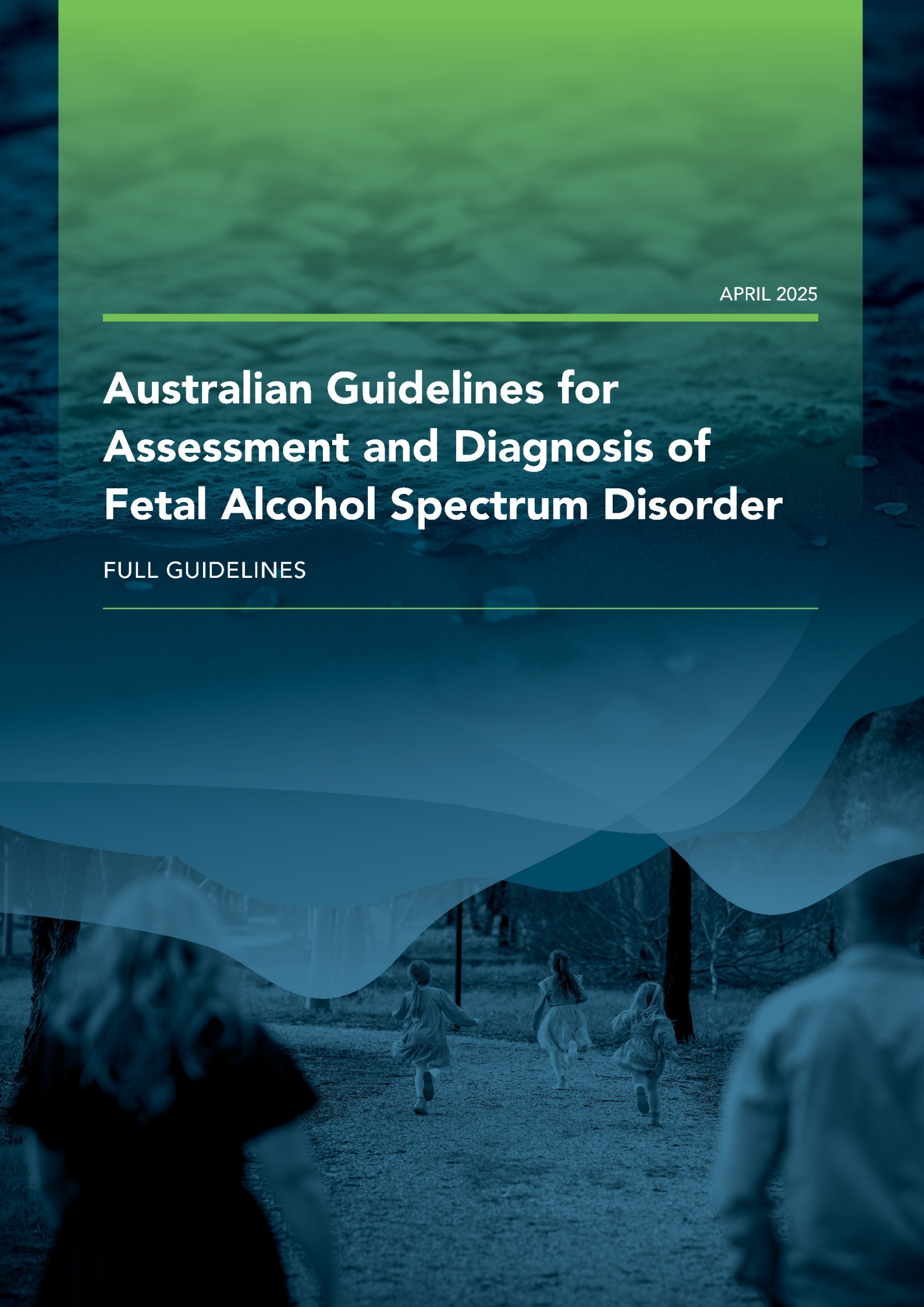
APRIL 2025

Australian Guidelines for Assessment and Diagnosis of Fetal Alcohol Spectrum Disorder

FULL GUIDELINES



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Disclaimer	These guidelines are a general guide to best practice, to be applied with consideration of the circumstances, needs and preferences of the individual attending for assessment, and the health professionals' clinical judgement and values. 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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Acknowledgements

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See the Administrative and Technical Report for member affiliations 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 transitioned in her fifties to undertake a Master's in Tropical Health and a PhD in Medical Anthropology. Aunty Jan grew up on a farm in the New South Wales Pilliga Scrub. 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), bringing together experts from a wide range of disciplines, initiating a program of FASD research at the University of Queensland that continues today. Aunty Jan was a dedicated educator, providing countless presentations nationally and internationally. Known for her ability to connect with people from all walks of life, she had a wicked sense of humour and was never shy of a challenge, even setting a world record for powerlifting in her 70s.

Dr. Rochelle Watkins qualified as a physiotherapist and earned 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 informing the 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 Kids-University of Sydney NHMRC Centre of Research Excellence and served on the boards of the National Organisation for Fetal Alcohol Spectrum Disorders Australia (2012-2015) and Neurological Council of Western Australia (2010-2015). Rochelle was highly regarded by her collaborators and contributed significantly to state and federal health policy. She is remembered for her generosity to students, colleagues, and the community.

Ms. Heather Jones began her work at the Telethon Kids Institute WA in the project team developing the 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 and 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 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 conducted 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 practices regarding alcohol use in pregnancy and FASD. In 2007, she pursued a PhD to develop and evaluate educational resources for health professionals, with a strong focus on consumer and community involvement in research. Jan 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 respect to Elders past, present, and emerging.

I would also like to acknowledge all people in Australia living with fetal alcohol spectrum disorder (FASD). A central tenet throughout the development of these guidelines was maintaining respect for and inclusivity of diverse perspectives. We hope these guidelines respect and honour people's diverse experiences, enhance assessment and diagnostic practices, reduce stigma, and improve the quality of life for all people living with FASD in Australia.

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

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

I am grateful for the special opportunity we had to collaborate with our Aotearoa (New Zealand) colleagues. Thank you to Dr. Andi Crawford, Ms. Sarah Goldsbury, Ms. Tania Henderson, Mr. Haami Harmer, Dr. Raewyn Mutch, Ms. Jo Van Wyk Mutch (The Aotearoa Project Team), 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 nations.

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

Content Chair, Guidelines Development Group
Senior Research Fellow & Clinical Psychologist
The University of Queensland
Faculty of Health, Medicine, and Behavioural Sciences
Child Health Research Centre

While FASD is a lifelong disability, clearer understanding of the impacts of the condition, can help individuals and their families with more access to care, increased referral pathways, and improved diagnostic accuracy. However, with no biomarkers or internationally agreed-upon diagnostic criteria, 'traditional' guideline development remains challenging.

Recognising these challenges, it was crucial that a diverse group of people were involved in the development of these guidelines.

The Guidelines Development Group comprised 26 members, including experts in guideline development, First Nations representatives, individuals with living/lived experience, researchers, as well professionals from the various disciplines involved in assessment and diagnostic process. This diversity brought a wealth of perspectives and expertise to the table, enriching the development process.

Additionally, an extended Advisory Group provided invaluable input, setting initial priorities, and offering critical feedback on draft recommendations and documents. This group included individuals with a wide range of experiences and perspectives, further enhancing the guideline's relevance and applicability.

Overall, this collaborative process led to the development of 11 GRADE diagnostic recommendations, 11 Lived Experience statements, and 40 Good Practice Statements. These comprehensive and innovative guidelines reflect the collective wisdom and dedication of all involved and we are quietly confident that the integration across these different perspectives will help improve outcomes for people with FASD and their families.

We extend our heartfelt gratitude to everyone who contributed to this important work. Your dedication and insights have been instrumental in shaping guidelines that we believe will make important differences in the lives of people living with FASD.

Lastly, we must acknowledge the expertise and dedication of Dr Natasha Reid, whose leadership of these complex guideline processes was so effective, collegiate, and inspirational.

Professor Philippa Middleton

Independent Chair, Guidelines Development Group

South Australian Health and Medical Research Institute

Adelaide University

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 practices 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 and diligence embedding Indigenous perspectives throughout guidelines focused on FASD.

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

We recognise that FASD and awareness of FASD are impacted and compounded by stigma in all communities. In this respect, our Indigenous worldview and approaches towards FASD 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 has driven 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 is 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 also mobilised and continue to lead the way in healing from the impacts of FASD.

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, Dr. June Oscar AO, Ms. Maureen Carter, Ms. Emily Carter AM, and countless others. Our worldview is inherently strengths-based, healing-informed, and culture-centred, offering immeasurable benefits to both Indigenous and non-Indigenous knowledges and practices. Our leadership is driven by urgent advocacy and the need for equitable access to support our children, adolescents, and adults with FASD. 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 to create equitable access to assessment and diagnosis of FASD and the healing that can accompany it. It is important that our ways of knowing, being, and doing are not side documents only for 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 they believe this knowledge is relevant to them. The reality is that Aboriginal and Torres Strait Islander peoples are overrepresented

in justice and child protection systems, and many of these vulnerable populations live with FASD 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 are 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 to deliver culturally responsive services 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 more accessible to all cultures living in Australia. If you wish to deepen your learning journey to be inclusive of Indigenous worldviews on FASD, 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 and members of the Guidelines Cultural Advisory Group, we give you permission to be the change that ensures our people have access to culturally responsive and healing-informed FASD knowledge, assessment, diagnosis, and support.

Ms. Nicole Hewlett Palawa Research Associate and PhD student, University of Queensland (Chair, Cultural Advisory Group)

Dr. and Aunty Lorian Hayes Inigai-Bidjera Elder and academic, University of Queensland

Associate Professor Robyn Williams Noongar academic, Curtin University

Ms. June Riemer Gumbaynggirr-Dunghutti woman, Deputy CEO First Peoples Disability Network

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Ms. Lorelle Holland Mandandanji academic, Lecturer, and PhD student, University of Queensland

Chapter 1
Introduction

Chapter 1: Introduction

Clinical practice guidelines establish standards of care supported by scientific evidence to optimise service provision. They assist practitioners and clients in making informed decisions by translating complex research into relevant, individualised recommendations, rather than adopting a one size fits all approach. High-quality guidelines are based on systematic reviews of scientific evidence and involve a transparent development process, including input from experts, end users, and people with living experience (NHMRC, 2018).

Fetal alcohol spectrum disorder (FASD), a condition arising from prenatal alcohol exposure (PAE), requires high-quality guidelines to optimise care. The critical importance of FASD 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). In 2020, The Australian Department of Health funded this revision and update of the 2016 Guide. This update aligns with the National Health and Medical Research Council (2020) procedures and requirements.

1.1 Rationale for the Current Approach

A key consideration in developing these guidelines was the lack of unified diagnostic criteria for FASD internationally. Given the complex and varied nature of presentations, different research groups have prioritised different clinical features and implemented various diagnostic terms to describe FASD. However, this lack of consistency and standardisation complicates research and diagnostic processes, negatively impacting individuals and families. Therefore, there is need for a more structured approach based on systematic reviews of the evidence, integrating relevant person-level factors (i.e., patient/client values, needs and preferences, and cultural context) into an aetiological and functional diagnostic framework.

To inform the development of these guidelines, a comprehensive systematic literature review and meta-analysis of PAE and its association with diagnostic outcomes was undertaken. The results demonstrate that higher levels of PAE are associated with an increased risk of harm, and a higher likelihood of FASD diagnosis.

These guidelines employ a best practice approach to advancing FASD diagnostic criteria using the GRADE framework, a systematic method for developing evidence-based clinical recommendations (GRADE Working Group, 2013). By applying GRADE, these guidelines provide a summary of the best available evidence and a structured approach to interpreting the evidence and developing recommendations.

1.2 Distinguishing Public Health Messages on Prenatal Alcohol Exposure from Diagnostic Requirements for FASD

These Guidelines align with Australian Guidelines to Reduce the Risks from Drinking Alcohol (2020), which state that **"no safe level of alcohol consumption during pregnancy has been identified."** The evidence review examining the diagnostic criteria unequivocally supports this position, highlighting the potential for adverse health effects at all PAE levels.

It is important to note that a significant body of literature on PAE's potential impacts was not covered in the evidence review for these guidelines. For example, there is literature on how PAE can affect the health of pregnant individuals (e.g., mental health, nutrition, absorption of nutrients), the structure and function of the placenta, other adverse pregnancy outcomes (e.g., miscarriage, stillbirth, preterm delivery), and various child outcomes that have not been examined (e.g., experimental study designs, functional magnetic resonance imaging [MRI], and physiological outcomes). As such, **these guidelines do not endorse a safe level of PAE** and provide advice consistent with Australia's public health messaging on PAE.

While PAE poses risks at all levels, these guidelines specifically address the outcome of FASD. Health practitioners must consider the level of PAE alongside other risk and protective factors when diagnosing FASD. "FASD is both an etiological diagnosis (i.e., identifying the cause), and a functional diagnosis (i.e., identifying consequences and needs; The Canada National FASD Database 2019 Annual Report, p. 2)." PAE is a risk factor for adverse physical and neurodevelopmental outcomes and possible diagnosis of FASD. Not every exposure is results in neurodevelopmental impairments and/or adverse physical outcomes, and these features may also result from a range of other genetic and environmental factors. Health practitioners need evidence-based information to make informed clinical decisions about PAE risks, supporting accurate diagnostic decision making.

Although developing public health messages on PAE is beyond the scope of these guidelines, it is critical that public health messages to prevent PAE are evidence based. This requires moving away from fear-based messages directed at pregnant individuals in isolation, which focus nearly exclusively on FASD as the only adverse outcome (May et al., 2023; Schölin & Heenan, 2022), without considering the wellbeing of the pregnant individual and the wide range of other potential adverse outcomes.

1.3 Diagnostic Terminology

Internationally, diagnostic terminologies for FASD vary, with some using FASD as a diagnostic term and others applying different terminologies (Coles et al., 2023). Consultative groups discussed the advantages and disadvantages of the different terminologies but reached no consensus; some stakeholders preferred the term FASD, and others preferred the term Neurodevelopmental disorder associated with prenatal alcohol exposure, or similar. Some people with living experience emphasised that FASD was critically important to them, which influenced the decision to retain this term. However, flexibility in terminology is important in clinical practice to accommodate those who do not identify with terminology of FASD.

Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE) is recognised as a "Condition for Further Study" in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR). It encompasses a range of neurodevelopmental disabilities linked to PAE, whether or not physical effects are present (Kable et al., 2016; p. 336). In the DSM-5-TR, FASD can already be classified as Other Specified Neurodevelopmental Disorder – Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure. Similar terminology is also now included in the International Classification of Disease, 11th Revision (ICD-11). The inclusion of these terms in major classification systems reflects significant progress in the field, opening doors for greater service accessibility as more health practitioners may now consider PAE within their scope of practice.

The current update to the Australian Guidelines comes at a crucial time, as scientific research on PAE and lived experiences continues to grow. These guidelines must remain flexible to incorporate new evidence, ensuring they reflect the evolving understanding of PAE and its impacts.

Framing the effects of PAE as Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure alongside FASD, helps us recognise that the impacts extend beyond the fetal period and contribute to lifelong neurodivergence. This broader perspective also allows us see PAE in relation to a wide range of other environmental exposures, including adverse childhood experiences and positive and protective influences. By remaining open to a range of terminologies, these guidelines build on the exceptional work already done in Australia and ensure that the effects of PAE are considered within the wider context of ongoing research on neurodiversity.

While the terminology of FASD is applied throughout these guidelines, the diagnostic criteria are designed to enable documentation of all relevant features regardless of the specific terminology used. Practitioners are encouraged to engage in shared decision-making with individuals, their families, and significant others, to determine the most appropriate diagnostic terminology.

1.4 Note Regarding Other Terminology Choices Throughout These Guidelines.

Terminology varies across disciplines and clinical settings, and these guidelines are designed to be flexible in that regard. For example, while the term 'clinically significant impairments' is used in the diagnostic criteria, practitioners may prefer alternatives like 'severe impairments' or other discipline specific terms. Similarly, the guidelines mention 'standardised tests', but practitioners may prefer 'standardised measures', 'validated tests', or 'measures'. The language provided here is intended as guidance to support practitioners in their work, not as a prescription.

Use of the term prenatal alcohol exposure (PAE) is intentional to help de-stigmatise alcohol use during pregnancy. By focusing on the exposure, rather than on the behaviour, this term aims to reduce feelings of blame and shame. These guidelines also use gender-inclusive language, using phrases such as 'pregnant individuals' to acknowledge that individuals of different gender identities can be pregnant.

1.5 Challenges and Opportunities in Developing the Current Guidelines.

The Guideline Development Group discussed a range of challenges, many extending beyond the FASD field. Transparent discussion of these issues can inspire collaboration and future research. A summary of key challenges and opportunities is provided here.

- In developing the diagnostic criteria and actionable statements (i.e., recommendations) the Guidelines Development Group aimed to balance detailed guidance with flexibility for individual client care. 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 was discussed. The need for the diagnostic criteria and actionable statements to support accurate diagnosis, and that are accessible to practitioners in different disciplines and settings, were key considerations in the development process.
- The review process highlighted a lack of structured, evidence-based approaches to developing diagnostic criteria, an issue affecting many conditions in the 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 developing these diagnostic criteria represent the highest standard and provide an exemplar for improving diagnostic criteria beyond the FASD field.
- Challenges were noted in applying DSM-5-TR neurodevelopmental diagnoses. Specifically, the neurodevelopmental domain does not easily accommodate co-occurring neurodevelopmental conditions or the impact of adverse childhood experiences (ACEs) and other postnatal adversities. The group discussed the potential for future DSM revisions to consider conditions such as "Neurodevelopmental disorder associated with early life adversity", and/or "ADHD associated with prenatal alcohol exposure", to help differentiate conditions and improve support pathways. This approach aligns with CATALISE recommendations, which advocate for diagnoses that specify the underlying condition, such as “Language disorder associated with X” (Bishop et al., 2017).
- All diagnoses face the ‘line drawing problem’ (Schwartz, 2007), where arbitrary cut-offs are applied in binary classifications (i.e., disease vs. no disease). To the Guidelines Development Group’s knowledge, there is no evidence linking an increased risk of adverse life outcomes to a specific clinical cut-off for FASD diagnostic features. This issue is common in neurodevelopmental and medical conditions, and further research is needed to understand the meaningfulness and utility of clinical cut-offs for diagnosis of FASD in the Australian context.

1.6 Overall Objectives

The objective of these guidelines is to support practitioners in undertaking assessment and diagnosis of FASD across the lifespan. This document provides actionable statements based on information collected from multiple sources, including:

- Rigorous review of the best available evidence regarding associations between PAE and diagnostic outcomes.

- Information collected from people with living experience of FASD.
- Insights from Aboriginal and Māori people with FASD knowledge and expertise.
- Contributions from practitioners and researchers with knowledge and expertise in the assessment and diagnosis of FASD.

1.7 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 diagnosis.

Secondary users of these guidelines may include:

- Individuals who have challenges that may be explained by a diagnosis of FASD and who want to understand the assessment process.
- Family members and support networks of individuals with suspected FASD who seek to understand the assessment process.
- Professionals in health, education, child protection, disability and justice/police sectors who work with individuals presenting with challenges that may be explained by a diagnosis of FASD and who want to understand the assessment process and ensure appropriate supports are provided.
- Government and non-government service providers seeking to understand 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 their capability to work with individuals with FASD.
- 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.
- 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.

The Guidelines Development Group aimed to create an inclusive document relevant to various practitioners (e.g., midwives, paediatricians, allied health, and general practitioners) working across diverse 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 specific 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’ is used in some instances to allow for the necessary flexibility in implementing certain actionable statements.

