC comment concerns children, this should also be considered in the adult justice context.

To support collection of accurate PAE information and supports the following implementation considerations are provided:

- Where appropriate, collect and document information about PAE alongside other relevant prenatal (e.g., other illicit substance exposure, domestic violence, family medical history) and postnatal factors and use this to inform referrals to local assessment providers.
- Provide information about accurate collection and documentation of PAE and local referral pathways to all professionals in legal and justice contexts as part of staff training and practice manuals.
- Where consent/assent is provided, information about plans for assessment, assessment/diagnostic outcomes and support planning should be documented on an individual's police and justice records to help inform approaches to support.
- Consider non-custodial therapeutic diversionary options where possible, including appropriate place-based culturally responsive programs for individuals identified with impairments and neurodevelopmental conditions, including FASD/ND-PAE.

It is also important to acknowledge that irrespective of age, and disability type, people with disabilities are proportionally over-represented in the criminal justice system as offenders and victims, and often reach this status and experience greater negative consequences due to inherent structural biases within those systems and the underpinning frameworks (Baidawi et al., 2022).

Medical Assessment

"Without an informed doctor to go to, I internalised all the difficulties - all the mistakes and humiliation, there's nowhere for those feelings to go. Assessment is so important for individuals to gain understanding as to why these difficulties are happening, and most importantly, what the difficulties are! Without that, navigating life becomes impossible."

ADULT WITH FASD AND ADVISORY GROUP MEMBER

Medical Assessment

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

The following good practice statements (GPS) were developed based on the available literature and with input from the Advisory Groups to support assessment of facial and other dysmorphic features and physical health conditions:

GPS	Practitioners should consider the appropriateness of all parts of the medical assessment for the individual and their family and ideally collaborate with individuals and families to make decisions about what the assessment will involve.
GPS	When assessing facial features, use the University of Washington (UW) Lip-Philtrum Guide. Guide 1 Caucasian is recommended for less full lips and Guide 2 African American for fuller lips.
GPS	When assessing facial features, use the Strömland et al. (1999) palpebral fissure norms. These norms are the best available for all Australians, covering birth to adulthood.
GPS	Use the University of Washington facial analysis software to measure palpebral fissure length and/or take measurements by hand using a small, clear plastic ruler if you are not able to use the facial analysis software.
GPS	Examine and document any other dysmorphic features of the face and the body and record any major birth defects of the central nervous, cardiac, renal, neurological, visual, auditory, and skeletal systems.
GPS	Consider other syndromes or genetic conditions in which dysmorphic features can also be present. If unsure, refer to a clinical geneticist for review.
GPS	With informed consent and assent, as clinically appropriate and in line with local health service guidelines, requests for a chromosome microarray (CMA) and DNA test for fragile X syndrome (FXS) may be made. These tests can be done using blood or buccal swabs. Refer to your local genetic health services for guidance if abnormalities are reported.
GPS	Medical professionals can request additional tests as clinically indicated to understand current functioning and exclude other potential impacts on functioning, such as thyroid tests, vitamin B12, iron studies and imaging.

Implementation considerations: accessing the UW lip/philtrum guide	More information about the University of Washington Lip-Philtrum Guides is available from the FAS DPN website, including instructions regarding how to order electronic versions: https://depts.washington.edu/fasdpn/htmls/lip-philtrum-guides.htm
Implementation considerations: accessing the UW facial analysis software	More information about the University of Washington Lip-Philtrum Guides is available from the FAS DPN website, including instructions regarding how to order a copy of the software, how to take and analyse the photos. https://depts.washington.edu/fasdpn/htmls/face-software.htm

The following good practice statements (GPS) were developed from the available literature with input from the Advisory Groups to support assessment of physical size, including head circumference:

GPS	Physical size can vary due to a wide range of demographic, maternal, placental, and fetal factors. Identifying what is atypical physical size should be based on a combination of medical assessment and consideration of individual risk factors, rather than relying exclusively on growth charts.
GPS	Assess birth weight, length and head circumference of full-term infants using the WHO (2006) growth standards. Information may be available in the birth record or baby's personal health records (e.g., red, blue, or yellow books).
GPS	Assess birth weight, length, and head circumference corrected for gestational age of preterm infants using the Fenton growth charts. This can be collected from the birth record or baby's personal health records (e.g., red, blue, or yellow books). Gestational age correction is completed until the baby is 24 months of age.
GPS	For children up to 2 years of age, assess postnatal weight, height and head circumference using the WHO (2006) growth standards. For children over 2 years of age, follow local health service guidelines, as there is some variation across states and territories. For example, most jurisdictions use CDC growth charts. The Northern Territory adopted the WHO (2006) growth standards for all children.
GPS	When available, review an individual's overall trajectory of weight-for-age, length/height-for-age and weight-for-length/height, or BMI-for-age (over 2 years) to understand how they are tracking.
GPS	Consider other causes for individuals outside of height, weight and/or head circumference norms, and investigate appropriately.

Holistic Developmental, Functional and Wellbeing Assessment

"Without correct assessment, the disability that you live with becomes the person that you are...I am not the difficulties that FASD creates. I just have to live with them, and that distinction is important for successful outcomes."

ADULT WITH FASD AND ADVISORY GROUP MEMBER

"Assessment is not a one size fits all approach. It is about understanding an individual's unique profile of strengths and challenges in the context of their environment, and this is not understood through a diagnosis of FASD alone."

CLINICIAN AND ADVISORY GROUP MEMBER

Holistic Developmental, Functional, and Wellbeing Assessment

It is suggested that the neurodevelopmental and medical assessment sit within a holistic value-based health care approach, by adopting a person-centred assessment process. This facilitates an assessment that extends beyond a focus on impairment and diagnosis to include a wide range of meaningful areas for individuals, such as functional, participatory, wellbeing, cultural, and environmental factors.

The following good practice statements (GPS) have been prepared to support assessment, informed by available evidence and input from the Advisory Groups.

GPS Take a holistic needs-based and family-centred approach to the assessment. This can involve considering strengths and challenges, functioning, environment, culture and supports. Gather this information in ways that work best for the individual and their family/support network.

GPS In taking a holistic approach, consider all the factors that individuals and families may be experiencing, and the potential influence on functioning, wellbeing, and participation. Figure 8 below provides a visual representation of the results of the scoping review about the factors individuals with FASD/ND-PAE may be experiencing to help inform holistic approaches to assessment (see the Technical Report for further details).

GPS Collaborative goal setting and talking/yarning with individuals and their support network can help practitioners take a holistic approach to assessment. This allows for gathering personalised information about child and family strengths, interests, available resources, and future hopes and plans for both the individual and family.