1.8 Stakeholder Inclusion

Collaborating with stakeholders has been critical to the development of these guidelines. Extensive time was committed to stakeholder inclusion to incorporate a wide range of perspectives. Research supports that 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 the *Guidelines Development Group*. The Administrative and Technical Report provides detailed information on these groups. In brief:

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

Four **Advisory Groups** including:

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

The **Guidelines Development Group** comprised practitioners, researchers, cultural and living experience members. The Guidelines Development Group was chaired by Professor Philippa Middleton and included Professor Zachary Munn as the Guideline Methodology consultant. For further details please see the Administrative and Technical Report.

1.9 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 on this process. In brief:

Review of current guidelines: A comprehensive review of all current international FASD diagnostic guidelines was undertaken, examining 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 the diagnostic criteria (i.e., prenatal alcohol exposure, dysmorphology, neurodevelopment and physical size)?

2. What are the experiences of individuals with FASD 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 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 as a possible outcome?

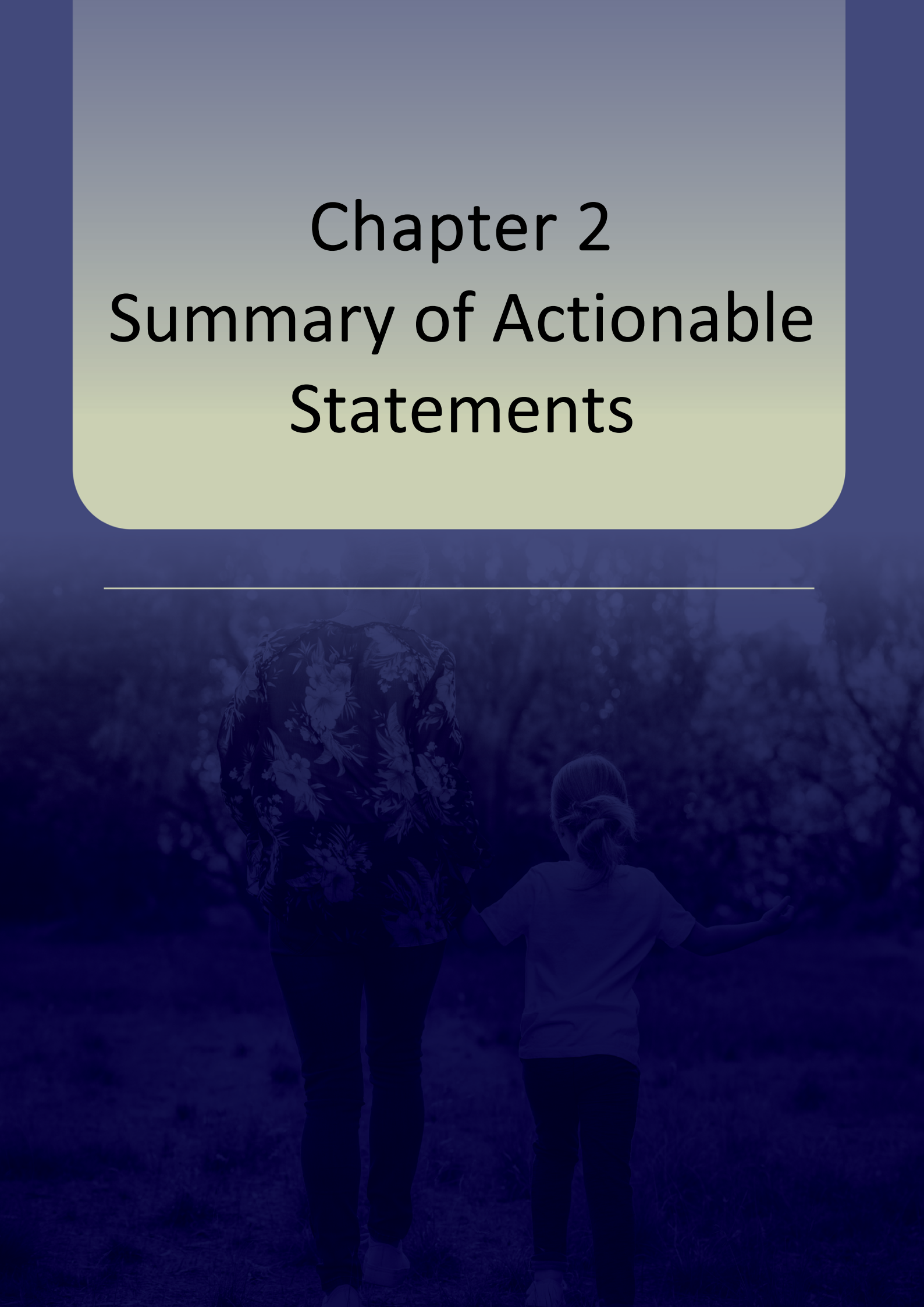
For a high-level overview of the evidence review process and findings, see the Administrative and Technical Report. For detailed information regarding the results of the evidence review, including methodology, results, and strengths and limitations, refer to each of the Technical Reports.

Advisory Group input: Advisory Groups provided detailed input and feedback through meetings, a priority-setting survey (Hayes et al., 2022; Administrative and Technical Report), co-design of the Australian FASD Indigenous Framework (Hewlett et al., 2023), and detailed feedback on draft diagnostic criteria and guidelines.

1.10 Future Updating of the Guidelines

The Guidelines Development Group will consider feedback from users, new research, and changes to international criteria in determining the timeline for updates. For details on monitoring, evaluation and updates see the Dissemination, Implementation and Evaluation Report.

Chapter 2
Summary of Actionable Statements



Chapter 2: Summary of Actionable Statements

2.1 Actionable Statements Format

For clarity and consistency, the framework proposed by Lotfi et al. (2022) was adapted to develop and present the actionable statements (i.e., recommendations) in these guidelines.

Based on the systematic review of lived experiences of the assessment and diagnostic process, a novel category of actionable statement was introduced: 'lived experience statements.'

Each type of statement is colour-coded in the document, corresponding with the Indigenous Framework artwork. Figure 1 provides an overview of different types of actionable statements. More details are available in the Administrative and Technical Report.

GRADE-based Recommendations	Lived Experience Statements
• Evidence-based • Based on systematic review and meta-analysis. • Direct and clear links to research evidence. • Includes formal ratings of certainty of the evidence.	**1.** Based on a systematic review and qualitative synthesis of lived experiences of the assessment and diagnostic process. **2.** Provide guidance for practitioners from the point of view of people with lived experience.
Good Practice Statements	**Implementation Considerations, Tools, and Tips**
• Aid to clinical decision making. • Not based on synthesised summaries of the evidence. • Do not include formal ratings of certainty of the evidence.	• Supporting information to help practitioners implement recommendations.

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

2.2 Defining GRADE-based Recommendations.

Two different types of GRADE-based recommendations are included in this document:

→ Strong recommendations

A strong recommendation implies that most or all individuals will be best served by the recommended course of action.

These recommendations are phased as:

"The Australian FASD Guidelines Development Group recommends."

→ Conditional recommendations

A conditional recommendation implies that not all individuals will be best served from the recommended course of action. Individual circumstances, preferences, and values need to be more carefully considered by practitioners. This is likely to require practitioners to allocate more time to shared decision-making, ensuring they clearly and comprehensively explain the potential benefits and harms to individuals, families, or support people.

These recommendations are phased as:

"The Australian FASD Guidelines Development Group suggests."

Important note from the GRADE Handbook: "Clinicians, patients, third-party payers, institutional review committees, other stakeholders, or the courts should never view recommendations as dictates. Even strong recommendations based on high-quality evidence will not apply to all circumstances and all patients."

2.2.1 Evidence synthesis and evidence-to-decision framework domains that contributed to the strength of a recommendation.

Chapter 11, Appendix B, the Administrative and Technical Report, the association between prenatal alcohol exposure, physical size, dysmorphology and neurodevelopment systematic review report, supplemental files, and the peer reviewed publication (Akison, Hayes et al. 2024) provide detailed information regarding the evidence review process and findings.

Figure 2 offers a visual overview of the evidence synthesis process underpinning the GRADE-based recommendations. Figure 3 provides a visual overview of the domains that contributed to the strength of a recommendation through the individual evidence-to-decision frameworks for each of the candidate diagnostic features and the overarching evidence-to-decision framework for the diagnostic criteria.

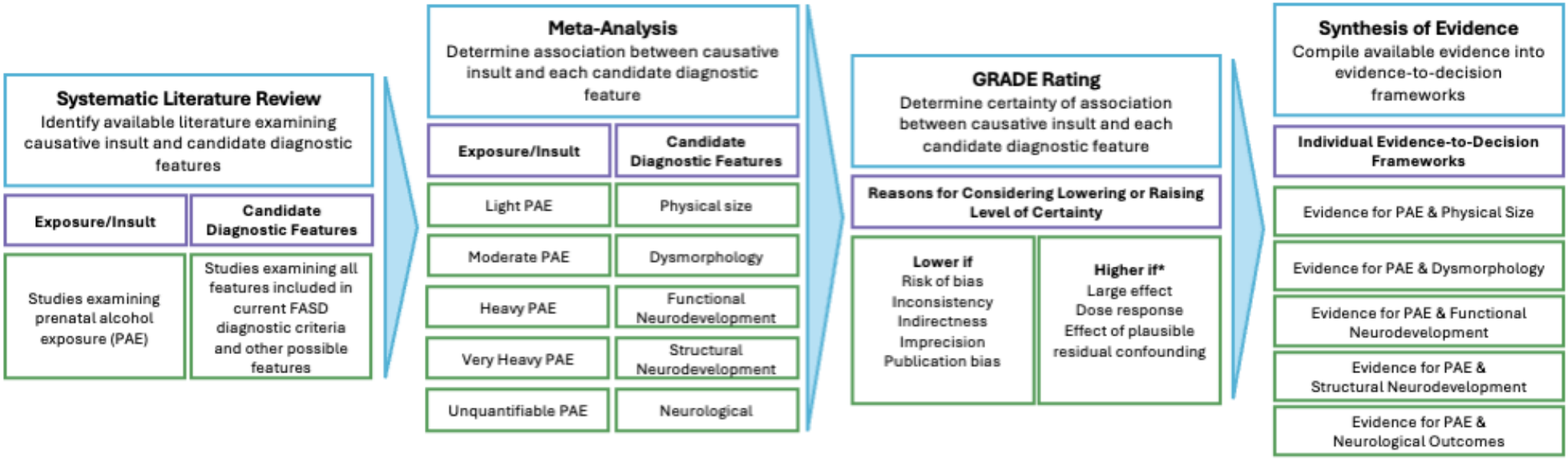


Figure 2. Evidence synthesis process underpinning the GRADE-based recommendations.

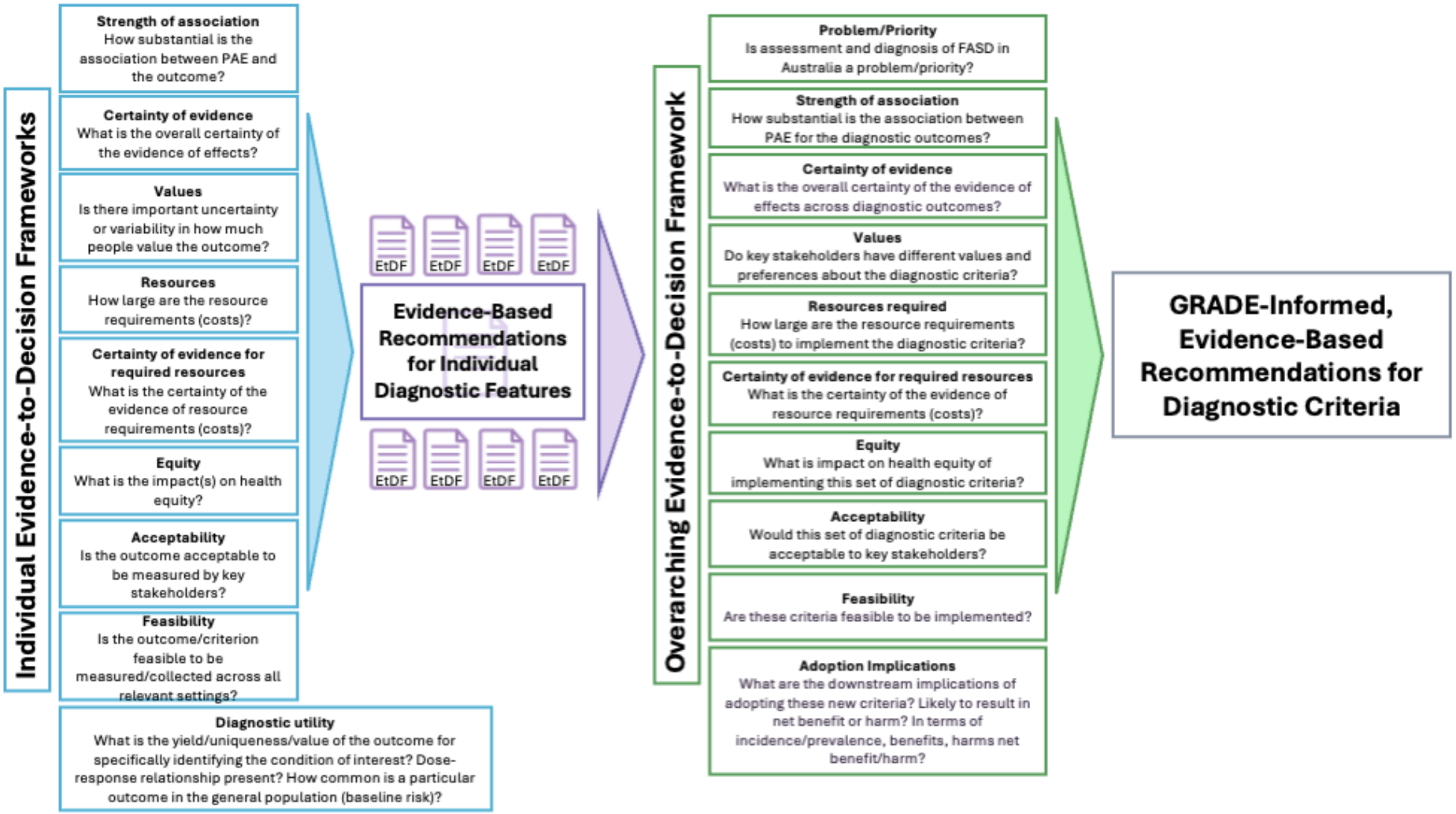


Figure 3. Multi-stage evidence-to-decision framework process applied in the development of the GRADE-based recommendations.

2.3 Overview of Actionable Statements (Recommendations)

GRADE-based Recommendation 1 **Conditional**	The Australian FASD Guidelines Development Group suggests the following key diagnostic considerations: • evidence of prenatal alcohol exposure above a low risk level for diagnosis of FASD at any time during gestation. Or, in the absence of a confirmed history of PAE following exclusion of other causes, the presence of three sentinel facial features (short palpebral fissures, thin upper lip and smooth philtrum) • presence of pervasive and clinically significant neurodevelopmental impairments • the neurodevelopmental impairments result in functional impacts that necessitate significant supports across multiple areas • the onset of neurodevelopmental impairments is evident during the developmental period • an individual's presentation is not better attributed to another condition or exposure • any of the relevant diagnostic specifiers are applied (i.e., physical size, head circumference and/or facial features) (Variable Certainty).
GRADE-based Recommendation 2 **Conditional**	The Australian FASD Guidelines Development Group suggests that birthweight, corrected for gestational age, according to the appropriate age- and sex-specific charts, be considered in the diagnosis of FASD and to account for individual variability it has been listed as a diagnostic specifier (Low to Moderate Certainty).
GRADE-based Recommendation 3 **Conditional**	The Australian FASD Guidelines Development Group suggests that birth length, corrected for gestational age, according to the appropriate age- and sex-specific charts, be considered in the diagnosis of FASD and to account for individual variability it has been listed as a diagnostic specifier (Very Low to Low Certainty).
GRADE-based Recommendation 4 **Conditional**	The Australian FASD Guidelines Development Group suggests that postnatal child weight, according to the appropriate age- and sex-specific charts, be considered in the diagnosis of FASD and to account for individual variability it has been listed as a diagnostic specifier (Very Low to Low Certainty).
GRADE-based Recommendation 5 **Conditional**	The Australian FASD Guidelines Development Group suggests that postnatal height, according to the appropriate age- and sex-specific charts, be considered in the diagnosis of FASD and to account for individual variability it has been listed as a diagnostic specifier (Very Low to Low Certainty).

GRADE-based Recommendation 6 **Conditional**	The Australian FASD Guidelines Development Group suggests that philtrum smoothness, vermilion thinness, and palpebral fissure length be considered in the diagnosis of FASD and to account for individual variability it has been listed as a diagnostic specifier (Very Low to Low Certainty).
GRADE-based Recommendation 7 **Strong**	The Australian FASD Guidelines Development recommends against including other congenital anomalies in the diagnostic criteria for FASD (Low to Low Certainty).
GRADE-based Recommendation 8 **Conditional**	The Australian FASD Guidelines Development Group suggests that head circumference, corrected for gestational age according to the appropriate age- and sex-specific charts, be considered in the diagnosis of FASD and to account for individual variability it has been listed as a diagnostic specifier (Very Low to Low Certainty).
GRADE-based Recommendation 9 **Strong**	The Australian FASD Guidelines Development Group recommends against including structural brain abnormalities observed on clinical imaging in the diagnostic criteria for FASD (Very Low Certainty).
GRADE-based Recommendation 10 **Strong**	The Australian FASD Guidelines Development Group recommends against including neurological conditions of hearing and vision impairments, seizures, and cerebral palsy in the diagnostic criteria for FASD (Very Low to Low Certainty).
GRADE-based Recommendation 11a **Conditional**	The Australian FASD Guidelines Development Group suggests that neurodevelopmental outcomes of communication, motor skills, intellectual abilities, attention, memory, executive function, emotional and/or behavioural regulation, literacy and/or numeracy, and adaptive/social functioning, be considered in the diagnosis of FASD (Very Low to Low Certainty).
GRADE-based Recommendation 11b **Strong**	The Australian FASD Guidelines Development Group recommends against including neurodevelopmental outcomes of social cognition, social communication/pragmatics, motor speech impairments, speech-sound impairments, and sensory processing in the diagnostic criteria for FASD (Very Low to Low Certainty).
Lived Experience Statement 1	Listen to, and take seriously, concerns raised by parents/caregivers about their child's development and behaviour in the context of prenatal alcohol exposure (Moderate to High Certainty).

Lived Experience Statement 2	Provide or refer for assessment if a parent/caregiver is concerned about their child's development in the context of prenatal alcohol exposure (Moderate to High Certainty).
Lived Experience Statement 3	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 services, child development services, adolescent and adult private and public health services, primary care, mental health, disability, justice, and child protection services (Moderate Certainty).
Lived Experience Statement 4	Provide non-judgemental and non-stigmatising support that acknowledges and respects the individuals', and their parent/caregivers,' experiences and concerns (Moderate Certainty).
Lived Experience Statement 5	Understand that receiving a diagnosis can bring about mixed emotions. Plan feedback and recommendations with this in mind (High Certainty).
Lived Experience Statement 6	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 (High Certainty).
Lived Experience Statement 7	Recognise an individual's strengths and challenges to identify the most appropriate supports to facilitate positive outcomes post-assessment (High Certainty).
Lived Experience Statement 8	Be mindful that parents/caregivers and family members can have concerns regarding their child's future diagnosis. Provide recommendations to relevant local services that can provide emotional supports (Moderate to High Certainty).
Lived Experience Statement 9	Tailor feedback sessions and reports to individual and family needs, including relevant social and cultural factors (High Certainty).
Lived Experience Statement 10	When writing reports, emphasise the individual's strengths and interests, whilst also addressing areas needing support (High Certainty).
Lived Experience Statement 11	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 (High Certainty).

Good Practice Statement 1	If there is information suggesting prenatal alcohol exposure above a low risk level, including before pregnancy recognition, discuss assessment options, and after obtaining informed consent, provide assessment information or support access to assessment.
Good Practice Statement 2	If there is information documenting clinically significant neurodevelopmental impairments, distinctive facial features, and/or confirmed or suspected prenatal alcohol exposure above a low risk level, discuss assessment options, and after informed consent, provide assessment information and support to access appropriate assessment.
Good Practice Statement 3	Sensitively and respectfully include discussions about alcohol use and potential risks as part of routine antenatal and postnatal care.
Good Practice Statement 4	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 5	To support accurate assessment of risk, assess prenatal alcohol exposure both before and after pregnancy recognition. Standardised screening tools, such as the AUDIT-C, are recommended to assess alcohol intake.
Good Practice Statement 6	Explain what a standard drink of alcohol is before asking about alcohol use, and consider using a standard drinks guide to help obtain accurate information on intake (e.g., see the NHMRC Alcohol Guidelines). Where appropriate, practitioners can also gather information on intake and later convert the amount consumed to standard drinks.
Good Practice Statement 7	Be mindful there are many factors that may have influenced alcohol use during pregnancy, and it is important to collect information in a supportive, compassionate, and non-judgemental way.
Good Practice Statement 8	Recognise that individuals might face ongoing challenges with alcohol or other complex issues and provide appropriate support and referrals.
Good Practice Statement 9	Contact biological parents directly, if possible and appropriate, to assess prenatal alcohol exposure. 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 pregnancy is not sufficient to confirm exposure.
Good Practice Statement 10	Consider that self-reports of prenatal alcohol exposure 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, reported in antenatal records, or later in the child's life). Practitioners may wish to re-contact biological parents to check previously collected information.
Good Practice Statement 11	Sometimes there may be inconsistencies in the available information about prenatal alcohol exposure. In instances where information is collected directly from the pregnant individual during an assessment, this information should be prioritised over other sources. Practitioners can document inconsistencies in information and indicate that re-assessment may be considered should additional information arise.
Good Practice Statement 12	Practitioners should consider the appropriateness of all aspects of a 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 13	When assessing facial features, the University of Washington (UW) Lip-Philtrum Guide is recommended. Guide 1 (Caucasian) is recommended for less full lips, and Guide 2 (African American) for fuller lips.
Good Practice Statement 14	When assessing facial features, the Strömland et al. (1999) palpebral fissure norms are recommended. These norms are the best available for all Australians, and span birth to adulthood.
Good Practice Statement 15	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 facial analysis software is not available.
Good Practice Statement 16	Photographs and/or clinical measurements and analysis can be undertaken by practitioners with specific facial feature measurement training, and/or with instruction provided by experienced practitioners. Adequacy and interpretation of photographs needs to be considered in conjunction with an experienced medical practitioner.
Good Practice Statement 17	Examine and document any 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 18	Consider other syndromes, genetic conditions, or teratogenic disorders in which dysmorphic features and/or neurodevelopmental impairment can also be present. If unsure, refer to a clinical geneticist for review.
Good Practice Statement 19	With informed consent and assent, as clinically appropriate and in line with local health service guidelines, request chromosome microarray (CMA) and DNA test for fragile X syndrome (FXS). These tests can be done using blood

	or buccal swabs. Refer to a local genetic health service for guidance if abnormalities are reported.
Good Practice Statement 20	Medical professionals should complete and request additional tests as clinically indicated to identify and monitor current physical health (e.g., cardiovascular-kidney-metabolic health), and exclude other potential impacts on functioning, such as thyroid tests, vitamin B12, iron studies and imaging.
Good Practice Statement 21	Physical size can vary due to a wide range of demographic, maternal, placental, and fetal factors. Identifying what is an 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 22	The WHO (2006) growth standards are recommended to assess birth weight, length and head circumference of full-term infants. Information may be available in hospital birth records or a baby's personal health records (e.g., red, blue, or yellow books).
Good Practice Statement 23	The Fenton growth charts are recommended to assess birth weight, length, and head circumference corrected for gestational age of preterm infants. Information may be available in hospital birth records or a 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 24	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 has adopted the WHO (2006) growth standards for all children.
Good Practice Statement 25	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 assess how they are developing physically.
Good Practice Statement 26	Take a holistic needs-based and family-centred approach to assessment. This can involve considering strengths and challenges, functioning, wellbeing, environment, culture, participation and supports. Gather this information in ways that work best for the individual and their family/support network.
Good Practice Statement 27	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 28	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, 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 29	There are no standardised tools specific for the diagnosis of FASD. Where appropriate, practitioners should use discipline specific standardised tools relevant to the neurodevelopmental domain being assessed. Practitioners need to apply their discipline specific knowledge, professional expertise, and clinical judgement to determine the most appropriate approaches for examining the individual within the context of the assessment. Allied health practitioners have specialist knowledge and skills to assess the neurodevelopmental domains. If unsure, practitioners should seek clinical supervision.
Good Practice Statement 30	Depending on a person's presentation, conducting assessment across different timepoints can assist in determining whether challenges are persistent. These assessments can happen in various places, including primary health care, schools, and private practice, not just at specialist services.
Good Practice Statement 31	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 whether they meet criteria for diagnosis.
Good Practice Statement 32	It is important to consider the neurodevelopmental challenges in the context of environmental factors. Interpreting assessment results requires a holistic 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 33	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 supporting the same results, or current assessment is unable to be completed due to significant behavioural challenges). The decision to retest an individual will depend on the context, referral question and the individual's needs.
Good Practice Statement 34	Assessment will naturally vary based on the availability of resources. Where multi-disciplinary services are not available or cannot be accessed, engagement with other services through a shared-care approach is suggested to support accessibility to assessment and diagnostic services.
Good Practice Statement 35	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 36	Practitioners should consider, offer, and explain one or more diagnostic possibilities in their formulation, 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 37	Involve individuals and families in diagnostic decisions. Individuals and families have the right to decide if diagnoses are appropriate for them, and the diagnostic terminology that is applied, given their personal, social, and cultural context and beliefs. Sometimes, challenges can arise balancing the rights of the individual and the rights of the parent/caregiver; actively engaging and supporting all parties throughout the assessment can help to overcome these challenges.
Good Practice Statement 38	With consent, provide developmentally appropriate feedback to individuals attending for assessment, in coordination with parents/caregivers and/or other support people.
Good Practice Statement 39	Recognise that observed challenges might have multiple explanations and communicate this to individuals and families to enable effective supports.
Good Practice Statement 40	Include individuals and families in the development of report recommendations, respecting their preferences and needs, given their personal, social, and cultural context.

Implementation Consideration, Tool, and Tip 1	Practitioners can integrate the International Classification of Functioning, Disability, and Health (ICF) into their assessments. The background history taking, and case formulation templates provided in Appendix D include some of the relevant ICF areas.

Implementation Consideration, Tool, and Tip 2	Practitioners are encouraged to use shared decision making. See Shared decision making: an overview for further general information. '*Finding your way*' is a shared decision-making resource 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, in the assessment process section of this document, and in the FASD Indigenous Framework.
Implementation Consideration, Tool, and Tip 3	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 Consideration, Tool, and Tip 4	For individuals and families where English is a second/additional language, it is a requirement of The National Safety and Quality Health Service Standards that interpreting services are available where appropriate. https://www.safetyandquality.gov.au/standards/nsqhs-standards
Implementation Consideration, Tool, and Tip 5	Assessment and diagnosis of FASD 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
Implementation Consideration, Tool, and Tip 6	In line with the FASD Indigenous Framework, the informed consent and assent process needs to 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 are equally valued.

	To support a culturally comfortable and safe environment, practitioners can incorporate information and visual resources to explain: • what the referral and/or assessment is for • what the assessment process generally involves • what the potential outcomes and follow-up from the assessment may involve • the potential benefits and risks. Where appropriate, this may include the use of other languages, and support from an interpreter or cultural consultant. 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 involved have genuine control over decisions about their healthcare. This can only be achieved if the person and their family have been supported to make an informed choice about whether an assessment is something they want to undertake.
Implementation Consideration, Tool, and Tip 7	Different approaches to informed consent and assent may be required depending on the assessment context. For example, where the referral question is about assessing the possibility of FASD, informed consent and assent specific to FASD should be obtained at the outset. In circumstances where information about PAE emerges later in the assessment process (i.e., is not the basis of the referral), obtaining additional informed consent and assent related to FASD assessment is warranted.
Implementation Consideration, Tool, and Tip 8	To support early identification of prenatal factors that can influence developmental outcomes, information that could affect longer-term health outcomes for children 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 on the parents should be included. The Advisory Groups reported that transfer of information from the pregnancy record is 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 in Victoria, where information from the Birthing Outcomes system is automatically copied from the maternal discharge to the newborn discharge. During the guideline development process, a procedure was also established in Queensland to support the automatic transfer of a minimum

	amount of prenatal information through the integrated Electronic Medical Record.
Implementation Consideration, Tool, and Tip 9	Prenatal alcohol exposure 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 not to make assumptions about the likelihood of prenatal alcohol exposure or FASD based on an individual's sociodemographic features. Members of the Living Experience Advisory Group described experiences where they were not asked about prenatal alcohol exposure 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 prenatal alcohol exposure.
Implementation Consideration, Tool, and Tip 10	A practitioner resource in Appendix D provides an overview of the Alcohol Use Disorders Identification Test-Consumption (AUDIT-C) tool structured to collect information on alcohol consumption pre- and post-pregnancy recognition.
Implementation Consideration, Tool, and Tip 11	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, information regarding FASD is sometimes included (as reported by the Advisory Groups). Where available, we suggest that information about FASD and local services can be uploaded to Health Pathways or other available electronic referral systems to support provision of information to primary health care professionals and facilitate streamlined assessment processes.
Implementation Consideration, Tool, and Tip 12	Challenges with gathering prenatal history for children in out-of-home care were discussed as a major barrier to assessment across Advisory Groups. To support collection of accurate prenatal alcohol exposure information the following implementation considerations are noted:

- Information about prenatal alcohol exposure should be documented alongside other relevant prenatal factors (e.g., other drug exposures, domestic violence, family medical history).
- As part of training resources for child protection staff, include information on how to collect and document information accurately on prenatal alcohol exposure, as well as local referral pathways.
- Prenatal alcohol exposure is not a reason for a child to be placed into out-of-home care. There can be many reasons why prenatal alcohol exposure occurs, including exposure that occurred before an individual knew they were pregnant, pre-existing alcohol use disorder or drinking to cope with domestic violence, or other traumatic circumstances. Pregnant individuals need to feel safe to discuss their concerns and to seek help for themselves and their children, without the fear of their children being removed.
- Information about assessment, diagnosis, and recommendations should be incorporated into a child's health management plan and this information be provided to foster and kinship carers.

Implementation Consideration, Tool, and Tip 13

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."* While the UNCRC comment concerns children, this should also be considered in the context of adult justice.

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).

To facilitate collection of accurate prenatal alcohol exposure information in these contexts, and the provision of appropriate supports, the following implementation considerations are noted:

	• Where appropriate, collect and document information about prenatal alcohol exposure 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 appropriate assessment providers. • Provide information and training about accurate collection and documentation of prenatal alcohol exposure and local referral pathways to all professionals in legal and justice contexts. • 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.
Implementation Consideration, Tool, and Tip 14	More information about the University of Washington Lip-Philtrum Guides is available from their website, including instructions regarding how to order the electronic versions: https://depts.washington.edu/fasdpn/htmls/lip-philtrum-guides.htm
Implementation Consideration, Tool, and Tip 15	A palpebral fissure norm calculator can be accessed from the University of Washington website: https://depts.washington.edu/fasdpn/htmls/diagnostic-tools.htm
Implementation Consideration, Tool, and Tip 16	Appendix D provides an example history taking template that includes prenatal, developmental, behavioural, functional, wellbeing and participation domains that could be adapted to suit different clinical contexts.
Implementation Consideration, Tool, and Tip 17	Appendix D provides a holistic profile and diagnostic formulation template that can be adapted to suit different clinical contexts.
Implementation Consideration, Tool, and Tip 18	Appendix E provides information regarding and example resources to support collaborative goal setting, which can be used to develop tailored recommendations.

Chapter 3 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

Chapter 3: Foundational Considerations

These guidelines aim to be transtheoretical integrating 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 4).

Combining these perspectives is essential because FASD 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 "is not an equal opportunity birth defect." Alcohol use does not occur in a vacuum; it is related 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 (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. These factors can either exacerbate or ameliorate the effects of the exposure. These foundational considerations aim to support practitioners in adopting a broader perspective in the assessment and diagnosis of FASD.

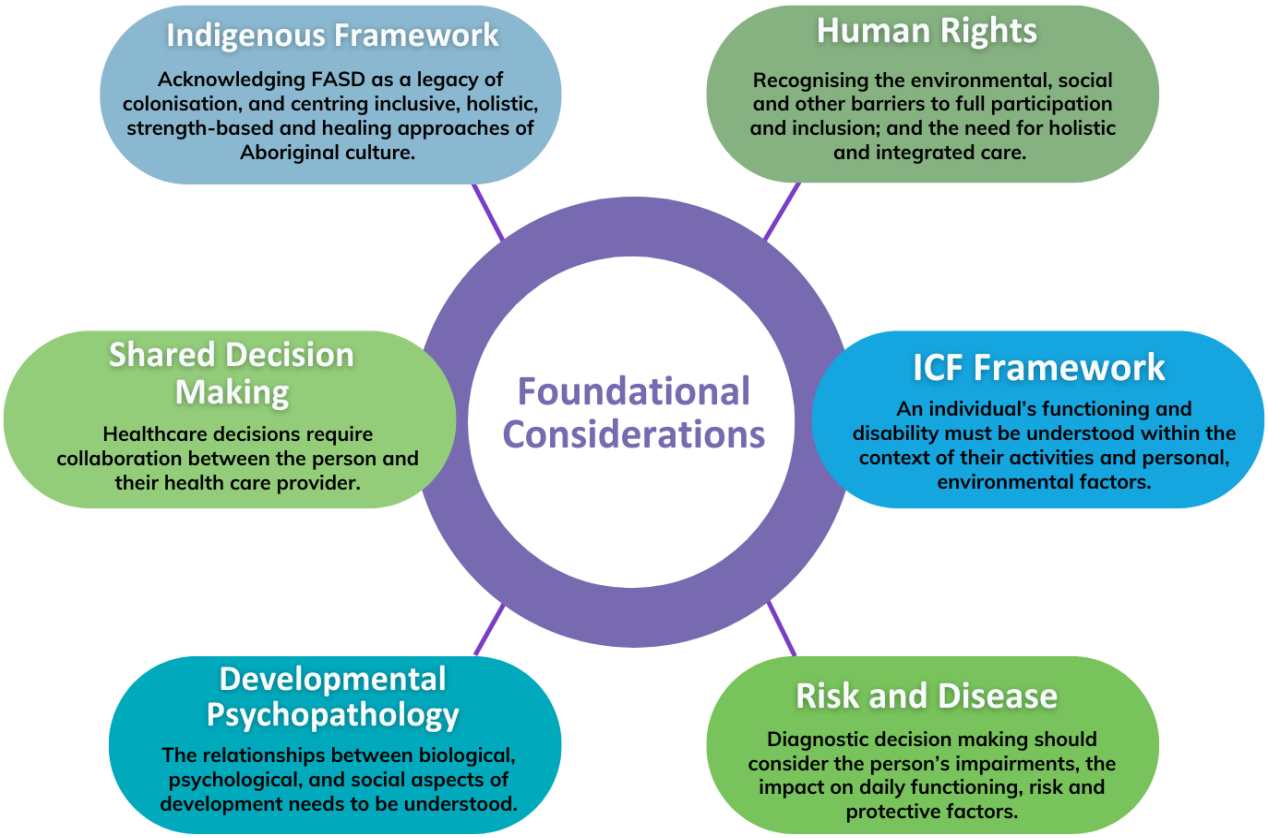


Figure 4. Overview of the conceptual frameworks underpinning the guidelines

3.1 Indigenous Framework

In the spirit of genuine reconciliation, truth-telling, and justice, a fundamental driver of these 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 was 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. 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 of eliminating Aboriginal and Torres Strait Islander culture from Australian society. These 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 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 5; Table 1). The colours from the artwork have been incorporated throughout the guidelines 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 knowledge, services, and support among Aboriginal peoples (Figure 6). The Framework presents an opportunity for all Australians to walk alongside each other, in solidarity, to heal the impacts of FASD on the Australian community. This is achieved by drawing on the wisdom of Western health approaches and therapeutic models and the wisdom of strengths-based Aboriginal approaches grounded in holistic and integrated support, creating new knowledge and practice that offers immense benefit to the quality of assessment and support for all Australians. 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 5. 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

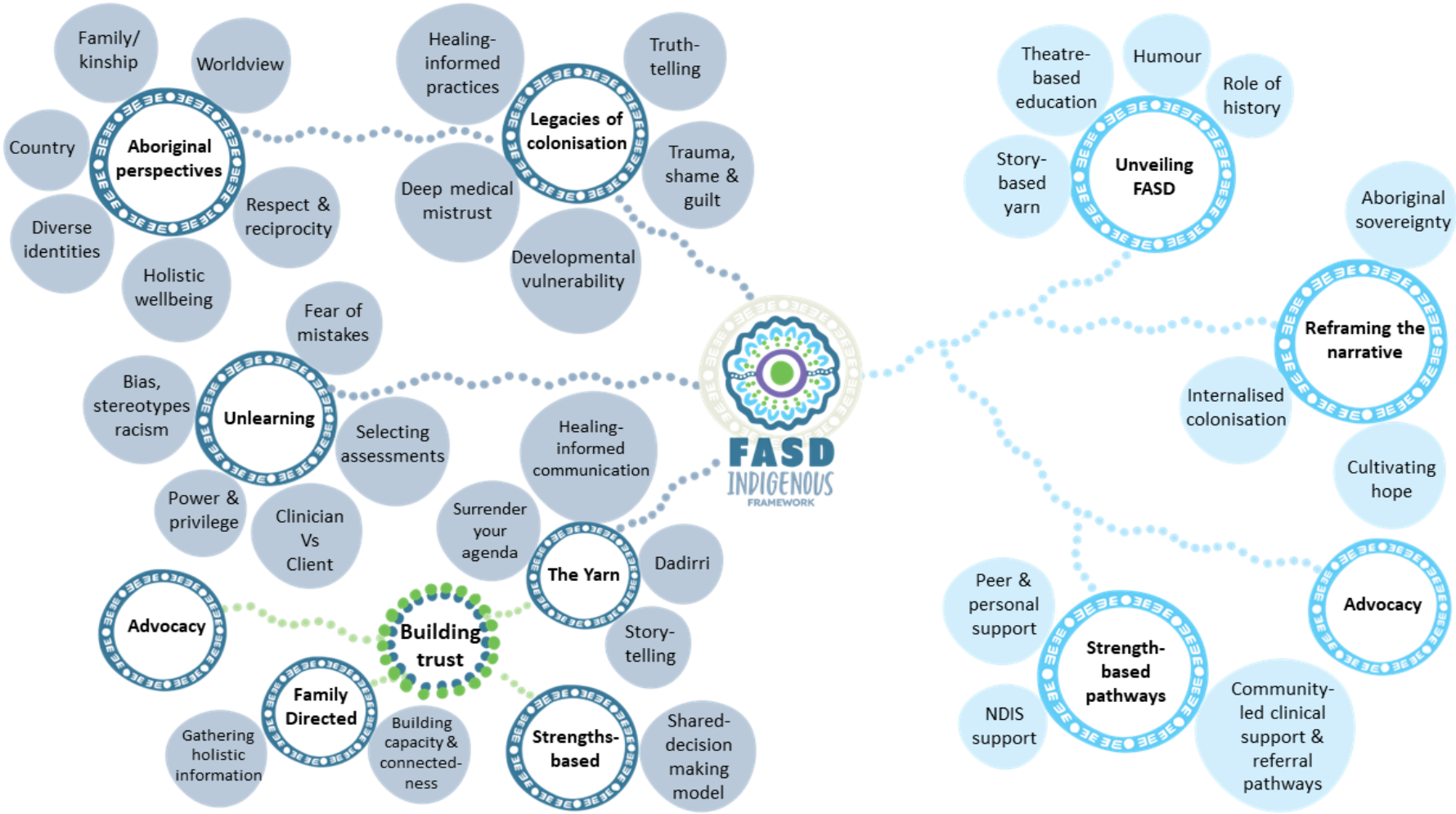


Figure 6. The FASD Indigenous Framework. The dark blue represents what practitioners need to know, be, and do to deliver culturally responsive and healing-informed FASD knowledge, services, and support, to Aboriginal peoples. The light blue represents what Aboriginal communities at a grass roots level need to know, be, and do to access FASD knowledge, services, and support.