GPS Each person attending for assessment should have a plan tailored to their specific developmental needs. This plan should consider current concerns, developmental age, history, past assessments, and other source documents (e.g., available medical and school records), ability to engage in an assessment, assessment adaptations and adjuncts including interpreters and any other relevant cultural and social factors. Assessment should include hearing and vision tests if these have not been done before.

GPS Depending on a person's presentation, it might be best to plan and recommend assessment across different timepoints to see if their challenges are persistent. These assessments can happen in various places, including primary health care, schools, and private practitioners, not just at specialist services.

GPS While it can be helpful to do a comprehensive assessment to understand developmental challenges, sometimes it may not be possible or appropriate. Practitioners should decide the neurodevelopmental domains to prioritise based on need and how much assessment is necessary to determine whether there are clinically significant impairments and if they meet criteria for diagnosis.

GPS It is important to understand the overlap of neurodevelopmental domains and influence of environmental factors. Interpreting assessment results requires looking

	at the whole picture or taking a gestalt approach, including considering how valid measures are for different groups of people and the range of prenatal and postnatal factors that can influence outcomes.
GPS	It is useful to gather information from various sources and methods, such as naturalistic observation, assessing function, direct testing, and getting input from different observers (e.g., self-report, parents or other family members, teachers, work colleagues, support workers, treating professionals). This is important to overcome limitations of any single method.
GPS	It is advantageous to assess neurodevelopmental domains concurrently. However, at practitioners' discretion, previous assessments may be used (e.g., in situations where impairment levels are unlikely to have changed, where there have been multiple previous assessments or current assessment is unable to be completed due to current significant behavioural challenges). The decision to retest an individual will depend on the context, referral question and the individual's needs.
GPS	Assessment will naturally vary based on availability of resources. Where multi-disciplinary are not available or cannot be accessed, engagement with other services through a shared-care approach is suggested to support accessibility of assessment and diagnostic services.

Implementation considerations: clinical interview guide	Appendix D provides an example history taking template that includes prenatal, developmental, behavioural, functional, wellbeing and participation questions that could be adapted to suit your clinical context.

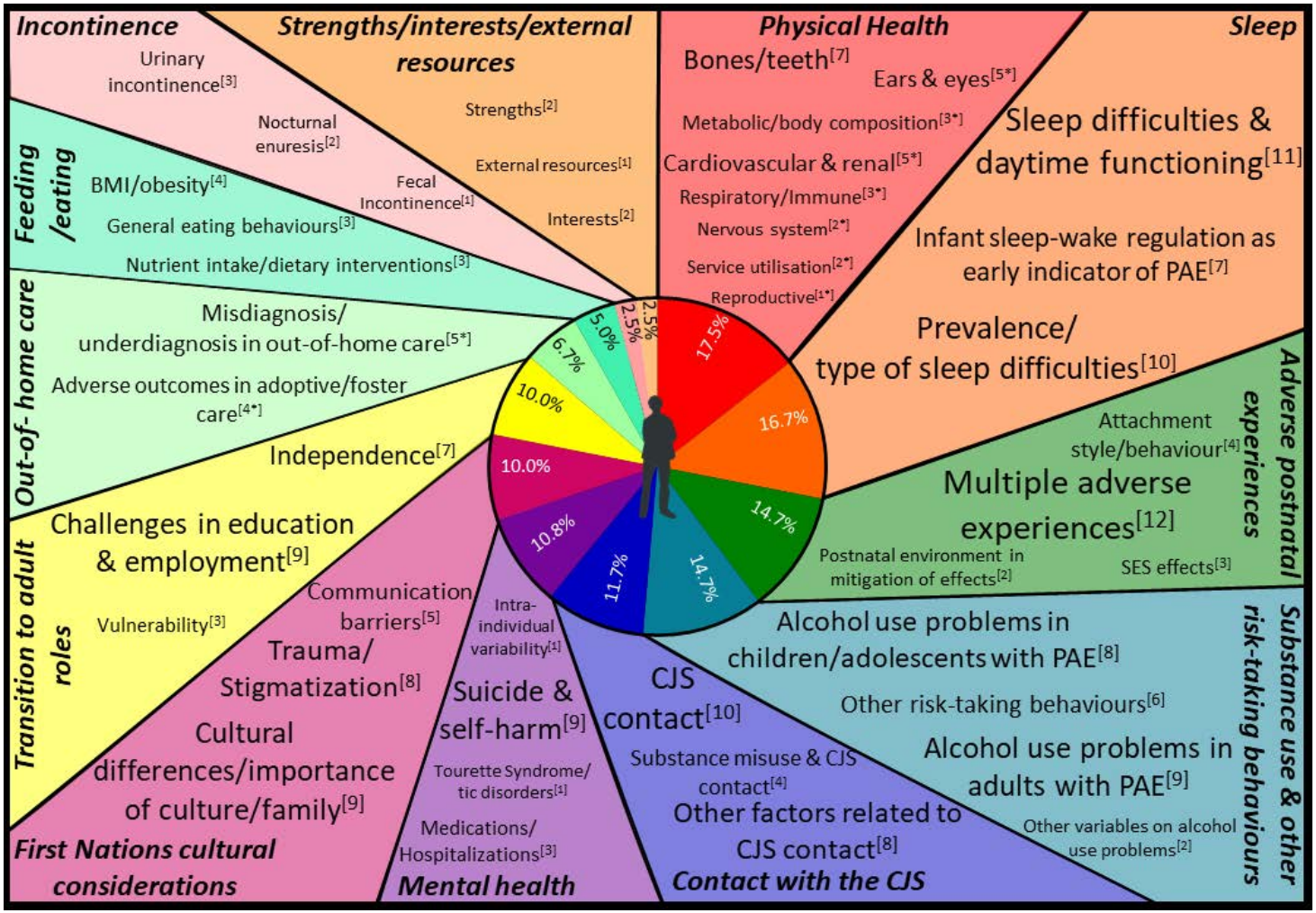


Figure 8. Overview of scoping review findings regarding the range of factors practitioners could consider outside of the diagnostic criteria to support holistic assessment.

Note. The percentage included in the middle circle represents the number of studies identified that included that area. Size of the text and numbers in square brackets represent the number of studies identified that included those themes. For more information on these review findings please see the Technical Report and associated peer reviewed publication (Reid et al., 2023).

Holistic Profile, Formulation and Strengths-Based Pathways

"FASD is lifelong, but it doesn't need to be a life sentence. These kiddos have deficits, but they also have superpowers. Everything we do with our kids needs to be strengths-based."

BIOLOGICAL MOTHER AND ADVISORY GROUP MEMBER

"Your knowledge, understanding and ability to break down the 'why' when someone in your clinic presents with complex challenges and accomodate their needs effectively is integral for successful outcomes."

ADULT WITH FASD AND ADVISORY GROUP MEMBER

Holistic Profile and Diagnostic Formulation

Developing a holistic profile is an opportunity to bring all the assessment information together, in a strengths-based way to increase understanding of the individual attending for assessment and their family/support system. This approach also serves to generate hope and facilitate a collaborative process with individuals and their family/support system.

The diagnostic formulation process allows practitioners to bring together all the assessment findings and discuss and consider how all the exposures and events that an individual may have experienced have potentially impacted on their outcomes. Based on the available information, the most appropriate diagnostic outcomes can be considered.

The following good practice statements (GPS) were developed to support the holistic profile and diagnostic formulation process:

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

Implementation considerations: holistic diagnostic formulation resource	Appendix D provides a holistic profile and diagnostic formulation template that can be adapted to suit different clinical contexts.

Co-occurring and differential diagnosis

FASD/ND-PAE can co-occur with a wide range of neurodevelopmental and mental health conditions, and different aetiologies can combine to lead to complex presentations and multiple diagnostic outcomes (e.g., someone who presents with strong family history of ASD, ADHD, or ID in combination with heavy PAE). There can also be a range of co-occurring mental health challenges (e.g., anxiety, depression, suicidal ideation), that may be related to the impacts of PAE, associated with living with FASD/ND-PAE, and/or due to other etiological factors. A systematic review undertaken by Popova et al. (2016) identified there were 428 co-occurring conditions for individuals with FASD, which spanned 18 of the 22 chapters of the ICD-10. Consequently, co-occurring conditions are common and represent an area of complexity within the FASD/ND-PAE diagnostic process.

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

There also may be situations where a differential diagnostic approach is more appropriate in the context of other neurodevelopmental or mental health conditions (e.g., strong family history of ASD, ADHD, or ID and low PAE or insufficient information regarding the PAE history to determine if it was a relevant risk factor). There can also be a range of environmental or biological factors that can co-occur or be differential considerations, depending on the level of risk of these factors (e.g., prenatal medications or other drug exposures, extreme environmental neglect, prematurity). Practitioners are tasked with weighing up the probability of all the relevant risk factors in determining what the best explanation/s are for an individual's presentation.

Additionally, genetic syndromes that share some of the clinical features of FASD/ND-PAE exist should be considered as differentials in the diagnostic process. Chromosome microarray results showing variants of uncertain or unknown clinical significance can co-occur with FASD/ND-PAE. Consequently, a wide range of conditions and risk factors could either be co-occurring or be differential considerations, and this needs to be determined through an individual case formulation. Understanding an individual's unique profile of clinical features, including all the relevant co-occurring conditions enables treatments and supports to best target an individual's needs. Figure 9 provides a visual summary of the factors that could influence neurodevelopmental outcomes that practitioners may consider as potentially co-occurring or differential depending on an individual's presentation.

Trauma and prenatal alcohol exposure (PAE)

Given the high prevalence of co-occurring adverse childhood experiences (ACEs) and PAE this area warrants further discussion. In a research context some studies have highlighted some of the potential differential and compounding impacts of adverse life exposures and events and PAE. An overview of these studies is provided in Figure 10.

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

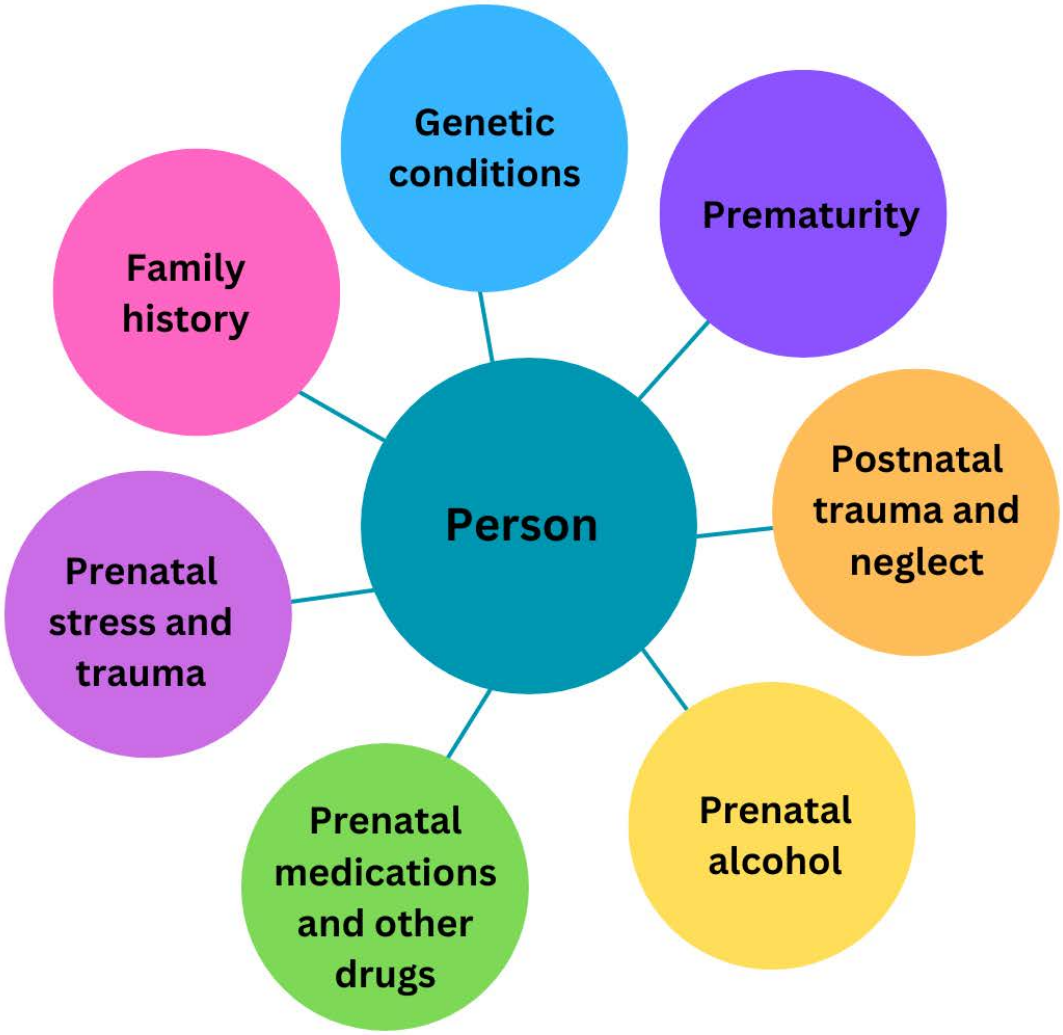


Figure 9. Overview of potentially co-occurring or differential factors/conditions

Adapted from Mukherjee (2021).