3.2 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, along with the Leave No One Behind Principle (LNOB; United Nations, 2017), provide critical recommendations for the design and delivery of assessment and diagnostic services.

To align with a human rights model of disability, assessments should not soley focus on an individual's impairments (Waddington & Priestley, 2021). Instead, they should also explore social determinants of health, strengths, wellbeing, environmental and personal factors, and the support requirements of persons with disabilities. This holistic approach is supported by recent research in the field of FASD, highlighting the importance of 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, 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, acknowledging them 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.

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

One approach supports 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 7).

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.

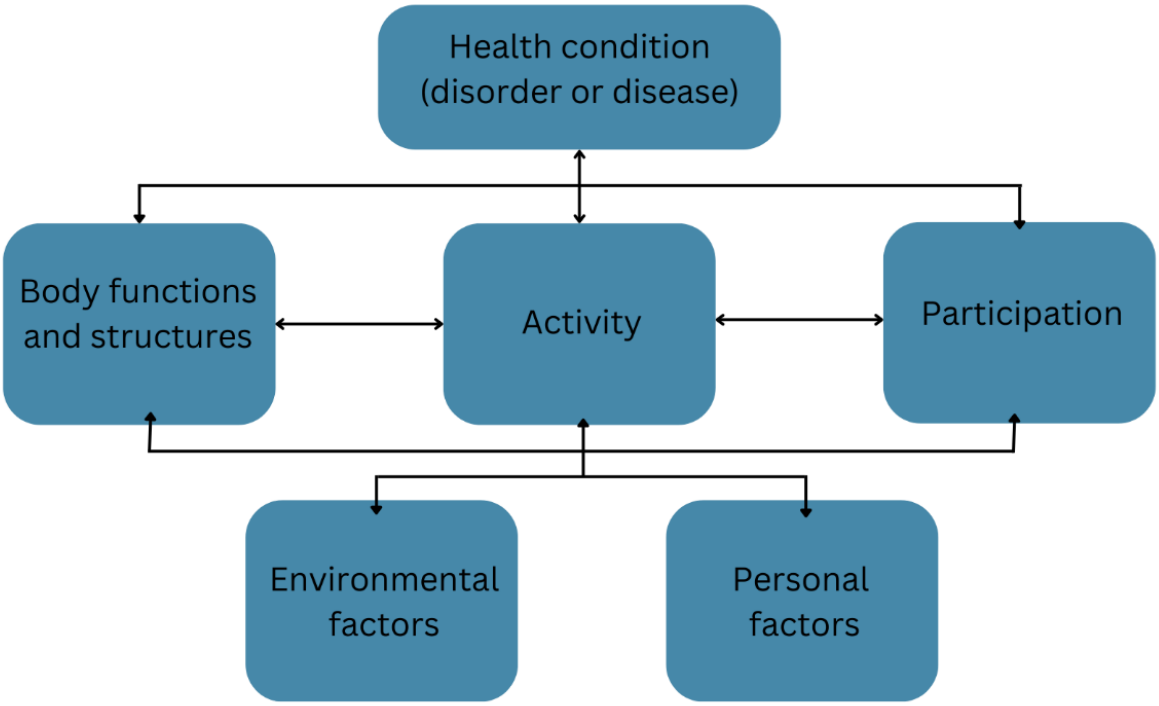


Figure 7. Interactions between components of the International Classification of Function Framework

Source: WHO 2001: 18.

Implementation Consideration, Tool, and Tip 1	Practitioners can integrate the International Classification of Functioning, Disability, and Health (ICF) into their assessments. The background history taking, and case formulation templates provided in Appendix D include some of the relevant ICF areas.

3.4 Shared Decision-Making

Shared decision-making is an approach that can support assessment and diagnostic practices aligns with human rights models. It *"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 asking questions, making informed decisions, and expressing 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. 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. 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 applications 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). Advocating for involving allied health professionals to identify the necessary resources required to assist people in shared decision-making.

Implementation Consideration, Tool, and Tip 2

Practitioners are encouraged to integrate shared decision-making into the assessment process.

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

'*Finding your way'* is a shared decision-making resource 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, in the assessment process section of this document, and in the FASD Indigenous Framework.

As the model below illustrates, physical, social, and emotional wellbeing is the goal of this practice, and surrounding this, is the scaffolding required to support this goal. This tool offers prompts to facilitate a yarn in a way that Aboriginal and Torres Strait Islander peoples can feel safe and can make informed decisions. These decisions are based on each family's unique circumstances, values and beliefs.

The model highlights important areas that can be yarned about to enable informed decision-making. These yarns are circular as illustrated in the model. There is no standard linear way to hold these yarns, but it is important that they are led by the Aboriginal or Torres Strait Islander person and their family.

3.5 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).

This approach has been applied to the study of FASD to help understand and support the self-regulatory challenges of individuals with FASD (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, this approach can assist in integrating areas such as 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 adopt 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.

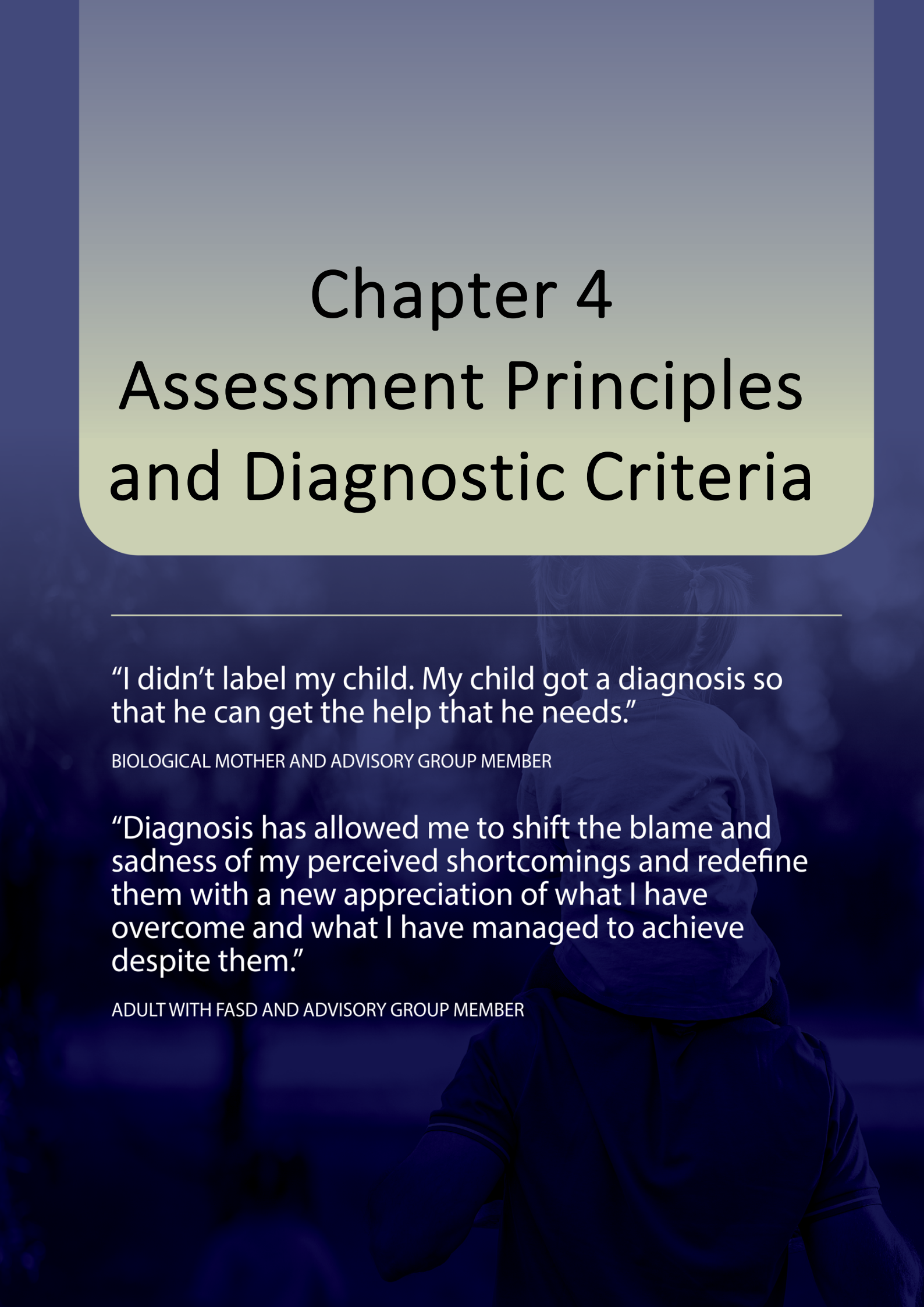
3.6 Risk and Disease

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. In the disability field, this is more commonly referred to *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. Further information is provided to support practitioners in reflecting on these elements in their decision-making.

Chapter 4
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

Chapter 4: Assessment Principles and Diagnostic Criteria

4.1 Assessment Principles to Support Application of the Diagnostic Criteria.

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

- For those already diagnosed with FASD under previous criteria, re-assessment is only needed if clinically indicated.
- PAE can result in a wide range of whole-body outcomes from subtle to severe. In diagnosing FASD, the aim is to identify individuals who are experiencing pervasive, persistent, and clinically significant impairments that impact daily functioning.
- Assessment should include input from health professionals across multiple disciplines and be guided by value-based and person-centred care principles. This approach places the individual and their support network at the centre of care, fostering trust, mutual respect, and active engagement in decision-making.
- 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 available information is essential to determine the best explanations for an individual's presentation.
- 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 can and should take place across the lifespan. Individual attributes that may manifest as barriers to equitable inclusion may only become evident with age. Periodic Review should occur when clinically indicated, considering the supports in place, and the potential impacts of major life transitions on functioning.
- In providing a diagnosis of FASD, practitioners determining that an individual is impacted by a life-long condition. This means impairments are not transient, due to changes in current circumstances or enduring environmental adversity. However, practitioners also need to consider how an individual may change over time due to life experiences and opportunities, formal supports or the lack thereof, as well as changing expectations across life stages and contexts.
- Practitioners are encouraged to seek relevant discipline-specific professional development and clinical supervision, preferably from those with specific FASD expertise to support them in undertaking assessment and diagnosis in their specific settings, whilst also being mindful of professional and ethical guidelines.

4.2 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). Therefore, the following criteria do not form strict rules for diagnosis but provide evidence-based guidance to inform assessment, diagnostic reasoning, and case formulation.

Please note that additional information is provided in the sections following the diagnostic criteria to support implementation.

Fetal alcohol spectrum disorder (also termed neurodevelopmental disorder associated with prenatal alcohol exposure).

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

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

1. Prenatal alcohol exposure (PAE) above a low risk level at any time during gestation, including prior to pregnancy recognition. *See the additional information for further details to support assessment of PAE risk.* 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, following the exclusion of other causes, 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.

B. Presence of pervasive neurodevelopmental impairments.

This is evidenced by clinically significant impairments in three or more neurodevelopmental domains (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 by 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 impairments. Practitioners should use standardised tests where appropriate, but not rely solely on these tests in assessing the significance of impairments and functional impacts. *See further information below on defining clinically significant impairments.*

Note: In infants and young children, in the absence of direct evidence of clinically significant impairments, following exclusion of other causes, microcephaly (≤ 3rd percentile) may be used as an indicator of neurodevelopmental impairment, meeting criterion B.

C. The neurodevelopmental impairments result in functional impacts that necessitate significant supports across multiple areas of functioning, relative to an individual's developmental stage and cultural context.

D. The onset of neurodevelopmental impairments is evident during the developmental period

Note:

- 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 the demands of life and context exceed developmental capabilities. Repeat assessments may therefore be required.

E. An individual's presentation is not better attributed to another condition or exposure.

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

- *Predisposing/familial (*e.g., family history of learning disorders, cognitive impairments, mental ill-health, intergenerational trauma).
- *Genetic conditions (*e.g., Fragile X, chromosomal variants including microdeletion or duplication syndromes, or single gene disorders 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., nutritional deficiencies during 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 [e.g., genetic epilepsy syndromes, developmental and epileptic 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 the following physical features:

- 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: These physical features provide clinically meaningful information and are an important part of the assessment. These features are not provided as specifiers to diminish their importance but because not all individuals will present with these physical features. This approach encourages practitioners to document these physical features along a continuum, informing both current and future clinical care and research.

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

Co-occurring conditions: FASD can co-occur with a wide range of conditions. This includes but is not limited to other neurodevelopmental conditions (e.g., ADHD, ASD, language disorder, specific learning disorder) and mental health conditions (e.g., anxiety, depression, trauma and other stressor-related conditions, substance use conditions). Assessment should consider 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 assist in understanding the individual's needs.

At risk of FASD: In situations where PAE above a low risk level is confirmed and developmental concerns are identified, but available assessment is insufficient to determine if pervasive and clinically significant impairments exist, or assessment could not be completed due to a young child's capacity to engage in assessment, individuals may be considered 'at risk of FASD' with follow-up and reassessment recommended. Practitioners should specify why the 'at risk' designation has been used. This designation should not be used when neurodevelopmental impairments are present, and PAE is suspected, but has not been confirmed (see alternate diagnostic terminology below); or when an assessment and diagnosis are not possible due to limited resources.

Diagnostic terminology: There are different diagnostic terminologies available for the diagnosis of FASD and associated presentations. DSM-5-TR terminologies and codes include:

DSM-5-TR: Other Specified Neurodevelopmental Disorder (F88)

- Neurodevelopmental disorder associated with prenatal alcohol exposure. This is equivalent to a diagnosis of FASD and may be applied interchangeably.

DSM-5-TR: Unspecified Neurodevelopmental Disorder (F89)

This terminology could be applied for individuals who have clinically significant neurodevelopmental impairments, where PAE was not confirmed, and/or when an individual does not meet full criteria for any of the conditions in the neurodevelopmental disorders diagnostic class. This terminology could also be applied where individuals and families do not want to specify the prenatal alcohol exposure.

There are also terminologies included in the **ICD-10** (other congenital malformations - fetal alcohol syndrome [Q86.0] and **ICD-11** (fetal alcohol syndrome [LD2F.00]; other specified neurodevelopmental disorder [6A0Y] - neurodevelopmental syndrome due to prenatal alcohol exposure) that may be relevant for public health system coding requirements.

Individuals and families may have a preference to use these or other non-medical self-identifying terms (e.g., neurodivergent) that support their autonomy in defining their own identity.

Recognising the diverse perspectives on diagnostic terminology in Australia, and in alignment with the foundational considerations of these guidelines, it should be considered a right of an individual and their family to have choice and control over the terminology that is applied.

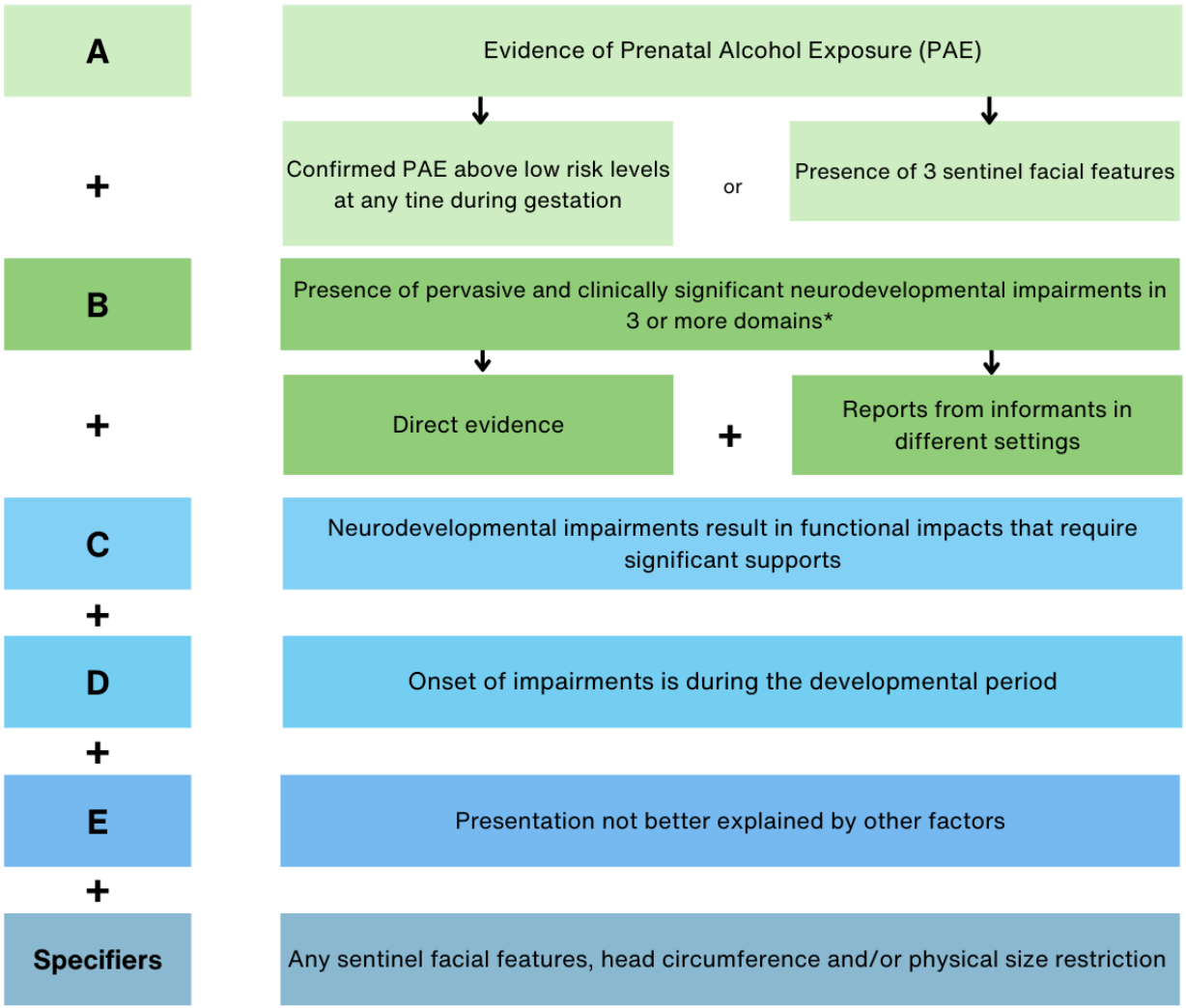


Figure 8. Visual summary of the diagnostic criteria

4.3 Additional Information

4.3.1 Structure of the diagnostic features, diagnostic specifiers, and associated features.

A diagnostic framework aligned with other neurodevelopmental conditions included in the DSM-5-TR was used to integrate the findings from the evidence review. Clinical features with sufficient evidence that must be present were included as diagnostic features. Clinical features with sufficient evidence that may or may not be present, were included as diagnostic specifiers. Other features without sufficient evidence but that may be present at higher rates in individuals with FASD were included as associated features. This structure reflects the heterogeneity of FASD presentations and provides an evidence-based framework adaptable to new evidence.

4.3.2 Criterion A: Prenatal alcohol exposure (PAE)

PAE is a key factor in differentiating FASD from other conditions. Practitioners need reliable evidence of PAE at levels that could lead to adverse outcomes.