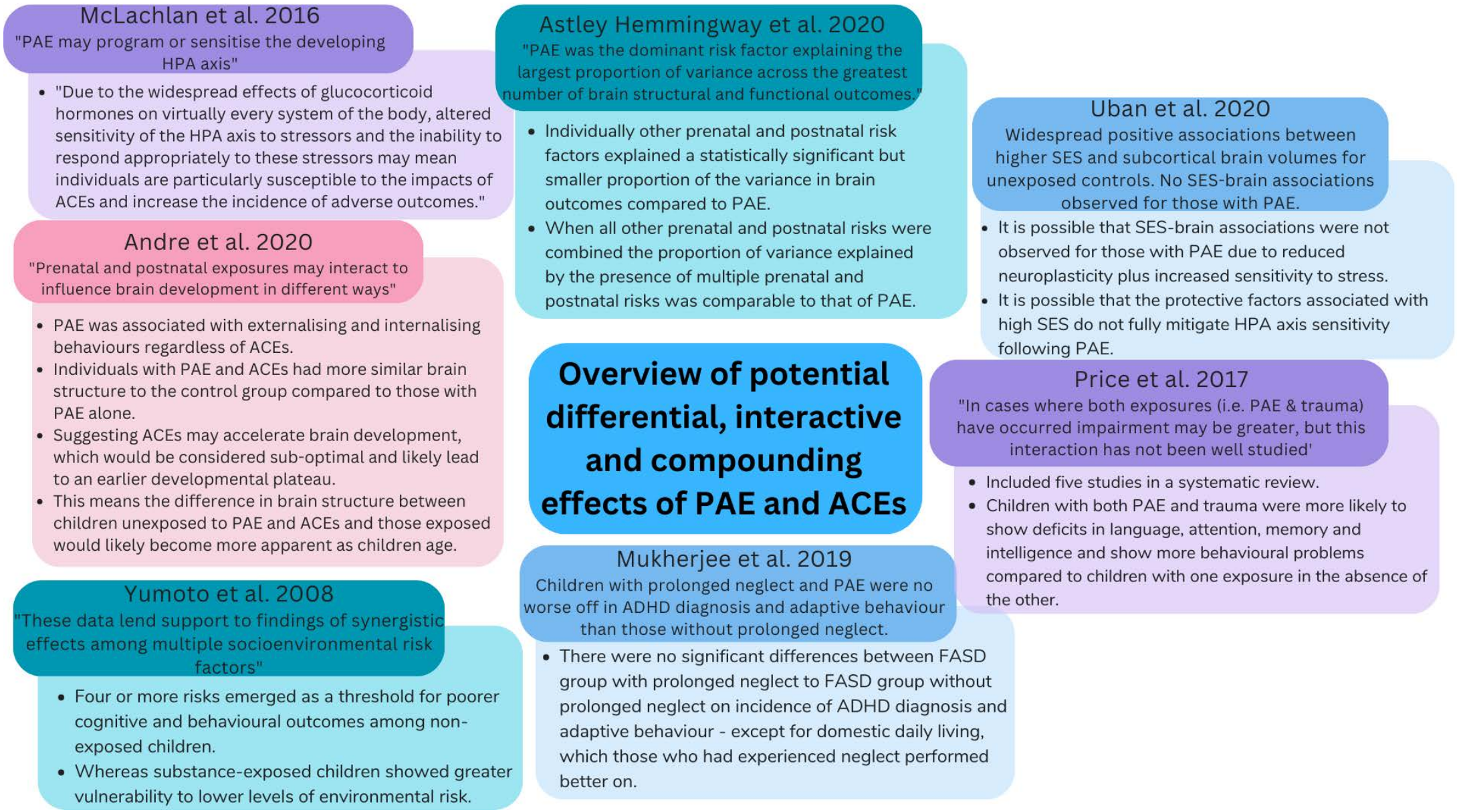


Figure 10. Overview of studies comparing outcomes following prenatal alcohol exposure (PAE) and adverse childhood experiences (ACEs).
Note. SES = socioeconomic status; HPA = hypothalamic-pituitary-adrenal axis; ADHD = attention deficit hyperactivity disorder; FASD = fetal alcohol spectrum disorder.
(Andre et al., 2020; Astley Hemingway et al., 2020; McLachlan et al., 2016; Mukherjee et al., 2019; Price et al., 2017; Uban et al., 2020; Yumoto et al., 2008)

Feedback and Strengths-Based Pathways

The following lived experience statements were developed from the systematic review and qualitative synthesis of lived experiences of the assessment and diagnostic process (Hayes et al., 2023):

Lived experience statement	Understand that receiving a diagnosis can bring mixed emotions. Plan feedback and recommendations with this in mind.
Lived experience statement	Assessment results help understand behaviour. When communicating outcomes, provide specific information and examples clearly linking assessment results to observed or reported challenges in daily functioning to support understanding and insight.
Lived experience statement	Recognise both an individual's strengths and challenges to identify the most appropriate supports to enable positive outcomes post-assessment.
Lived experience statement	Be mindful that parents/caregivers and family members can have concerns regarding their child's future following diagnosis. Provide recommendations for specific local services that can provide emotional supports.
Lived experience statement	Tailor feedback sessions and reports to individual and family needs, including relevant social and cultural factors.
Lived experience statement	When writing reports, emphasise the individual's strengths and interests, while also addressing areas needing support.
Lived experience statement	When writing reports, prioritise recommendations that are important for the individual/family, and limit recommendations to those that are practical and achievable in their household and community.

The following good practice statements (GPS) were developed to guide the feedback and recommendations process:

GPS	Involve individuals and families in diagnostic decisions. Individuals and family have the right to decide if diagnoses are appropriate for them, given their personal, social, and cultural context and beliefs. Sometimes, challenges can arise balancing the rights of the child and the rights of the parent/caregiver, but actively engaging and supporting all parties throughout the assessment can help to overcome these challenges.
GPS	With consent, provide developmentally appropriate feedback to individuals attending for assessment, in coordination with parents/caregivers or other support people and tailored to their needs.
GPS	Recognise that observed challenges might have multiple explanations and communicate this to individuals and families to enable effective supports.
GPS	Include individuals and families in the development of report recommendations, respecting their preferences and needs, given their personal, social, and cultural context.

Implementation considerations: Collaborative goal setting	Appendix E provides information regarding resources and tools to support collaborative goal setting, which can be used to inform a personalised approach to developing targeted recommendations.

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Appendices

Appendix A: Glossary of technical terms, acronyms, and abbreviations

Term, acronym, or abbreviation	Meaning
ACEs	Adverse childhood experiences
Actionable statements	Types of statements or recommendations included in the guidelines.
ADHD	Attention deficit hyperactivity disorder
APA	American Psychiatric Association
AUDIT-C	Alcohol Use Disorders Identification Test (AUDIT), Consumption version. The AUDIT-C is a modified version of the 10 question AUDIT instrument.
ASD	Autism spectrum disorder
CATALISE	A multinational and multidisciplinary consortium to identify language impairments in children.
CDC	Centers for Disease Control and Prevention
Central nervous system infections	Infections involving the brain, spinal cord, or optic nerves. Can include meningitis, encephalitis, and abscesses.
CMA	Chromosome microarray. A genetic test that can look for extra or missing pieces of genetic material or DNA (i.e., copy number variants).
Copy number variants (CNVs)	Small genetic deletions or duplications. Many of these variants appear to have no impact on health, but some are associated with diseases or can have clinically relevant effects.
Developmentally informed	Providing a tailored approach to assessment that is individualised to the developmental needs of the person attending for assessment.
DSM-5-TR	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition, Text Revision
Epilepsy encephalopathies	Are a group of disorders in which unremitting epileptic activity contributes to severe cognitive and behavioural impairments and these may worsen over time leading to progressive dysfunction.
FASD	Fetal alcohol spectrum disorder
FXS Testing	Fragile X Syndrome Testing
GPS	Good practice statement
GRADE	Grading of Recommendations, Assessment, Development and Evaluations. The most widely used framework for establishing certainty in the evidence and moving from evidence to decisions (recommendations).
Hypoxic ischaemic encephalopathy	Is a serious brain injury that prevents adequate blood flow to the brain as a result of a hypoxic-ischemic event during the prenatal, intrapartum or postnatal period.
ICF	International Classification of Functioning, Disability and Health
ID	Intellectual disability
LNOB	Leave No One Behind Principle is the commitment from UN Member States to eradicate poverty, end discrimination and exclusion and reduce inequalities and vulnerabilities that undermine the potential of all individuals.
MBS	Medical Benefits Scheme
MRI	Magnetic resonance imaging
Mucopolysaccharidoses	A group of inherited metabolic disease use to the absence or malfunctioning of certain enzymes the body needs to break down molecules called glycosaminoglycans.

NHMRC	National Health and Medical Research Council
PAE	Prenatal alcohol exposure
Practitioners	The terminology of practitioners is used throughout the document to be inclusive of all types of clinicians and practitioners working across health, justice, education and child protection settings who can be involved in the assessment and diagnostic process.
Pregnant women or people	The terminology of pregnant women or people or pregnant woman/person has been used to be inclusive of transmen, who may become pregnant, but not identify as a woman.
ND-PAE	Neurodevelopmental disorder associated with prenatal alcohol exposure
Sodium valproate	Sodium valproate or valproic acid (Epilim) is from a group of medications called antiepileptics or anti-convulsants. It is predominately used for the treatment of seizures or epilepsy. This medication should not be taken during pregnancy due to the risk of congenital malformations and development effects.
UNCRC	United Nations Convention on the Rights of the Child
UNCRPD	United Nations Convention on the Rights of People with Disabilities
Value-based health care	Evidence-based and person-centred approach that aims to improve patient experiences care, improve health outcomes, reduce costs, and improve practitioner experiences.
WHO	World Health Organization

Appendix B: Additional information to support use and interpretation of standardised tests.

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

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

1. There are different definitions of a percentile. These include the percentage of:
   - scores that fall below the point at which a given scores lies in a specified distribution.
   - scores that fall at or below the point at which a given score lies in a specified distribution.
   - half the scores that fall at or below the point at which a given score lies in a specified distribution.
2. The difference between percentiles obtained with these definitions can be marginal or considerable, which in turn impacts interpretation of the individual's score in an assessment. Contributors to this include:
   - size of the normative sample
   - whether the range of scores in the normative sample is narrow or wide
   - the nature of the test or measure (having few items or many items)
3. Percentile ranks are essentially point estimates, which depending on the normative sample may carry a small to large level of fallibility. As with all point estimates, the level of uncertainty/certainty should be clarified by using confidence intervals (interval estimates such as 95% or 90%), that quantify the uncertainty.
4. The performance rating of an individual suspected of a condition of interest (such as FASD/ND-PAE) under the normative data constructed from a sample of people without the condition of interest, can be vastly different to the performance rating when compared to normative data constructed from people with the condition of interest. Unfortunately, normative data sets for FASD/ND-PAE samples are not currently available, and so calculating the probability of clinical group association is not possible. Therefore, practitioners cannot be certain that a given percentile on any assessment measure defines the presence or absence of FASD/ND-PAE.

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

- Normal intra-individual variability and frequency of low scores in normal populations. Important to note that having low scores is common in healthy individuals and the more scores that are derived the higher likelihood that low scores will occur.

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

Appendix C: Evidence gaps

High quality research studies with quantified levels of PAE

This is currently a key research gap across all diagnostic domains, excluding physical size. The most common study type with quantified PAE information are the pregnancy/birth cohort studies. This is where studies recruit pregnant women/people, enabling detailed information to be captured regarding the level, frequency, and timing of PAE. Longitudinal follow-up then allows for repeated assessment of all the relevant diagnostic features. These types of research studies are the most informative for understanding the relationship between PAE and diagnostic outcomes.

Based on the available research, more comprehensive evidence was available in areas where pregnancy/birth cohort studies had included commonly measured diagnostic outcomes (e.g., birth weight, neurodevelopmental outcomes). Whereas alcohol specific outcomes were not examined as often in these types of studies (e.g., dysmorphology).

Future research would greatly benefit from exposure specific pregnancy cohorts, which could examine all prenatal and postnatal exposure and events, including all the relevant FASD/ND-PAE diagnostic outcomes. It would be beneficial for these types of future studies in Australia to recruit people from a wide variety of different social and cultural backgrounds. Pregnancy cohort studies could also support the prospective testing of the current differences between different diagnostic criteria (e.g., various clinical cut offs and tools and norms) and examination of areas where we currently lack evidence-based information (e.g., clinical imaging and other neurological conditions).

Pregnancy cohort studies would also allow for the opportunity to explore the potential biological basis of different clinical cut offs. For example, Perumal et al (2018) argue that there is no biological basis for the current 2 standard deviation definition of ‘stunting’ and that this is an ‘arbitrary’ cut point, and “in reality the risk of undesirable outcomes including mortality does not change drastically when you cross the magic cut point” (p. 2044S). This is the case for all clinical cut points currently applied in the diagnostic criteria. Future research is required to explore the real-life meaningfulness of these clinical cut points for individuals who have experienced PAE.

Local tools and norms to support assessment of facial features

Feedback from the Advisory Groups indicated that this is an important area for future research in Australia to target. Members would like to see the development of a range of local tools and norms to support the assessment process including:

- Lip/Philtrum Guides
- Palpebral fissure norm charts
- Facial features analysis digital tools (e.g., computer software and applications that could be used with phones and other devices).
- Examination of the clinical and diagnostic utility of using 3D photos.