- Risk and protective factors for harm need to be considered at all PAE levels.
- Increased risk for FASD is observed with increased exposure. However, no safe level of PAE has been established.
- The PAE standard drink levels from the evidence review were included to compare diagnostic outcomes at different exposure levels but should not be used as clinical cut-offs for diagnosis.
    - In the absence of quantifiable PAE, practitioners should consider available information to inform the assessment of risk. For example, biological parents may not be available to interview, or the biological parents may not recall precise details. However, other information, such as self-reported information, witness reports, or available records that document episodes of intoxication during the pregnancy, can inform risk assessment.
    - In such instances, after considering the reliability of the information (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.
- Figure 9 provides additional information to support the assessment of FASD risk.

See the prenatal alcohol exposure assessment section for good practice statements and implementation considerations.

Also see the additional information section below on facial features and the medical assessment section to support implementation of Criterion A2.

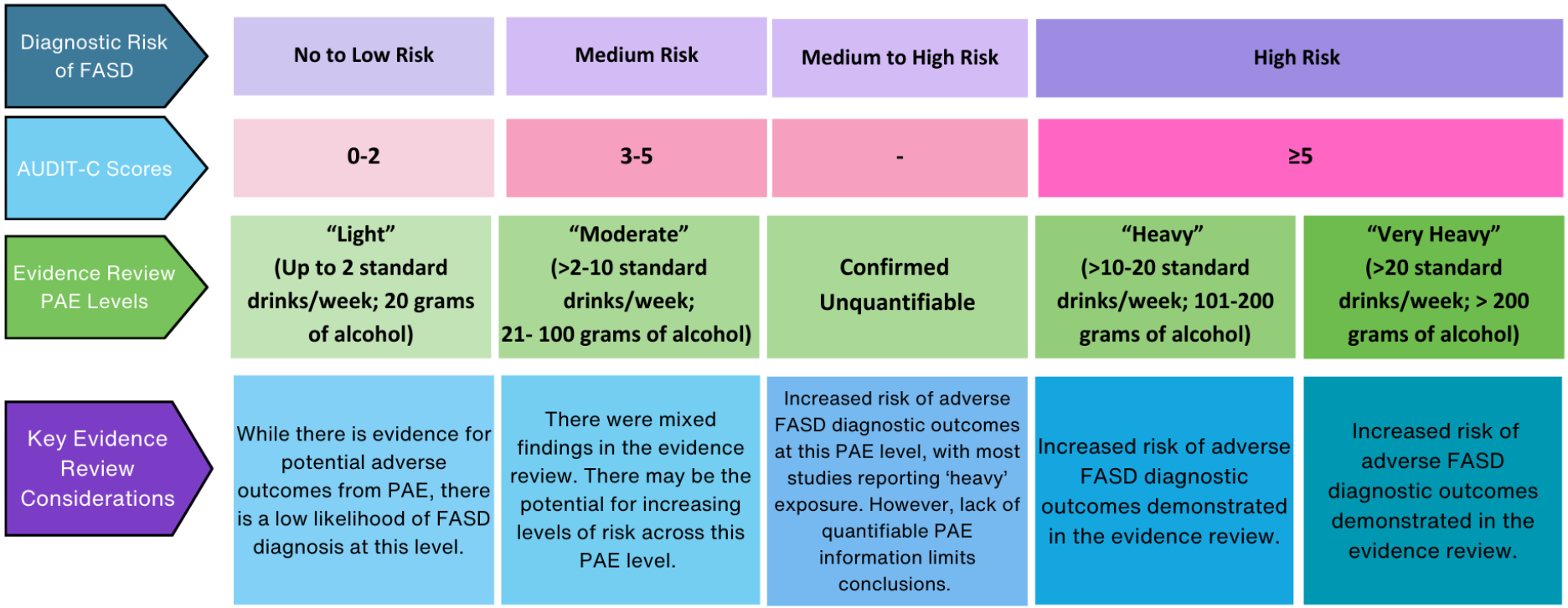


Figure 9. Visual to support the assessment of risk for FASD.

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 was included in the evidence review 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.

4.3.2.1 Further details regarding 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 interpreting PAE risk. Consequently, an extensive evidence review was undertaken. To facilitate appropriate comparisons across the diagnostic outcomes, available evidence was quantified based on the grams of ethanol exposure per week and grouped into different exposure levels (as per Figure 6). However, several key limitations must be considered when applying this evidence in practice at an individual level:

- The review could not 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 limited number of studies available assessing the same outcomes at the same PAE level.
- PAE assessment is typically based on self-report, which remains the most accurate method to assess PAE, due to lack of accuracy of currently available biomarkers and screening tools (e.g., for recent review see Kable and Jones, 2023). However, self-reported PAE information can have limitations, such as memory recall issues and under-reporting due to stigma.
- It is possible that a lower level of PAE at a critical period of gestation could result in adverse outcomes and practitioners need to use clinical judgement when assessing PAE risk.
- Although adjusted outcomes were used where possible, the review often could not control for, or compare, various individual, prenatal, parental, and child factors that may exacerbate or ameliorate the impacts of PAE (e.g., prenatal nutrition, metabolic rates, genetic factors, biochemical and inflammatory responses to alcohol).
- Similarly, although 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 the impacts of PAE (e.g., postnatal environments and traumatic events, postnatal nutrition).

For the full results, see the Association between Prenatal Alcohol Exposure Physical size, Dysmorphology and Neurodevelopment: Systematic Review Report and associated Supplemental Files.

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

4.3.3 Criterion B: Presence of pervasive neurodevelopmental impairments

The evidence review indicated that PAE exposure increases the potential for adverse outcomes across all neurodevelopmental areas included in the diagnostic criteria, wither high levels of PAE associated with increased risk for adverse outcomes.

To demonstrate the pervasive nature and clinical significance of these impairments, there must be evidence that an individual's daily functioning across contexts is negatively impacted in multiple

domains. As such, the Guidelines Development Group have retained the *three or more neurodevelopmental domains criterion*.

Importantly, as discussed in the risk and disease section, while PAE is a risk factor for neurodevelopmental impairments, it is not a predetermined outcome. Practitioners must recognise that having three or more neurodevelopmental domains with clinically significant impairments is neither specific to, nor discriminatory for, FASD, and a wide range of neurodevelopmental conditions must be considered. As such, practitioners will need to consider other possible factors that could explain or contribute to the observed neurodevelopmental impairments (Criterion E) and may need to apply a higher threshold for pervasive impairments in the presence of multiple comorbidities.

The Guidelines Development Group acknowledges that further research is needed to empirically validate criterion B.

4.3.3.1 Applying standardised tests in the assessment

Consistent with the 2016 Guide, Criterion B recommends using standardised tests as part of the assessment. While some of the tests listed in the previous Guide were included in the available evidence contributing to the evidence-to-decision framework outcomes, no studies focused on comparing the clinical utility of specific tests over others within the diagnostic process.

Feedback from the Clinical Advisory Groups indicated that the list of example standardised tests included in the 2016 Guide was potentially being applied rigidly, resulting in assessments that were not person-centred and culturally responsive.

It is widely recognised across professions that there may be circumstances where standardised tests are not appropriate. Some examples include *(note – non limiting list)*:

- Individuals who are extremely low functioning, where standardised tests would not likely produce valid results, 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.
- 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.

In such circumstances, practitioners are encouraged to exercise their professional judgement in the assessment process (including determining to not assess a domain) and to note any limitations to assessment and formulation that may result.

It is also important to reiterate that most normative studies of standardised tests do not include representatives from Australia's culturally diverse population. Therefore, caution must be exercised when using normative data to determine the presence of clinically significant impairments for individuals from different cultures to the population on whom the tests were developed and normed.

Therefore, based on the acknowledged limits to the broad application of tests and their normative data, the expert input from the Clinical Advisory Group, and the lack of evidence found in the current review, the Guidelines Development Group determined that specifying examples of standardised tests was not appropriate. This position is broadly supported by professional representative bodies both in Australia and internationally through their respective Codes of Conduct, Codes of Ethics, and

ethical or practice guidelines on the use of psychometric tests, which in summary direct practitioners to understand the theoretical basis, psychometric properties, and other influences on utility when selecting and using tests and measures in their clinical practice.

The Guidelines Development Group recommends that practitioners apply their discipline specific knowledge, professional expertise, and clinical judgement to determine the most appropriate approaches for examining the individual within the context of the assessment.

4.3.3.2 Determining the clinical significance of neurodevelopmental impairments

There is no universally agreed formal definition of "impairment" (see Assessment Principles section for discussion), and no test, or score can unequivocally determine the presence of an impairment. As such, to decide if clinically significant impairments are present and whether they should contribute to a diagnosis, practitioners are required to consider all the information collected during the assessment. **A percentile range is provided to support diagnostic decision-making (i.e., scores Below Average – Exceptionally Low Scores may be indicative of clinically significant impairments; Table 3)**, but practitioners should be mindful of the following aspects:

Interpreting Standardised Tests

When considering the results of standardised tests, practitioner are reminded that:

- "Scores cannot be impaired; only a function can be impaired" (Guilmette et al., 2020, p. 442); therefore, single test scores do not equal impairment and should not be used in isolation to define impairment, but rather in combination with functional correlates; and
- While tests may contribute to multiple domains due to the connection with various aspects of functioning, a single test score or construct (e.g., attention, working memory, communication) should not be used to establish impairments in multiple neurodevelopmental domains.
- It is the responsibility of the practitioner to understand the theoretical basis of the tests and apply an individualised formulation process to interpret test results and decide how particular test scores and constructs are counted across the neurodevelopmental domains.

Percentiles

Percentiles are a simple and popular metric for interpreting and conveying assessment outcomes. However, practitioners should be familiar with the relevant considerations and challenges in relation to interpreting percentiles in clinical practice (Crawford et al., 2009). Appendix C provides a brief overview of some key considerations for using percentiles.

Cut Scores

The *Standards for Educational and Psychological Testing* (American Educational Research Association et al., 2014) lay the foundational requirements for the development of many widely applied standardised tests used in clinical work across the professionals who may contribute to the FASD diagnostic process. Standards 5.21 through 5.23 specifically address the nuances of developing and applying test cut scores. Readers are directed to this resource to further their understanding.

Beyond the requirements of the above Standards, several other authoritative professional groups have addressed the use of cut scores and the interpretation of test scores more generally (non-exhaustive example list below).

- American Psychological Association Task Force on Psychological Assessment and Evaluation Guidelines: Guidelines 5 through 8 (American Psychological Association, 2020).
- International Guidelines for Test Use: Guideline 2.7, particularly sub-point 2.7.9 (International Test Commission, 2011).
- CATALISE: A multinational and multidisciplinary Delphi consensus study: Identifying language impairments in children: Consensus statement 12 and associated supplemental material (Bishop et al., 2016).
- Ethical guidelines for psychological assessment and use of psychological tests: Guideline 10 (Australian Psychological Society, 2014).
- International clinical practice recommendations on the definition, diagnosis, assessment, and intervention of developmental coordination disorder: Recommendations 11, 12 and 13 (Blank et al., 2019).

Practitioners are encouraged to review and consider their discipline specific and relevant other discipline and interprofessional guiding principles in the application of cut scores and exercise their informed professional judgement in the application of these to the FASD diagnostic process.

The process for determining cut scores, particularly in high stakes decisions (i.e., determining the presence or absence of a diagnosis) relies on applying at least one of several processes, all of which are well informed clinically, technically, empirically, and statistically (for thorough review of the various processes options for developing cut scores see Cizek & Bunch, 2007). While the 2016 Australian FASD Guide specified that equal to or less than the 3rd percentile or 2 standard deviations below the mean was a suitable cut-off for designating severe impairment in a neurodevelopmental domain; explanation of the rationale and process used to establish that cut-off in the diagnosis of FASD was not provided.

Demonstrating the diagnostic meaningfulness for clinical cut-offs requires evidence that there are differences in important life outcomes between people above and below that cut-off. The body of evidence investigating associations between PAE and neurodevelopmental outcomes considered in the current GRADE process provided no evidence to support the clinical validity of specific percentiles or standard deviation cut-offs. Until such evidence becomes available, the Guidelines Development Group determined that the interpretation of test scores to characterise impaired functioning is better informed by:

1. The practitioner exercising their clinical reasoning anchored in consensual expert guidance and/or best practices that apply to test interpretation in their specific professional field.
2. An integrative analysis of the whole person, conducted by practitioners who exercise their professional expertise in synthesising relevant historical, cultural, medical and allied health, behavioural and other information into evidence-based clinical formulations.

Note. Points 1 and 2 are drawn from Guilmette et al (2020).

As per Table 3, test scores in the Below Average and Exceptionally Low Score Ranges could be considered significantly below the normative level and may be indicative of impairment.

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

The Guidelines Development Group considered this to be a reasonable guide but noted that the table likely does not apply for tests that have non-normal score distributions. These categories may vary by a few or several standard scores or percentiles depending on the specific nature of a test's score distribution.

Given the complexity in interpreting test scores, it is recommended that practitioners consult the manuals and relevant psychometric research for all tests used in the diagnostic process to ensure that the characterisation of an individual's performance aligns with established best practices and naming conventions for interpreting test results.

Confidence Intervals

All standardised tests, produce scores that contain both the individual's true ability, plus measurement error. To account for the uncertainty introduced by measurement error, most tests provide confidence intervals for subtests/domains, index, and full-scale/general scores. Some also provide confidence intervals for percentiles. Where confidence intervals are available or can be calculated, practitioners should use them together with the suggestions in Appendix C to support interpretation.

4.3.3.3 Assessing neurodevelopmental domains in practice

FASD is a complex and multifaceted condition best assessed and diagnosed via an interprofessional framework. Practitioners in multidisciplinary settings should not contribute isolated assessment findings, but contribute to all domains, bringing their relevant scope of practice to the assessment process and collaborating in case formulation.

Ideally, specific disciplines will bring their unique expertise to the assessment of certain domains (e.g., speech pathology assessing communication, occupational therapy or physiotherapy assessing motor skills). However, in settings where all disciplines are not available, practitioners can still work

within their qualifications, training, and experience to provide assessment and formulation within their scope of practice. Upskilling to develop interdisciplinary skills can also be beneficial. Practitioners working in isolation or in limited multidisciplinary contexts are reminded that external consultation and supervision are helpful approaches to supporting sound diagnostic assessment and formulation.

While a comprehensive assessment likely provides the greatest support to the individual, practitioners are reminded that assessment of all domains is not always required to consider a diagnosis of FASD. For further discussion see the Holistic Developmental, Functional and Wellbeing Assessment Section.

An overview of the neurodevelopmental domains and specific considerations for assessment are provided in Table 4. Descriptions and assessment considerations for the domains are provided based on the results of the evidence review, discipline specific guidance from the Clinical Advisory Groups, and consultation with the Guidelines Development Group.

Assessment of infants and young children

Consistent with the principles underpinning these guidelines and good clinical practice, practitioners should consider the appropriateness of all assessment components to the individual infant or young child and their family. Given the limited availability of standardised tests for this age group, young children with microcephaly and three sentinel facial features may meet criteria for FASD, provided other causes are excluded. While standardised tests may not be available across all domains, practitioners can still have access to a range of clinical information regarding current development to consider alongside microcephaly in infants and young children to inform diagnostic decision-making. There is also the option of assigning 'at risk of FASD' in sufficient information is not available. See the at risk of FASD section below for further information.

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 including 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 evaluate an individual's functioning in each of the neurodevelopmental domains based on all the available information and determine if there are clinically significant impairments.

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

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

Domain	Definition	Specific assessment considerations

Communication
(Language skills)
	Communication involves receiving and convey ideas, thoughts, and feelings to others. Language skills refer to the words, syntax, morphology, and pragmatics we use understand and communicate in oral, sign, and written forms. The domain focuses on language as a developmental process that can be disrupted by PAE. 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 according to best practice recommendations.
	
	There is 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 diagnosis but are important to the overall clinical profile and treatment of a client and should be characterised and
		Impairment is present in this domain if the individual's language skills are found to be *disordered*.
		
		Assessment should follow best practice principles (Bishop et al., 2016; Bishop et al., 2017), specifically:
		
		• Consider that disordered language skills are heterogenous and a thorough assessment should examine the principal dimensions of language:
		  ○ Syntax/morphosyntax
		  ○ Word finding and semantic knowledge
		  ○ Discourse/narrative
		  ○ Phonology (where indicated and considered linguistic in origin, though phonology should not solely contribute to meeting the criteria)
		  ○ Verbal learning/memory (if best attributable to communication skills rather than memory abilities).
		• Consider functional language skills as part of the assessment (e.g., how the person performs in everyday meaningful tasks).
		• For assessment involving Aboriginal and Torres Strait Islander peoples and other culturally and linguistically diverse individuals, use relevant Practice Guidelines produced by Speech Pathology Australia to guide practice.

	documented in reports, with recommendations made as appropriate.	• Evaluate the prognostic indicators for poor outcomes resulting from disordered language skills. • If an individual meets criteria for FASD and disordered language is identified, the appropriate diagnosis relating to language disorder is 'Language Disorder associated with FASD' (as per Statement 6; Bishop et al., 2017). • Diagnostic terminology should not distinguish between 'expressive' and 'receptive' diagnostic subtypes, as these categories are not 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.	• Assessing more than one aspect of motor skills is recommended to understand 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. • 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. • Ensure 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.

		• Consider other causes of motor challenges, such as dysfunction of the vestibular system, executive function, musculoskeletal system, or peripheral nervous system.
Intellectual abilities (Cognition)	Practitioners should apply generally accepted models of intelligence, which is often defined to 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.	• Impairment in this domain may be established through deficits in an underlying general factor of intelligence ('*g*' e.g., full-scale intellectual quotient) or one or more major subdomains that load on this factor according to established models of intelligence. Examples include Verbal Comprehension, Visual Spatial Index (visual perception), Fluid Reasoning, Working Memory, and Processing Speed constructs as defined in the Wechsler paradigm or broad and narrow constructs as defined by the Cattell-Horn-Carroll Model. • 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	Generally considered the cognitive skill that connects sensory activity with mental processing (Posner & Petersen, 1990), attention is a complex cognitive activity with strong influences both to and from other cognitive skills, particularly working memory, and executive function. As such, it affects every aspect of what we do and experience (McDowd, 2007). At an operational level, attention has been characterised as a filter (Wickens, 2021) or selection (Angelopoulou & Drigas, 2021) mechanism for information from the environment that when operating effectively admits only relevant information to the task at hand for further processing. Other theories have operationalised attention as consisting of alerting, orienting, and executive control functions (Posner & Petersen, 1990), or modality-specific, bottom-up modulation or top-down modulation functions (Mesulam, 2000). Practitioners should consider relevant models of attention when constructing and interpreting results.	• There are many models of attention, which may place differing degrees of emphasis on indirect (e.g., questionnaire) and direct measures of attention. Models derived from both sets of measures may be considered under this domain, although factors which also fall directly under the definition of intellectual or executive functioning should be considered within those domains instead. • 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, which require coalition of multiple abilities including attention and executive functioning (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, which 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.

	Several sub-skills have been proposed across the various attention models and theories. The following may be useful characterisations of attention: • Selective attention: focusing on one source of information for processing and not processing other sources of information available in the environment. • Sustaining attention: maintaining focus to a task over prolonged periods of time. • Attention switching: alternating focus and resources between different tasks or sources of information. • Divided attention: processing more than one source of information at a time or performing more than one task at a time by sharing capacity between them. Attention encompasses 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 for the individual.	

Memory	Memory includes the ability to encode, store and retrieve information. It is traditionally 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, a comprehensive memory assessment should evaluate these capabilities to provide a thorough understanding of an individual's memory challenges, to identify memory disorders, and inform targeted supports.	• 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. Based on test performance determine the best explanation for impairments. • Consider self or informant reported 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-dimensional nature of this ability, including the impacts of executive function (e.g., Ji et al., 2021; Martin et al., 2003).
Executive Function (EF)	There are multiple different definitions of EF, with no universally accepted conceptualisation. EFs are traditionally defined as a set of 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).	• Capabilities and deficiencies in EF are best captured through a combination of standardised tests, domain specific questionnaires, and semi-structured interviews. • Consider performance 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 report their level

		of functioning. In such instances, convergent information from a reliable informant should be sought (e.g., via questionnaires). • For older children, adolescents, and adults, EFs are generally considered multi-factorial, including different inter-related and inter-dependent skills that act within an integrated top-down control system. • For young children, some research indicates that EFs could be considered as a unitary concept that 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., varying from 6 to 12 years). Clinical judgement is required to determine if multi-component assessment of EF skills is beneficial, based on an individual's presentation. • For assessment and formulation purposes, practitioners may find it helpful to distinguish 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 better assessed via clinical history, questionnaires, or direct observation (Salehinejad et al., 2021).