Tests, normative data, and culturally safe practice in neurodevelopmental assessment

The suitability of tests and normative data, in terms of clinical cohorts and culturally safe practice remains a much wider issue than the FASD/ND-PAE field. Though it was particularly evident in the review conducted for these guidelines.

There is a lack of culturally appropriate assessment tools and normative data across all age groups, neurodevelopmental areas, and conditions for First Nations people. This results in an inherent structural bias. Significant future research is urgently required to improve assessment tools, normative comparison data, and culturally informed and safe clinical practices in Australia.

The current review did not identify any studies that produced FASD cohort clinical norms or used such norms in the evaluation of domain deficits. Clinical normative data is crucial for understanding the nature and severity of cognitive deficits as it allows for direct association of the individual to the condition, instead of relying solely on measuring how far they diverge from neurotypical individuals. Significant future research is required to generate useful clinical normative data for application in the diagnostic process.

Interplay between genetics and environmental factors in understanding neurodevelopmental outcomes.

Genetics is a constantly evolving area of research that will provide critical evidence to improve clinical care in the future. Future research studies are needed that can examine the complex interplay between genetics, a wide range of environmental prenatal and postnatal factors, and neurodevelopmental outcomes.

In the diagnostic clinical context, several medical professionals around Australia are currently requesting genetic testing through the Victorian Clinical Genetics Services (VCGS). If medical professionals are requesting genetic testing through VCGS they can include *'FASD Project*' in the clinical notes section of the Request Form. This will support future research to review the results of all genetic testing completed through VCGS.

Application of the diagnostic criteria in clinical practice

Research is lacking regarding the clinical application of diagnostic criteria in Australia. Whilst Australia has a FASD Registry that collects information regarding individuals diagnosed with FASD (up to 16 years of age); there is currently no consistent approach to capturing assessment and diagnostic outcomes across clinics and practitioners in Australia. Having access to information from all individuals who attend for assessment irrespective of their diagnostic outcomes provides a critical opportunity to examine the impact of diagnostic criteria and monitor and evaluate changes in diagnostic criteria over time. Importantly, capturing clinical assessment data will provide vital information that could be used to improve the next revision of the diagnostic criteria and clinical practice guidelines. A REDCap database template is provided as an implementation tool to support consistent clinical data collection across Australia, but in a manner that is also consistent with data sovereignty principles.

Appendix D: Practitioner support templates

Assessment history taking form

Details of individual attending for assessment

Name	
Gender	Female ☐ Male ☐ Non-binary ☐ Other ☐
Date of birth (DD/MM/YYYY)	/ / / Age at assessment:
Racial/ethnic background	
Preferred language	
Referral source, date, and contact details	
Name of accompanying person	
Relationship to person	
Primary caregiver	
Legal guardian	
Assessment consent completed	Yes ☐
Birth mother's name	
Birth father's name	
Place of assessment	
Assessment form completed by	
Date of assessment (DD/MM/YYYY)	

Family and individual concerns

Current Functional Strengths and Challenges

(motor, cognition, communication, education, memory, attention, executive functioning, mood/behavioural regulation, adaptive/social, sensory)

Individual History

Prenatal history (e.g., planned or unplanned pregnancy, time of pregnancy recognition, alcohol and other substance use prior to pregnancy recognition, alcohol and other substance use after pregnancy recognition, prenatal stress including family violence, prenatal care, prenatal nutrition, pregnancy complications – gestational diabetes, preeclampsia)

Birth history (e.g., gestational age, APGAR scores, delivery type, any birth complications, any neonatal care)

Medical history (e.g., chronic conditions, injuries, any previous special investigations)

Mental health and behavioural history

Developmental history

School or Work History (e.g., current school/work, current teacher/supervisor, change of schools/workplaces, long absences, academic/work progress, current strategies/supports)

Postnatal exposures/events/adverse childhood experiences

Any justice/child protection issues

Family and Environmental History

Home environment (e.g., living arrangements, parent/child relationship, extended family relationships and supports)

Family health and support history (e.g., strengths, areas requiring support, mental health/addiction and learning challenges)

Social history (e.g., housing, transportation, financial challenges, community safety, community or friendship groups, or hopes for community/friendship connections)

Cultural context (e.g., cultural activities, events, spiritual beliefs, cultural identity, sense of purpose, or hopes for future cultural connections)

Marginalisation factors (e.g., LGBTQIA+, refugee)

Current supports and services

Previous supports and services (i.e., what has worked and not worked)

Personal Factors (i.e., both positive and negative influencing factors)

Strengths/interests, activities the individual participates in or other hobbies.

Personal assets, characteristics, or coping styles

Individual factors (e.g., gender, race, age) and past life experiences (e.g., experiences of bullying, racism), expectations

Prenatal alcohol exposure (PAE) AUDIT-C assessment

AUDIT-C Questions	**Score**	
	Pre-recognition of pregnancy[1]	Post-recognition of pregnancy[2]
Pregnancy recognition = _____weeks gestation		
How often did you have a drink containing alcohol? 0 Never 1 Monthly or less 2 2-4 times a month 3 2-3 times a week. 4 4+ a week		
How many standard drinks of alcohol did you have in a typical day when you were drinking? 0 1 or 2 1 3 or 4 2 5 or 6 3 7-9 4 10+		
How often did you have five or more standard drinks on one occasion? 0 Never 1 Monthly or less 2 Monthly 3 Weekly 4 Daily/ Almost Daily		

[1] from conception to recognition. [2] From recognition for the rest of the pregnancy.

Total score for pre-recognition:

Total score for post-recognition:

AUDIT-C Score	**Alcohol risk category**
0	No risk of alcohol related harm
1-2	Low risk of alcohol related harm
3-4	Medium risk of alcohol related harm
≥5	High risk of alcohol related harm

Further information regarding AUDIT-C scores

There may be situations where practitioners want to be able to provide additional information to a women or person who is pregnant or planning a pregnancy based on their AUDIT-C scores. The following recommendations are summarised from Goldman, Anderson, Dunlop and Wiggers (2017).

AUDIT-C Score	Recommended advice
0 = no risk of harm	• Provide positive reinforcement and encourage clients to continue not to drink any alcohol during pregnancy. • A score of zero indicates no risk of alcohol-related harm to the embryo/fetus. • Advise that it is safest not to drink any alcohol at all during pregnancy. • Advise that the risk of harm to the developing embryo/fetus increases with increasing amounts and frequency of alcohol consumption and that any score above zero indicates potential risk to the embryo/fetus.
1 - 2 = low risk of harm	• Advise that the risk to the embryo/fetus is likely to be low, but it is safest not to drink any alcohol at all during pregnancy. • Advise that the risk of harm to the developing embryo/fetus. increases with increasing amounts and frequency of alcohol consumption and that any score above zero indicates potential risk to the embryo/fetus. • Encourage the client to stop drinking alcohol during pregnancy and arrange a follow-up sessions as required.