		• Depending on assessment results, emotion driven (reward, arousal, affective based) behaviours 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, suicidal ideation) • Emotional regulation: 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. 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 be involved 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 skills	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, practitioners 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 according to 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. • Take into account 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). • Utilise direct functional assessments of adaptive and social skills, as well as informant rating scales. • Evaluate the functional impacts of language skills and pragmatic language skills on social functioning and social problem-solving abilities.

4.3.3.4 Neurodevelopmental domains: evidence for inclusion

Inclusion of domains was based on review of the best available evidence (see the ***Association between Prenatal Alcohol Exposure Physical Size, Dysmorphology and Neurodevelopment: Systematic Review Report***. For inclusion, the available evidence had to demonstrate an association between PAE and the neurodevelopmental outcome. Areas 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 and can be documented as 'associated conditions', 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 ***Association between Prenatal Alcohol Exposure Physical Size, Dysmorphology and Neurodevelopment: Systematic Review Report***). 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 were undertaken in the Guidelines Development Group regarding the conceptualisation of the neurodevelopmental domains. The complex interplay between neurodevelopmental domains was thoroughly discussed. 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 that it is better for practitioners to undertake these conceptualisations at the individual case formulation level. Additionally, the possibility of splitting the adaptive and social domain was discussed, however it was determined that further research is required to inform decision making in this area.

The conceptualisation of each of domain 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 available evidence was based on self and informant reports, with the most commonly available measure being the ASEBA Child Behaviour Checklist and Teacher Report Form. Thus, the available evidence focused on symptomatology not presence of psychiatric conditions. Updates were also made in the Communication (Language) domain to align with best practice recommendations produced by the CATALISE consortium (Bishop et al., 2016, 2017). This included, for example, discerning areas/dimensions of language difficulty and removal of references to subtypes of language disorder (i.e., expressive/receptive). The previously named 'academic achievement' domain is now termed

'literacy and/or numeracy' to more specifically communicate the impairments considered in this domain (i.e., to clarify that this is not related to general behaviour/functioning in educational settings).

4.3.4 Criterion C: The neurodevelopmental impairments result in functional impacts that necessitate significant supports.

It is important to demonstrate the connection between neurodevelopmental impairments, impacts on functioning, and the need for supports. As with other neurodevelopmental diagnoses, practitioners must use their clinical judgement to determine if a significant level of support is required, given the individual's level of impairment. As stated in the DSM-5-TR, assessing whether this criterion is met, is an inherently difficult clinical judgement. Information from the individual, family members, and other informants is necessary. 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 affect functioning).

4.3.5 Criterion D: Onset of neurodevelopmental impairments in the developmental period

Criterion D refers to the recognition that impairments are present during infancy, childhood, or adolescence. 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, it means that the overall pattern of available evidence indicates impairments were present in early development. Impairments are, therefore, 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.

4.3.6 Diagnostic Specifier: Sentinel facial features

4.3.6.1 Inclusion of three sentinel facial features

The review of current diagnostic criteria (overview of findings included in the Administrative and Technical Report [hyperlink to be inserted once available online]) 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, no evidence was cited to support this decision. No studies identified through the evidence review 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 diagnostic specifier aims to support documentation of facial features along the full continuum, enabling detailed assessment, monitoring, and future evaluation.

4.3.6.2 Palpebral fissures

Short palpebral fissures are defined at ≤ 3rd percentile (i.e., ≤ 2 SD). Due to limited evidence, comparison across different percentile cut-offs was not possible. The Guidelines Development Group also considered current implementation factors, noting that 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 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.

Due to the small number of studies and lack of reporting on the normative charts used in the available research, the evidence review could not examine the impacts of different palpebral fissure reference values on diagnostic outcomes. Limited has compared 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, particularly 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 limited evidence available, the Strömland palpebral fissure length charts are recommended for use across the lifespan.

4.3.6.3 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 should use clinical judgement to decide which lip/philtrum guide is most applicable based on the individual's physical features (i.e., Guide 1 Caucasians 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, there is a lack of 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 and implementation considerations to support facial features assessment in practice, including hyperlinks to access the University of Washington diagnostic tools.

4.3.6.4 Assessment of facial features for individuals from culturally diverse backgrounds

Concerns were raised regarding the lack of local palpebral fissure norms and lip/philtrum guides for the assessment of people from diverse ethnic backgrounds, including Aboriginal and Torres Strait Islander peoples (e.g., see 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 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.

4.3.7 Diagnostic 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) is included as a diagnostic specifier. However, as noted in the diagnostic criteria it is recommended practitioners report specific measures, including the 5th and 3rd percentile ranges, to capture the full continuum of these physical features. As described in the good practice statements in the medical assessment section, it is important to consider measurement error, interpretation of norm charts in the context of ethnicity, and assessments over time (where available) to avoid applying rigid cut-offs.

As per the assessment of infants and young children section, when direct information about the clinical significance of neurodevelopmental impairments is not available, microcephaly (≤ 3rd percentile) may be used as an indicator. A more stringent definition of small head circumference is applied when it is used as a proxy for assessment of neurodevelopmental impairments.

For further good practice statements supporting physical size assessment in practice, refer to the medical assessment section of this document.

4.3.8 Associated features

There was insufficient evidence for some physical, neurological, and neurodevelopmental outcomes to be included in the diagnostic criteria. However, collecting information on the presence of these features/conditions is useful as they can provide vital information to inform individualised referrals, treatment, and ongoing supports. Future research is needed to better understand the potential associations of these features/conditions with PAE.

4.3.8.1 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. Currently, available data from routine clinical MRI (i.e., qualitative radiological MRI) do not currently provide diagnostic utility. Therefore, if abnormal imaging results are available, it is recommended these are recorded as associated features. 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.

4.3.8.2 Reasoning regarding other neurological conditions

A review of the best available evidence indicated insufficient evidence to understand the association between PAE and neurological conditions of hearing and vision impairment, seizures, and cerebral palsy. Therefore, it is recommended that these neurological conditions be recorded as associated features. Some members 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 currently available evidence.

4.3.9 At risk of FASD

Feedback from the Clinical Advisory Groups indicated that the 'at risk' designation has been a helpful option for practitioners. Specifically, it was discussed that this designation can facilitate 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 the NDIS. Instead, it allows for more time and consideration of whether a lifelong diagnosis would be appropriate. However, it was noted that the decision to repeat testing should be made by an appropriately qualified practitioner, not an NDIS coordinator who may lack necessary qualifications to make these clinical decisions.

Concerns were raised by Advisory Group members that the 'at risk' designation can sometimes be inappropriately applied, leading to inequities for individuals and families, especially, 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.

4.3.10 Summary of GRADE-based recommendations for the diagnostic criteria

GRADE-based Recommendation 1 **Conditional**	The Australian FASD Guidelines Development Group suggests the following key diagnostic considerations: • evidence of prenatal alcohol exposure above a low risk level for diagnosis of FASD at any time during gestation. Or, in the absence of a confirmed history of PAE following exclusion of other causes, the presence of three sentinel facial features (short palpebral fissures, thin upper lip and smooth philtrum) • presence of pervasive and clinically significant neurodevelopmental impairments

	• the neurodevelopmental impairments result in functional impacts that necessitate significant supports across multiple areas • the onset of neurodevelopmental impairments is evident during the developmental period • an individual's presentation is not better attributed to another condition or exposure • any of the relevant diagnostic specifiers are applied (i.e., physical size, head circumference and/or facial features) (Variable Certainty).
GRADE-based Recommendation 2 **Conditional**	The Australian FASD Guidelines Development Group suggests that birthweight, corrected for gestational age, according to the appropriate age- and sex-specific charts, be considered in the diagnosis of FASD and to account for individual variability it has been listed as a diagnostic specifier (Low to Moderate Certainty).
GRADE-based Recommendation 3 **Conditional**	The Australian FASD Guidelines Development Group suggests that birth length, corrected for gestational age, according to the appropriate age- and sex-specific charts, be considered in the diagnosis of FASD and to account for individual variability it has been listed as a diagnostic specifier (Very Low to Low Certainty).
GRADE-based Recommendation 4 **Conditional**	The Australian FASD Guidelines Development Group suggests that postnatal child weight, according to the appropriate age- and sex-specific charts, be considered in the diagnosis of FASD and to account for individual variability it has been listed as a diagnostic specifier (Very Low to Low Certainty).
GRADE-based Recommendation 5 **Conditional**	The Australian FASD Guidelines Development Group suggests that postnatal height, according to the appropriate age- and sex-specific charts, be considered in the diagnosis of FASD and to account for individual variability it has been listed as a diagnostic specifier (Very Low to Low Certainty).
GRADE-based Recommendation 6 **Conditional**	The Australian FASD Guidelines Development Group suggests that philtrum smoothness, vermilion thinness, and palpebral fissure length be considered in the diagnosis of FASD and to account for individual variability it has been listed as a diagnostic specifier (Very Low to Low Certainty).
GRADE-based Recommendation 7 **Strong**	The Australian FASD Guidelines Development recommends against considering other congenital anomalies in the diagnostic criteria for FASD (Low to Low Certainty).
GRADE-based Recommendation 8 **Conditional**	The Australian FASD Guidelines Development Group suggests that head circumference, corrected for gestational age according to the appropriate age- and sex-specific charts, be considered in the diagnosis of FASD and to account for individual variability it has been listed as a diagnostic specifier (Very Low to Low Certainty).

GRADE-based Recommendation 9 **Strong**	The Australian FASD Guidelines Development Group recommends against including structural brain abnormalities observed on clinical imaging in the diagnostic criteria for FASD (Very Low Certainty).
GRADE-based Recommendation 10 **Strong**	The Australian FASD Guidelines Development Group recommends against including neurological conditions of hearing and vision impairments, seizures, and cerebral palsy in the diagnostic criteria for FASD (Very Low to Low Certainty).
GRADE-based Recommendation 11a **Conditional**	The Australian FASD Guidelines Development Group suggests that neurodevelopmental outcomes of communication, motor skills, intellectual abilities, attention, memory, executive function, emotional and/or behavioural regulation, literacy and/or numeracy, and adaptive/social functioning, be considered in the diagnosis of FASD (Very Low to Low Certainty).
GRADE-based Recommendation 11b **Strong**	The Australian FASD Guidelines Development Group recommends against neurodevelopmental outcomes of social cognition, social communication/pragmatics, motor speech impairments, speech-sound impairments and sensory processing being included in the diagnostic criteria for FASD (Very Low to Low Certainty).

4.3.11 Potential impact of GRADE-based recommendations

The GRADE approach to developing guideline recommendations has provided a structured, transparent, and evidence-based process. This affords practitioners confidence in the robustness of the diagnostic criteria and the guidance on current clinical practice in FASD. These recommendations intend to support accurate diagnosis of FASD and lay the foundation for more cohesive future research into the condition. Additionally, this approach facilitates future reviews of the research to support updates to the diagnostic criteria.

4.3.12 Summary of areas of major debate

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

- **PAE minimum threshold**

There was some variability in views in the Guidelines Development Group. Given this was an area where evidence was available to inform decision making, the final decision was to align with the best available evidence, while being mindful of the limitations of the evidence and the practicalities of taking applying this evidence 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 between domains. 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 decision making in this area.

- **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 diagnostic specifiers**

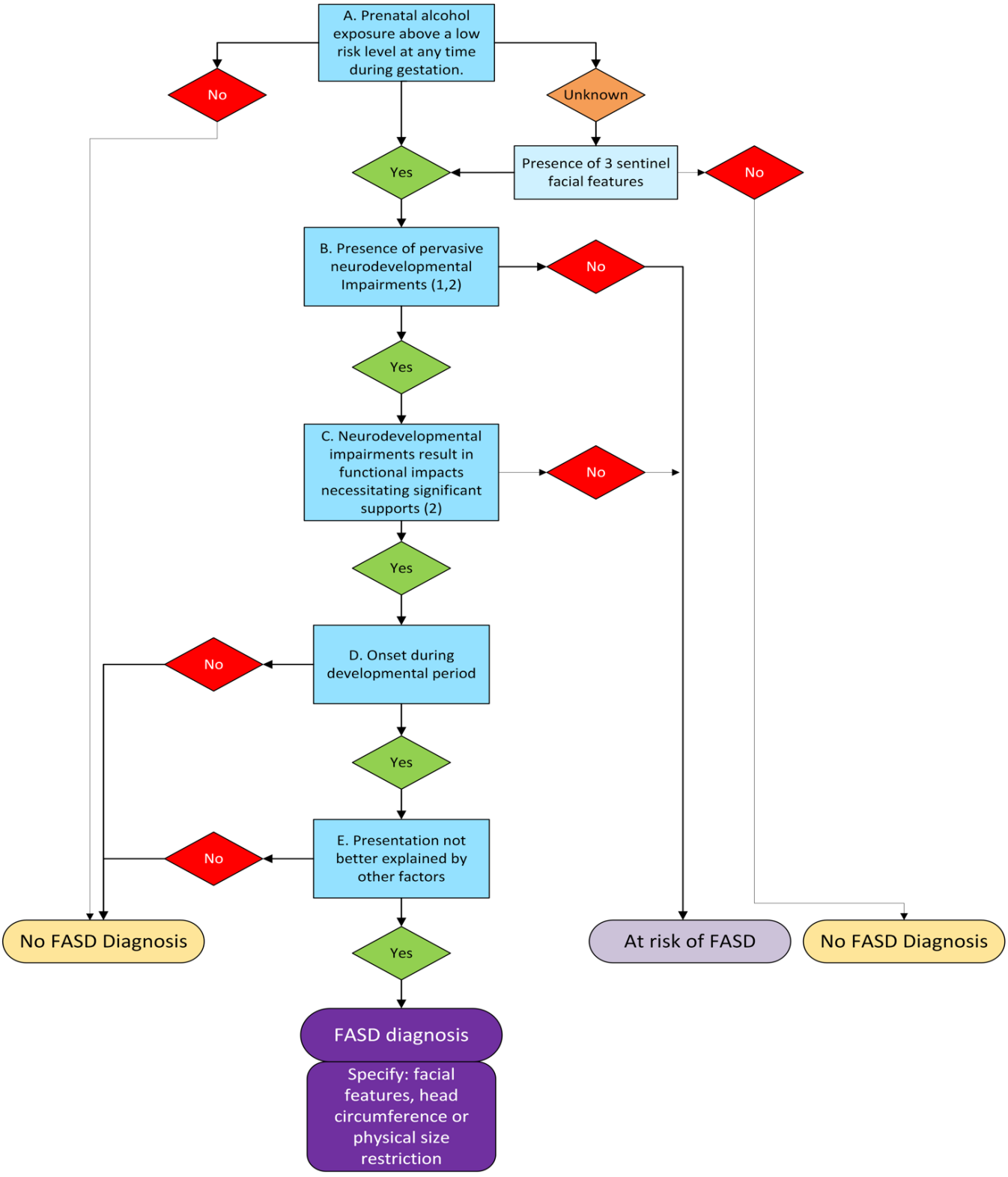
Some members of the Guidelines Development Group viewed the inclusion of the physical features as diagnostic specifiers as minimising the importance of these features. These concerns were weighed up in the context of the diagnostic structure being able to support more detailed documentation of physical features, enabling more comprehensive understanding of the heterogeneity of FASD presentations, and facilitating future research on the physical features. Additionally, this structure could simplify diagnostic nomenclature by using one term to capture all the potential neurodevelopmental and physical features.

- **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, while others were comfortable with making diagnosis based on microcephaly and three sentinel facial features. Limited evidence was available to inform decision making. Concerns about 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.

- **Diagnostic terminology**

There were differing perspectives and preferences regarding diagnostic terminology. At this time, no consensus could be reached across all consultative groups. As noted throughout the guidelines, it is ultimately the choice of the individual attending for assessment to decide the terminology applied.



(1) Presence of pervasive neurodevelopmental impairments meets Criterion B providing
- Clinically significant impairments in 3 or more neurodevelopmental domains.
- Documentation of impairments by multiple informants.
- Direct evidence of clinically significant impairments.

(2) In infants and young children
- Microcephaly (≤ 3rd percentile) could be used as an indicator of clinically significant neurodevelopmental impairment, providing the presentation is not better explained by another condition or exposure (Criterion E).

Figure 10. Diagnostic Algorithm

Chapter 5
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 confronting process and it needs to be the family's choice."

CLINCIAN AND ADVISORY GROUP MEMBER

Chapter 5: Assessment Process

5.1 Lived Experience Statements for the 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; Systematic Review and Qualitative Synthesis of Lived Experiences of the Assessment and Diagnostic Process Report):

Lived Experience Statement 1	Listen to, and take seriously, concerns raised by parents/caregivers about their child's development and behaviour in the context of prenatal alcohol exposure (Moderate to High Certainty).
Lived Experience Statement 2	Provide or refer for assessment if a parent/caregiver is concerned about their child's development in the context of prenatal alcohol exposure (Moderate to High Certainty).
Lived Experience Statement 3	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 services, child development services, adolescent and adult private and public health services, primary care, mental health, disability, justice, and child protection services (Moderate Certainty).
Lived Experience Statement 4	Provide non-judgemental and non-stigmatising support that acknowledges and respects the individual's, and their parent/caregivers,' experiences and concerns (Moderate Certainty).

5.2 Overview of the Assessment Process

Consistent with evidence from the systematic review of lived experiences of the assessment and diagnostic process (Hayes et al., 2023), the resource implications and models of care scoping review (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 can be completed either in one setting where available (i.e., multidisciplinary clinic) or across multiple settings (Figure 11).

The assessment process aims to encourage all practitioners, regardless of 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. It is hoped that the proposed assessment process will address some of the current resource limitations regarding the lack of specialist diagnostic services and result in cost efficiencies, although this is an empirical question that should be examined through future research.

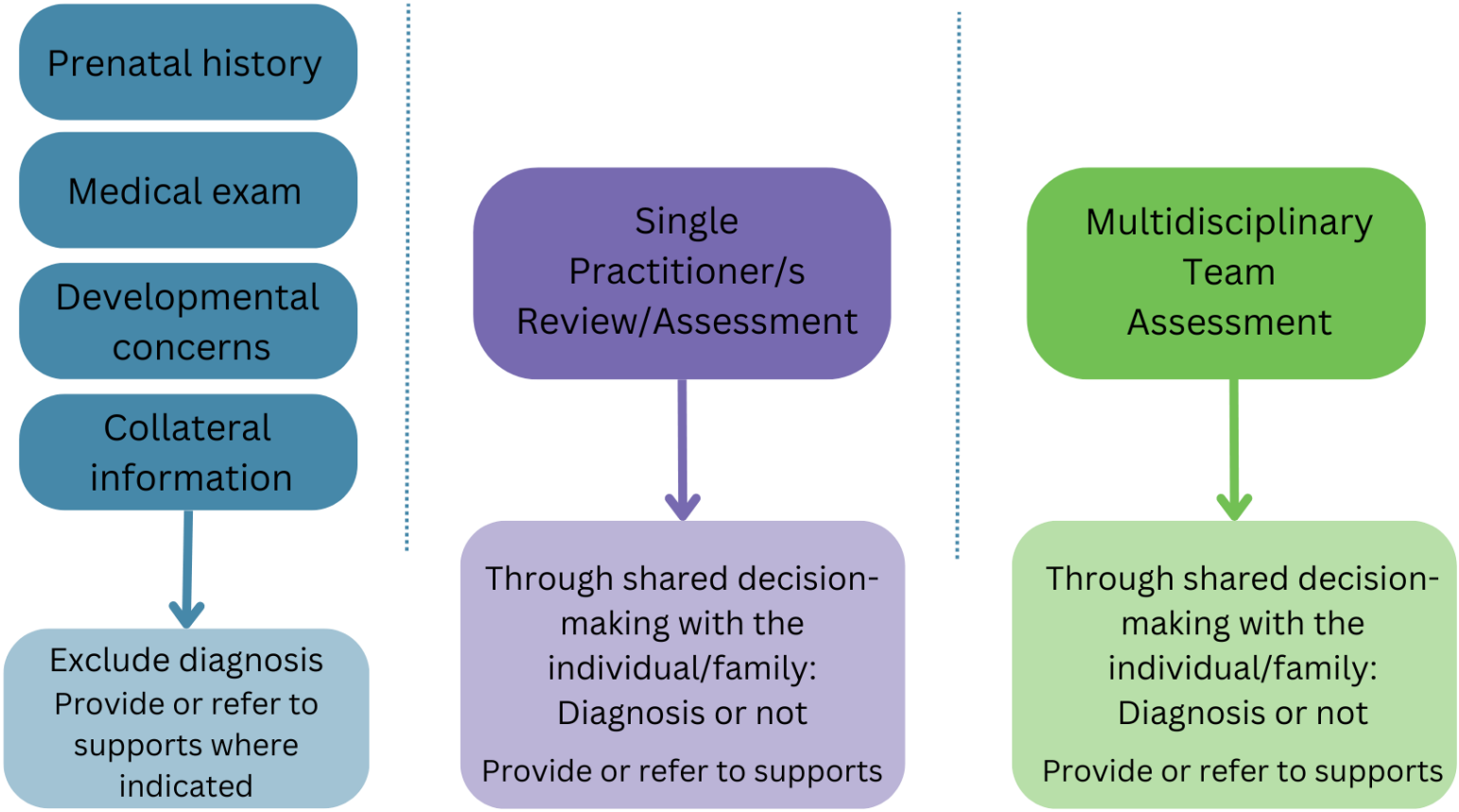


Figure 11. Overview of the assessment

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 practitioners available, the team can be flexible and also 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 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.
Interprofessional team assessment	In some settings, interprofessional or multi-disciplinary teams are available that can undertake all the assessments in one location.	Composition of 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 Consideration, Tool, and Tip 3	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 Consideration, Tool, and Tip 4	For individuals and families where English is a second/additional language, it is a requirement of The National Safety and Quality Health Service Standards that interpreting services are available where appropriate. https://www.safetyandquality.gov.au/standards/nsqhs-standards
Implementation Consideration, Tool, and Tip 5	Assessment and diagnosis of FASD 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

5.3 Informed Consent and Assent in the Assessment Process

Inclusion of this section was based on information gathered from members of the Advisory Groups (e.g., Hayes et al., 2022), who had witnessed situations where referrals for assessments or commencement of assessments 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 voluntary decision to agree to a healthcare service, provided after receiving accurate and relevant information and with adequate knowledge and understanding of the benefits and risks of the proposed service. More information can be found at: https://www.safetyandquality.gov.au/our-work/partnering-consumers/informed-consent

Informed assent involves individuals without competence (e.g., children and individuals deemed to not have cognitive abilities to provide informed consent) in decision making in ways that are developmentally appropriate (Joffe, 2003). This involves providing information so that individuals will know what will happen and allowing them to express their preferences and be heard (Spriggs, 2023).

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

Good Practice Statement 1	If there is information suggesting prenatal alcohol exposure above a low risk level, including before pregnancy recognition, discuss assessment options, and after obtaining informed consent, provide assessment information or support access to assessment.
Good Practice Statement 2	If there is information documenting clinically significant neurodevelopmental impairments, distinctive facial features, and/or confirmed or suspected prenatal alcohol exposure above a low risk level, discuss assessment options, and after informed consent, provide assessment information and support to access appropriate assessment.

Implementation Consideration, Tool, and Tip 6

In line with the FASD Indigenous Framework, the informed consent and assent process needs to 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 are equally valued.

To support a culturally comfortable and safe environment, practitioners can incorporate information and visual resources to explain:

- what the referral and/or assessment is for
- what the assessment process generally involves
- what the potential outcomes and follow-up from the assessment may involve
- the potential benefits and risks.

Where appropriate, this may include the use of other languages, and support from an interpreter or cultural consultant. 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 involved have genuine control over decisions about their healthcare. This can only be achieved if the person and their family have been supported to make an informed choice about whether an assessment is something they want to undertake.
Implementation Consideration, Tool, and Tip 7	Different approaches to informed consent and assent may be required depending on the assessment context. For example, where the referral question is about assessing the possibility of FASD, informed consent and assent specific to FASD should be obtained at the outset. In circumstances where information about PAE emerges later in the assessment process (i.e., is not the basis of the referral), obtaining additional informed consent and assent related to FASD assessment is warranted.

5.4 Integration of Shared Decision-Making into the Assessment Process

It is recommended that the diagnostic criteria be implemented within a dynamic, interactional, social-contextual, shared decision-making approach. This approach involves clinical reasoning, and collaboration with the individual and/or family 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 for the determination of if/when diagnosis is applicable/appropriate for each individual presenting for assessment.

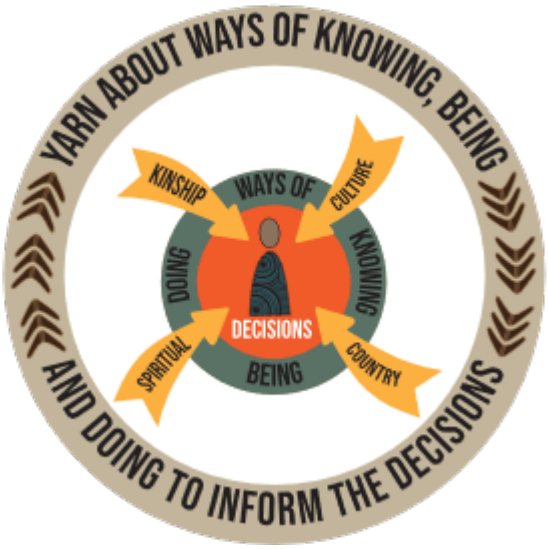
The application of the Finding Your Way Shared decision-making framework (Agency for Clinical Innovation) has the potential to benefit all Australians. The Finding Your Way model supports an assessment approach in which relationships are central, and everyone is connected and involved in the process. Below is an example of how practitioners may apply the Finding Your Way model to support assessment and diagnosis of FASD. Specific information about FASD and relevant references have been integrated into the original Finding Your Way model to support application of this model. Please see the FASD Indigenous Framework for more information.

It is important to note that this process is not a linear but more circular and can be applied in all sessions with individuals and their families. Each area of the model may change from session to session, so it is important that the yarn revisits these different aspects throughout the assessment.

Family

Yarn about family and where the individual and family attending for assessment are from. Also share 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 their knowledge, expertise, and lived experience, 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 supports 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 in front of you is to create a safe, trusted space, ask and then listen, deeply. You might yarn about:

- What is important to you? Why is it important?
- Do you participate in activities like language, art, singing, dancing, storytelling, ceremonies, hunting? Or would you like to?
- Are you connected to community in sport or employment?
- What do you know/believe about FASD and what feelings does this bring up?
- What do you know/believe about the assessment tools 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. 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.

Throughout the assessment 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 particularly when their **basic needs** of feeling supported, accepted, loved unconditionally, secure with a safe place (Kully-Martens et al., 2022) were met.

Having an understanding about the individual and family's social and emotional wellbeing will also help guide the structure of the assessment to ensure quality and accurate information is gathered. To understand and strengthen the family social, emotional, and wellbeing (Reid et al., 2022) you may begin by identifying the current needs and supports by:

- Yarning to assess the current level of formal and informal supports.
- Addressing any immediate social, emotional and wellbeing needs for the individual and family that arise during the assessment process.
- Developing a collaborative plan for how to build 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 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. Different options to yarn about could include, but are not limited to:

- The way the assessment 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. The individual/family can decide if they want these tools to be included or if they would prefer this is not part of the assessment.
- Having a diagnosis of FASD could have benefits in helping an individual and family understand about why a person is having the challenges in their life 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 diagnoses to Aboriginal children and families (Hamilton, Maslen, et al., 2020). Research shows 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 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 providing the opportunity for the individual/family to yarn and collaboratively plan what the next steps are.

Chapter 6
Prenatal Alcohol Exposure (PAE) 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

Chapter 6: Prenatal Alcohol Exposure Assessment

6.1 Actionable Statements for Prenatal Alcohol Exposure (PAE) Assessment

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

Good Practice Statement 3	Sensitively and respectfully include discussions about alcohol use and potential risks as part of routine antenatal and postnatal care.
Good Practice Statement 4	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 5	To support accurate assessment of risk, assess prenatal alcohol exposure both before and after pregnancy recognition. Standardised screening tools, such as the AUDIT-C, are recommended to assess alcohol intake.
Good Practice Statement 6	Explain what a standard drink of alcohol is before asking about alcohol use, and consider using a standard drinks guide to help obtain accurate information on intake (e.g., see the NHMRC Alcohol Guidelines). Where appropriate, practitioners can also gather information on intake and later convert the amount consumed to standard drinks.
Good Practice Statement 7	Be mindful there are many factors that may have influenced alcohol use during pregnancy, and it is important to collect information in a supportive, compassionate, and non-judgemental way.
Good Practice Statement 8	Recognise that individuals might face ongoing challenges with alcohol or other complex issues and provide appropriate support and referrals.
Good Practice Statement 9	Contact biological parents directly, if possible and appropriate, to assess prenatal alcohol exposure. 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 pregnancy is not sufficient to confirm exposure.
Good Practice Statement 10	Consider that self-reports of prenatal alcohol exposure 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, reported in antenatal records, or later in the child's life). Practitioners may wish to re-contact biological parents to check previously collected information.

Good Practice Statement 11	Sometimes there may be inconsistencies in the available information about prenatal alcohol exposure. In instances where information is collected directly from the pregnant individual during an assessment, this information should be prioritised over other sources. Practitioners can document inconsistencies in information and indicate that re-assessment may be considered should additional information arise.
Implementation Consideration, Tool, and Tip 8	To support early identification of prenatal factors that can influence developmental outcomes, information that could affect longer-term health outcomes for children 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 on the parents should be included. The Advisory Groups reported that transfer of information from the pregnancy record is 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 in Victoria, where information from the Birthing Outcomes system is automatically copied from the maternal discharge to the newborn discharge. During the guideline development process, a procedure was also established in Queensland to support the automatic transfer of a minimum amount of prenatal information through the Integrated Electronic Medical Record.
Implementation Consideration, Tool, and Tip 9	Prenatal alcohol exposure 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 not to make assumptions about the likelihood of prenatal alcohol exposure or FASD based on an individual's sociodemographic features. Members of the Living Experience Advisory Group described experiences where they were not asked about prenatal alcohol exposure 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 prenatal alcohol exposure.
Implementation Consideration, Tool, and Tip 10	A practitioner resource in Appendix D provides an overview of the Alcohol Use Disorders Identification Test-Consumption (AUDIT-C) tool structured to collect information on alcohol consumption pre- and post-pregnancy recognition.
Implementation Consideration, Tool, and Tip 11	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, information regarding FASD is sometimes included (as reported by the Advisory Groups). Where available, we suggest that information about FASD and local services can be uploaded to Health Pathways or other available electronic referral systems to support provision of information to primary health care professionals and facilitate streamlined assessment processes.
Implementation Consideration, Tool, and Tip 12	Challenges with gathering prenatal history for children in out-of-home care were discussed as a major barrier to assessment across Advisory Groups. To support collection of accurate prenatal alcohol exposure information the following implementation considerations are noted: • Information about prenatal alcohol exposure should be documented alongside other relevant prenatal factors (e.g., other drug exposures, domestic violence, family medical history). • As part of training resources for child protection staff, include information on how to collect and document information accurately on prenatal alcohol exposure, as well as local referral pathways. • Prenatal alcohol exposure is not a reason for a child to be placed into out-of-home care. There can be many reasons why prenatal alcohol exposure occurs, including exposure that occurred before an individual knew they were pregnant, pre-existing alcohol use disorder or drinking to cope with domestic violence, or other traumatic circumstances. Pregnant individuals need to feel safe to discuss their concerns and to seek help for themselves and their children, without the fear of their children being removed. • Information about assessment, diagnosis, and recommendations should be incorporated into a child's health management plan and this information be provided to foster and kinship carers.

Implementation Consideration, Tool, and Tip 13

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."* While the UNCRC comment concerns children, this should also be considered in the context of adult justice.

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).

To facilitate collection of accurate prenatal alcohol exposure information in these contexts, and the provision of appropriate supports, the following implementation considerations are noted:

- Where appropriate, collect and document information about prenatal alcohol exposure 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 appropriate assessment providers.
- Provide information and training about accurate collection and documentation of prenatal alcohol exposure and local referral pathways to all professionals in legal and justice contexts.
- 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

Chapter 7
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

Chapter 7: Medical Assessment

7.1 Actionable Statements for Medical Assessment

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

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

Good Practice Statement 12	Practitioners should consider the appropriateness of all aspects of a 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 13	When assessing facial features, the University of Washington (UW) Lip-Philtrum Guide is recommended. Guide 1 (Caucasian) is recommended for less full lips, and Guide 2 (African American) for fuller lips.
Good Practice Statement 14	When assessing facial features, the Strömland et al. (1999) palpebral fissure norms are recommended. These norms are the best available for all Australians, and span birth to adulthood.
Good Practice Statement 15	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 facial analysis software is not available.
Good Practice Statement 16	Photographs and/or clinical measurements and analysis can be undertaken by practitioners with specific facial feature measurement training, and/or with instruction provided by experienced practitioners. Adequacy and interpretation of photographs needs to be considered in conjunction with an experienced medical practitioner.
Good Practice Statement 17	Examine and document any 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 18	Consider other syndromes, genetic conditions, or teratogenic disorders in which dysmorphic features and/or neurodevelopmental impairment can also be present. If unsure, refer to a clinical geneticist for review.

Good Practice Statement 19	With informed consent and assent, as clinically appropriate and in line with local health service guidelines, request chromosome microarray (CMA) and DNA test for fragile X syndrome (FXS). These tests can be done using blood or buccal swabs. Refer to a local genetic health service for guidance if abnormalities are reported.
Implementation Consideration, Tool, and Tip 14	More information about the University of Washington Lip-Philtrum Guides is available from their website, including instructions regarding how to order the electronic versions: https://depts.washington.edu/fasdpn/htmls/lip-philtrum-guides.htm
Implementation Consideration, Tool, and Tip 15	A palpebral fissure norm calculator can be accessed from the University of Washington website: https://depts.washington.edu/fasdpn/htmls/diagnostic-tools.htm

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

Good Practice Statement 21	Physical size can vary due to a wide range of demographic, maternal, placental, and fetal factors. Identifying what is an 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 22	The WHO (2006) growth standards are recommended to assess birth weight, length and head circumference of full-term infants. Information may be available in hospital birth records or a baby's personal health records (e.g., red, blue, or yellow books).
Good Practice Statement 23	The Fenton growth charts are recommended to assess birth weight, length, and head circumference corrected for gestational age of preterm infants. Information may be available in hospital birth records or a 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 24	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 has adopted the WHO (2006) growth standards for all children.

Good Practice Statement 25

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 assess how they are developing physically.

Chapter 8
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

Chapter 8: Holistic Developmental, Functional and Wellbeing Assessment

8.1 Actionable Statements for Holistic Developmental, Functional, and Wellbeing Assessment

It is suggested that the neurodevelopmental and medical assessment be integrated 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 have been prepared to support assessment, informed by the available evidence and input from the Advisory Groups.

Good Practice Statement 26	Take a holistic needs-based and family-centred approach to assessment. This can involve considering strengths and challenges, functioning, wellbeing, environment, culture, participation and supports. Gather this information in ways that work best for the individual and their family/support network. Figure 12 provides a visual representation of the results of the factors to be considered as part of a holistic assessment: scoping review report *[hyperlink to be inserted once available online].*
Good Practice Statement 27	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 28	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, 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 29	There are no standardised tools specific for the diagnosis of FASD. Where appropriate, practitioners should use discipline specific standardised tools relevant to the neurodevelopmental domain being assessed. Practitioners need to apply their discipline specific knowledge, professional expertise, and clinical judgement to determine the most appropriate approaches for examining the individual within the context of the assessment. Allied health

	practitioners have specialist knowledge and skills to assess the neurodevelopmental domains. If unsure, practitioners should seek clinical supervision.
Good Practice Statement 30	Depending on a person's presentation, conducting assessment across different timepoints can assist in determining whether challenges are persistent. These assessments can happen in various places, including primary health care, schools, and private practice, not just at specialist services.
Good Practice Statement 31	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 whether they meet criteria for diagnosis.
Good Practice Statement 32	It is important to consider the neurodevelopmental challenges in the context of environmental factors. Interpreting assessment results requires a holistic 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 33	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 supporting the same results, or current assessment is unable to be completed due to significant behavioural challenges). The decision to retest an individual will depend on the context, referral question and the individual's needs.
Good Practice Statement 34	Assessment will naturally vary based on the availability of resources. Where multi-disciplinary services are not available or cannot be accessed, engagement with other services through a shared-care approach is suggested to support accessibility to assessment and diagnostic services.

Implementation Consideration, Tool, and Tip 16	Appendix D provides an example history taking template that includes prenatal, developmental, behavioural, functional, wellbeing and participation domains that could be adapted to suit different clinical contexts.

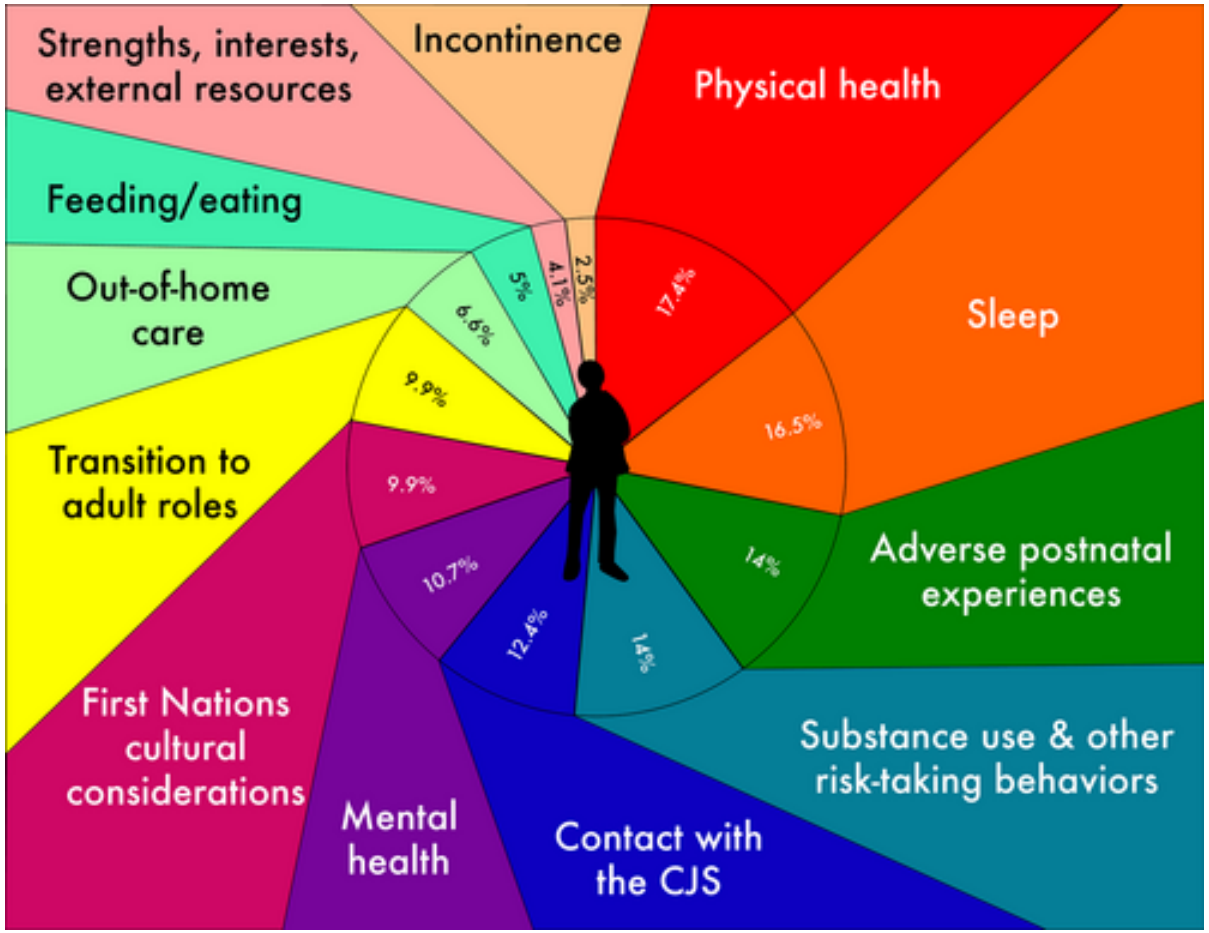


Figure 12. Overview of scoping review findings regarding the range of factors practitioners could consider outside of the diagnostic criteria to support holistic assessment.