3 - 4 = medium risk of harm	• Advise that the safest option is not to drink alcohol during pregnancy.
	• Discuss that the AUDIT-C score indicates drinking is at a level of increasing risk for the person's health.
	• Advise that the risk of harm to the developing embryo/fetus increases with increasing amounts and frequency of alcohol consumption.
	• Discuss the effects of current alcohol consumption levels and outline health concerns for both the client and their baby.
	• Reinforce the benefits of stopping drinking at any stage during pregnancy to minimise further risk to the client and baby.
	• Ask the client how they feel about cutting down of stopping and establish:
	  ◦ Positives and negatives of taking action
	  ◦ How confident they are in being able to cut down or stop
	  ◦ Tips, strategies and plans for taking action
	  ◦ If they would like assistance, including from support networks and partners
	  ◦ Offer to arrange referrals if additional support is required.
	• If you suspect that the client may be alcohol dependent refer to a local specialist treatment service.

5+=high risk of harm	• Discuss that the AUDIT-C score indicates that drinking is at a level of high risk for their health and high risk for the baby's health. • Discuss positives and negatives of taking action and determine what support is required to be able to cut down or stop. • Refer to a specialist alcohol service as they may be at risk of alcohol dependence. Specialist support should be organised before advising her to cut or stop alcohol

	consumption, as without support alcohol withdrawal can be dangerous to both the client and the baby's health.

References

Goldman S, Anderson A, Dunlop A, Wiggers J. Using the AUDIT-C with Pregnant Australian Women: Evidence Review. Newcastle, NSW: Hunter New England Local Health District and the University of Newcastle, 2017.

Physical examination

Physical examination form

Details of individual attending for assessment

Name	
Gender	Female ☐ Male ☐ Non-binary ☐ Other ☐
Date of birth (DD/MM/YYYY)	/ / / Age at assessment:
Racial/ethnic background	
Preferred language	
Referral source, date, and contact details	
Name of accompanying person	
Relationship to person	
Primary caregiver	
Legal guardian	
Assessment consent completed	Yes ☐
Birth mother's name	
Birth father's name	
Place of assessment	
Assessment form completed by	
Date of assessment (DD/MM/YYYY)	

Physical size

Birth	Gestational age	Birth length		Birth weight	
Date	weeks	cm	percentile	grams	percentile

Growth reference chart used: ☐ WHO ☐ Fenton ☐ Other (specify)

Postnatal	Age	Height		Weight	
Date	Months or years	cm	percentile	grams	percentile

Growth reference chart used: ☐ WHO ☐ CDC ☐ Other (specify)

Parental height (if available)

Mother's height (cm)	Father's height (cm)	Sex-specific target height (cm)	Sex-specific target height (percentile)

Specify factors that may explain physical size parameters (e.g., nutritional or environmental neglect, genetic conditions, prematurity, prenatal exposure to other drugs)

Physical size summary

Was there an unexplained deficit in height and/or weight identified at any time?
☐ Yes ☐ No

If Yes
At birth ☐ postnatally ☐

☐ height and/or weight ≤ 3rd percentile
☐ height and/or weight ≤ 5th percentile
☐ height and/or weight ≤ 10th percentile

Head circumference

	Gestational age (weeks)	Head circumference (cm)	Percentile
Birth			

Growth reference chart used: ☐ WHO ☐ Fenton ☐ Other (specify)

	Date	Age	Head circumference (cm)	Percentile
Postnatal				

Growth reference chart used: ☐ WHO ☐ CDC ☐ Other (specify)

If relevant, specify factors that may explain reduced head circumference:

Head circumference summary

Was there an unexplained deficit in head circumference identified at any time? ☐ Yes ☐ No
If Yes at birth ☐ postnatally ☐ ☐ ≤ 3rd percentile ☐ ≤ 5th percentile ☐ ≤ 10th percentile

Sentinel facial features

Palpebral Fissure Length (PFL)			Right PFL		Left PFL		Mean PFL	
Date	Age	Assessment method	mm	z score (SD)	mm	z score (SD)	mm	z score (SD)
		☐ direct measure						

Note. If using direct measures University of Washington Palpebral Fissure Length Z-score calculator: http://depts.washington.edu/fasdpn/htmls/diagnostic-tools.htm#pfl

PFL reference chart used: ☐ Stromland ☐ Other (specify)

Philtrum

Date	Age	Assessment method	UW Lip-Philtrum Guide 5-point rank
		☐ direct measure ☐ photo analysis	
		☐ direct measure ☐ photo analysis	
		☐ direct measure ☐ photo analysis	

Upper lip (Vermillion)

Date	Age	Assessment method	UW Lip-Philtrum Guide 5-point rank
		☐ direct measure ☐ photo analysis	
		☐ direct measure ☐ photo analysis	
		☐ direct measure ☐ photo analysis	

Lip-Philtrum Guide used: ☐ Guide 1 (Caucasian) ☐ Guide 2 (African American)

Note. University of Washington Lip-Philtrum Guides: http://depts.washington.edu/fasdpn/htmls/lip-philtrum-guides.htm

Sentinel facial features summary

Number of sentinel facial features present
☐ 0 ☐ 1 ☐ 2 ☐ 3

Other physical findings

Please specify (e.g., other dysmorphic facial features, minor or major birth defects, other system impairments):

Other structural and neurological findings

Please specify (e.g., structural brain abnormalities, neurological conditions – seizures, cerebral palsy, vision or hearing impairments)

Investigations

Chromosomal microarray: ☐ No ☐ Result pending ☐ Yes (specify result)
Fragile X testing: ☐ No ☐ Result pending ☐ Yes (specify result)

Other investigations as indicated (e.g., full blood count, ferritin, metabolic screen, creatinine kinase, lead, thyroid function). Please specify:

Holistic Formulation and Diagnostic Summary Form

Formulation Summary Table

Domain	Summary
Contextual factors	
Social	
Cultural	
Environmental	
Strengths, interests & external resources	
Prenatal and postnatal factors	
Prenatal alcohol exposure	
Prenatal factors	
Postnatal factors	
Facial features	
FASD facial features	Assessment: Interpretation:
Head circumference	
Birth	cm percentile
Postnatal	cm percentile
Current	cm percentile
Physical size	
Birth weight & length	Birth weight grams percentile Birth length cm percentile
Postnatal weight & heigh (if available)	
Current weight & height	
Associated conditions	

Neurodevelopmental domains	
Communication (language skills)	Reported strengths/challenges: Assessment results: Behavioural observations: Interpretation:
Motor skills	Reported strengths/challenges: Assessment results: Behavioural observations: Interpretation:
General intellectual abilities (cognition)	Reported strengths/challenges: Assessment results: Behavioural observations: Interpretation:
Attention	Reported strengths/challenges: Assessment results: Behavioural observations:

	Interpretation:
Memory	Reported strengths/challenges: Assessment results: Behavioural observations: Interpretation:
Executive function	Reported strengths/challenges: Assessment results: Behavioural observations: Interpretation:
Emotional and/or behavioural regulation	Reported strengths/challenges: Assessment results: Behavioural observations: Interpretation:
Literacy and/or numeracy skills	Reported strengths/challenges: Assessment results:

	Behavioural observations: Interpretation:
Adaptive/social behaviour	Reported strengths/challenges: Assessment results: Behavioural observations: Interpretation:

Diagnostic Summary

Differential Diagnosis

Offer and consider one or more relevant diagnostic possibilities, summarising what is most likely, considering what is less likely or unlikely yet important to consider given the individual's presenting concerns and assessment results.

FASD/ND-PAE Diagnostic Criteria Review

Criteria	**Summary**
Criterion A: Evidence consistent with a heavy level of PAE or presence of three sentinel facial features.	
Criterion B: Presence of pervasive neurodevelopmental impairments	
Criterion C: The neurodevelopmental impairments necessitate significant supports.	
Criterion D: Onset of neurodevelopmental impairments is in development.	
Criterion E: The symptoms are not better attributed to another condition or exposure.	
Specify • 1,2, 3 or no sentinel facial features • Head circumference restriction at birth and/or postnatally. • Physical size restriction at birth and/or postnatally.	
Associated with structural brain abnormalities, neurological conditions (e.g., seizures of	

unknown origin, cerebral palsy, vision or hearing impairments), congenital anomalies (e.g., cardiac, renal or other organ defects, ptosis, strabismus), musculoskeletal conditions, other system impairments, other health problems (e.g., sleep disorders, eating/feeding or toileting concerns).	

FASD/ND-PAE Diagnosis

☐ Meets criteria
☐ Does not meet criteria
☐ At risk of FASD/ND-PAE
☐ Incomplete assessment i.e., further investigations needed.

Co-occurring conditions

☐ Attention deficit hyperactivity disorder
☐ Intellectual disability
☐ Autism spectrum disorder
☐ Developmental coordination disorder
☐ Language disorder
☐ Specific learning disorder:
☐ Anxiety:
☐ Depression:
Other co-occurring conditions:

Appendix E: Collaborative goal setting

Practitioners are encouraged to use a collaborative goal setting approach with the individual attending for assessment and their support network as appropriate. Based on the results of the systematic review of lived experiences of the assessment and diagnostic process (Hayes et al., 2023), practitioners should be aware that families can feel overwhelmed by the volume of recommendations contained in assessment reports and can find the non-specific nature of recommendations unhelpful. Given the wide range of individual and family challenges that people present with collaborative goal setting can support individuals and families in understanding what are the most important and most urgent areas to be addressed at the current time.

Practitioners may choose to include goal setting at different stages of the assessment process depending on their client population and needs. For example, some practitioners include goal setting at the start of the assessment process to help support engagement and target the assessment process. Goal setting can be helpful way to build rapport with the individual and their family attending for assessment. Other practitioners find it helpful to incorporate goal setting at the end of the assessment process following the feedback of the assessment results. This can help the family in using the assessment results to inform the goal setting and planning process.

There are a range of goal setting tools that can be used to support the process, or practitioners can also make their own local tools to suit their context. Goal setting tools can be helpful as they can provide visuals to support individuals and families in engaging meaningfully in the goal setting process.

Some examples of some currently available tools include:

- **Perceived Efficacy and Goal Setting (PEGS):** Goal setting system for young children aged 5 to 9 years. The PEGS includes a set of cards that cover self-care, school and leisure activities to support children in identifying things that are challenging for them and areas that they want to work on. Has questionnaires for caregiver and educators to allow multiple perspectives. https://canchild.ca/en/shop/5-pegs-2nd-edition-complete-kit

- **The Family Goal Setting Tool (FGST):** Designed to help practitioners facilitate family-centred and holistic goal setting with parents/carers of children with significant global delays and/or multiple complex needs. https://autismqld.com.au/product/family-goal-setting-tool-disability-version/

- **The Adolescent/Adult Goal Setting Tool (AAGST):** Designed to enable autistic people and other neurodivergent individuals to actively engage in person-centred planning. The AAGST includes 75 goal cards and a range of resources to support the use of the tool. https://autismqld.com.au/product/adolescent-adult-goal-setting-tool-aagst/

- **Paediatric Activity Card Sort/PACS** is an interview-based self-report measure for children aged 5 to 14 years with/ without disabilities. It includes 75 pictures, each of which represents 1 typical activity within 4 childhood life domains (personal care, school/productivity, hobbies/social activities, sports). Children are asked to sort those pictorial cards into “yes” or “no” indicating whether they would like to do the

activities, and then into piles by varied activity frequency. http://www.widgetlibrary.knowledge.scot.nhs.uk/media/WidgetFiles/1010834/TorontoOTs_PACSinfo%20(1).pdf

- **Preschool Activity Card Sort (Preschool ACS)** is similar to the PACS, but it is a preschool version specifically for use with children aged 3 to 6 years with/without disabilities, and it is based on an interview with parents (not children). It includes photographs of 85 activities across 7 preschool life domains (self-care, community mobility, high demand leisure, low demand leisure, social interaction, domestic chores, education). Parents are asked to specify whether their child participates in each activity; if "yes," whether the child needs adult assistance or environmental accommodation is followed, while if "no," the reasons related to the child, parents, or environment are explored with discussion. In addition, the Preschool ACS requires the parents to identify 5 activities that they are not satisfied with their child's participation and to rate these identified activities in the aspects of the importance, frequency, level of participation, and satisfaction.

- **COSA V 2.2** The Child Occupational Self-Assessment (COSA) is a self-report of occupational competence and value for everyday activities influenced by components of the Model of Human Occupation (MOHO). The COSA measures how competently children feel engaging in and completing activities and the values associated with these activities (Kramer, Kielhofner, & Smith 2010). The COSA has been used in research with youth ages 7-17. However, age is not the primary determinate of the appropriateness of the COSA. It is possible that the COSA may be appropriate for youth as young as 6 or as old as 21. https://moho-irm.uic.edu/productDetails.aspx?aid=3

These goal setting tools come with associated planning documents to support practitioners in summarising the goals and plans that have been developed with the individual and their support network. However, if practitioners are not able to access to specific goal setting tools, The Collaborative Process for Participation Goals is a freely accessible resource that practitioners may find helpful to use in developing collaborative goals and action plans. https://canchild.ca/en/resources/335-the-collaborative-process-for-participation-goals