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 Factors to be considered as part of a Holistic Assessment: Scoping Review Report *[hyperlink to be inserted once available online]* and associated peer reviewed publication (Reid et al., 2023).

Chapter 9: 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

Chapter 9: Holistic Profile, Formulation and Strength-based Pathways

9.1 Holistic Profile and Diagnostic Formulation

Developing a holistic profile is an opportunity to bring all the assessment information together in a strengths-based way, enhancing 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 integrate all the assessment findings and discuss and consider how various exposures and events that an individual may have experienced have potentially impacted their outcomes. Based on the available information, the most appropriate diagnostic outcomes can be considered.

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

Good Practice Statement 35	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 36	Practitioners should consider, offer, and explain one or more diagnostic possibilities in their formulation, summarising what is most likely, after considering what is less likely or unlikely, given the individual's presenting concerns and assessment findings.

Implementation Consideration, Tool, and Tip 17	Appendix D provides a holistic profile and diagnostic formulation template that can be adapted to suit different clinical contexts.

9.2 Co-occurring and Differential Diagnosis

FASD can co-occur with a wide range of neurodevelopmental and mental health conditions. Different aetiologies can combine to lead to complex presentations and multiple diagnostic outcomes. For example, someone who presents with strong family history of ASD, ADHD, or IDD in combination with high risk PAE exposure may create a complex clinical picture. Additionally, co-occurring mental health challenges, such as anxiety, depression and suicidal ideation may be related to the impacts of PAE, living with FASD, and/or due to other etiological factors.

A systematic review by Popova et al. (2016) identified 428 co-occurring conditions for individuals with FASD, spanning 18 of the 22 chapters of the ICD-10. Consequently, co-occurring conditions are common and represent an area of complexity within the FASD diagnostic process.

Members of the Lived Experience Advisory Group strongly recommended that practitioners provide appropriate mental health diagnoses. They shared heartbreaking experiences of diagnostic overshadowing, where service providers solely attributed mental health concerns to FASD rather than recognising concurrent psychiatric conditions and how this had negatively impacted their child's ability to access mental health services.

In some cases, a differential diagnostic approach is more appropriate, especially when other neurodevelopmental or mental health conditions are present (e.g., strong family history of ASD, ADHD, or ID) and low levels of PAE or insufficient 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). Additionally, genetic syndromes that share some of the clinical features of FASD 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. Practitioners are tasked with weighing up the probability of all relevant risk factors to determine the best explanation/s for an individual's presentation.

Consequently, a wide range of conditions and risk factors could be either co-occurring or differential considerations; and this needs to be determined through an individual case formulation. Understanding an individual's unique profile of clinical features, including the relevant co-occurring conditions enables treatments and supports to best target an individual's needs. Figure 13 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.

9.3 Trauma and Prenatal Alcohol Exposure (PAE)

Given the high prevalence of co-occurring adverse childhood experiences (ACEs) with PAE, this area warrants further discussion. In a research context some studies have highlighted potential differential and compounding impacts of adverse life exposures and events and PAE. An overview of these studies is provided in Figure 14.

However, in practice, it can sometimes be challenging to access detailed historical information regarding the timing and magnitude of prenatal and postnatal factors. Practitioners are often 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.

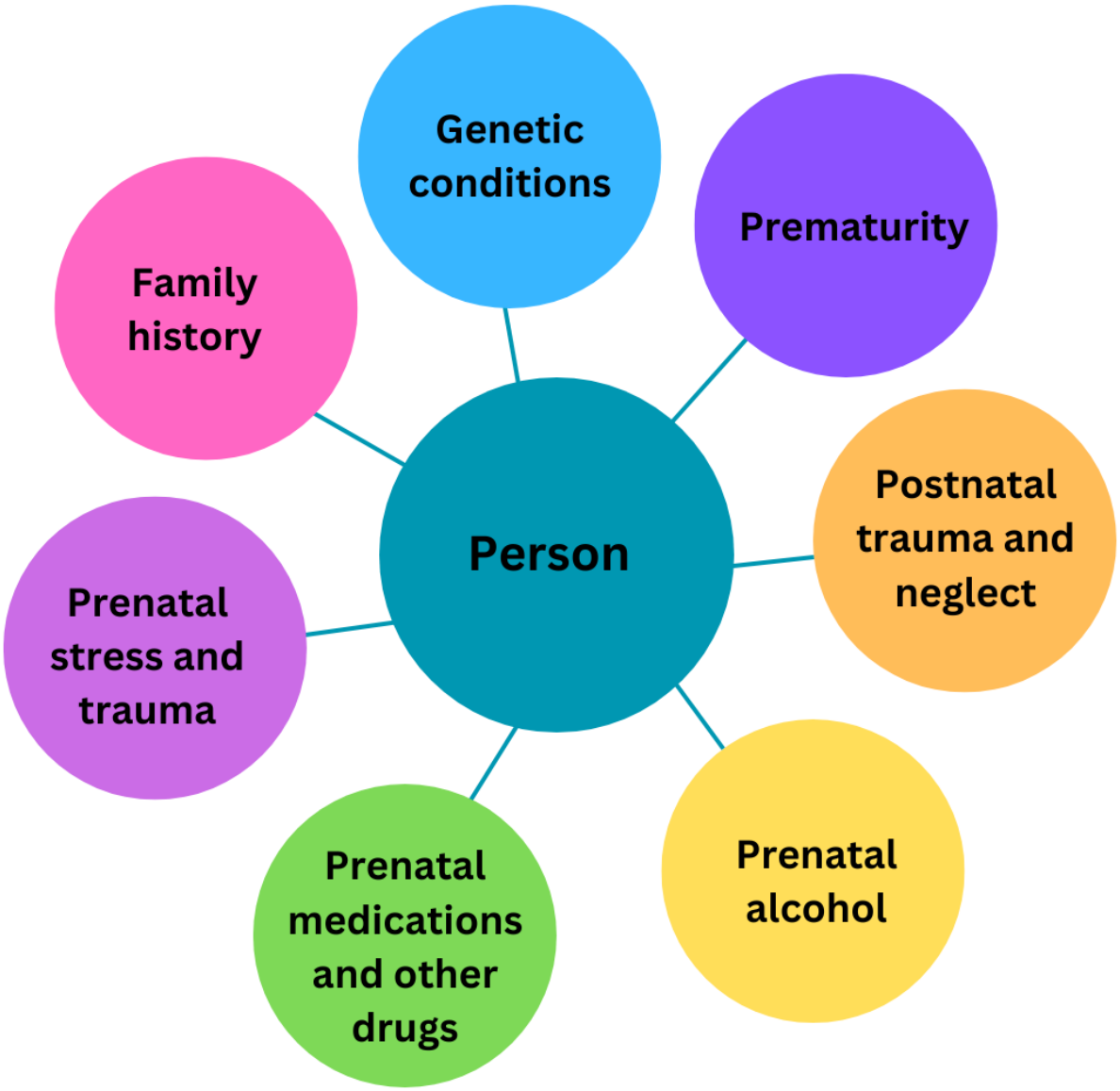


Figure 13. Overview of potentially co-occurring or differential factors/conditions

Adapted from Mukherjee (2021).

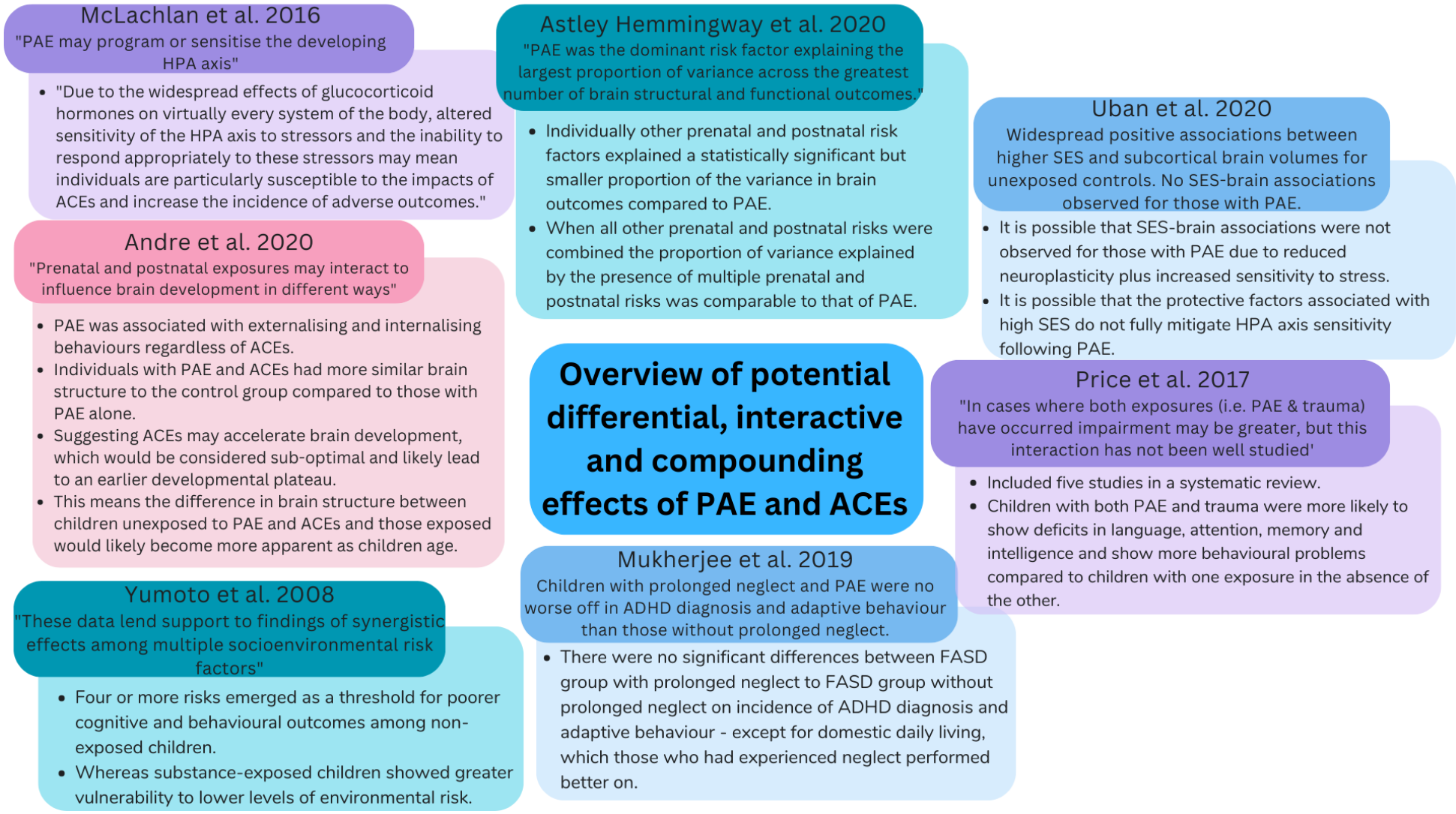


Figure 14. Overview of studies comparing outcomes following prenatal alcohol exposure (PAE) and adverse childhood experiences (ACEs).

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)

9.4 Feedback and Strengths-Based Pathways

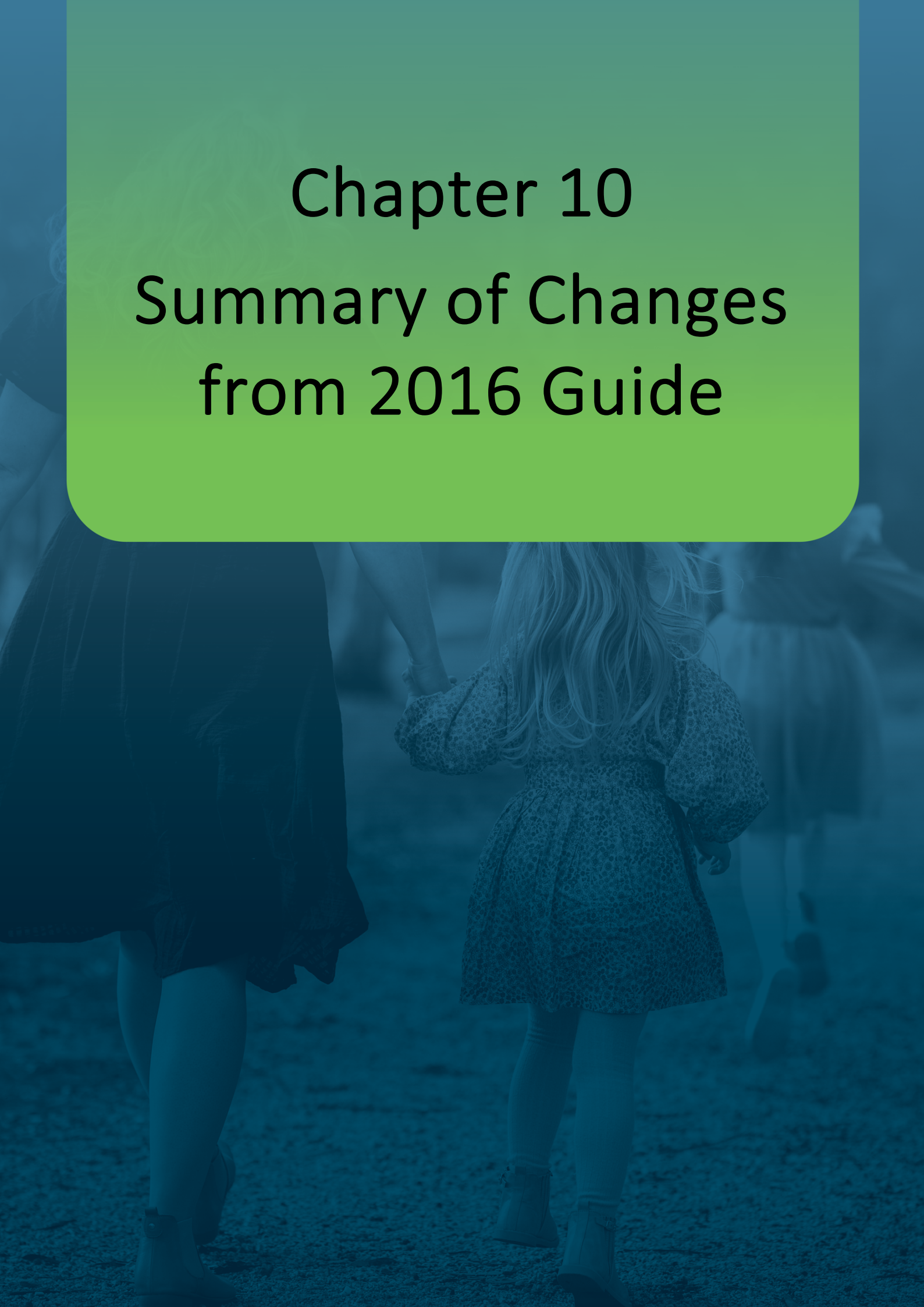
The following lived experience statements were developed from the systematic review and qualitative synthesis of lived experiences of the assessment and diagnostic process (Hayes et al., 2023):

Lived Experience Statement 5	Understand that receiving a diagnosis can bring about mixed emotions. Plan feedback and recommendations with this in mind (High Certainty).
Lived Experience Statement 6	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 (High Certainty).
Lived Experience Statement 7	Recognise an individual's strengths and challenges to identify the most appropriate supports to facilitate positive outcomes post-assessment (High Certainty).
Lived Experience Statement 8	Be mindful that parents/caregivers and family members can have concerns regarding their child's future diagnosis. Provide recommendations to relevant local services that can provide emotional supports (Moderate to High Certainty).
Lived Experience Statement 9	Tailor feedback sessions and reports to individual and family needs, including relevant social and cultural factors (High Certainty).
Lived Experience Statement 10	When writing reports, emphasise the individual's strengths and interests, whilst also addressing areas needing support (High Certainty).
Lived Experience Statement 11	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 (High Certainty).

The following good practice statements were developed to guide the feedback and recommendation process:

Good Practice Statement 37	Involve individuals and families in diagnostic decisions. Individuals and families have the right to decide if diagnoses are appropriate for them, and the diagnostic terminology that is applied, given their personal, social, and cultural context and beliefs. Sometimes, challenges can arise balancing the rights of the individual and the rights of the parent/caregiver; actively engaging and supporting all parties throughout the assessment can help to overcome these challenges.
Good Practice Statement 38	With consent, provide developmentally appropriate feedback to individuals attending for assessment, in coordination with parents/caregivers and/or other support people.
Good Practice Statement 39	Recognise that observed challenges might have multiple explanations and communicate this to individuals and families to enable effective supports.
Good Practice Statement 40	Include individuals and families in the development of report recommendations, respecting their preferences and needs, given their personal, social, and cultural context.

Implementation Consideration, Tool, and Tip 18	Appendix E provides information regarding and example resources to support collaborative goal setting, which can be used to develop tailored recommendations.



Chapter 10

Summary of Changes from 2016 Guide

Chapter 10: Summary of Changes

10.1 Summary of changes from 2016 Guide to FASD Diagnosis

10.1.1 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 the assessment and diagnostic approaches for all Australians.

10.1.2 Embedding living and lived experience perspectives

Through the valuable contributions of members of the Living Experience Advisory Group, Cultural Advisory Group, and Clinical Advisory Group, as well as findings from the systematic review and qualitative synthesis of lived experiences of the assessment process, these guidelines aim to incorporate a wide range of perspectives of people with living and lived experience to improve assessment and diagnostic practices. This approach seeks to promote equity, diversity, and inclusion, supporting fair treatment and participation of all individuals.

10.1.3 Taking a lifespan approach to assessment and diagnosis

The content and wording of these guidelines are designed to support assessment and diagnosis across the lifespan.

10.1.4 Importance of clinical judgement

The Guidelines Development Group balanced providing guidance with allowing flexibility for practitioners to use their clinical judgement to enable person-centred assessment across a wide range of clinical contexts. This includes 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. Practitioners are encouraged to access professional development and clinical supervision to support accurate assessment and diagnosis of FASD.

10.1.5 Diagnostic terminology

No consensus could be reached regarding diagnostic terminology. The term FASD is used throughout the document for consistency and clarity, with alternate terminology consistent with DSM-5-TR (Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure) also included. Consistent with the foundational considerations of these guidelines, it is the right of the individual and family to choose the terminology that is most appropriate for them.

10.1.6 Structure of the diagnostic criteria

A novel structure is proposed for the diagnostic criteria of FASD. The aim of this structure is to capture the heterogeneous nature of FASD, including that not all individuals present with the physical features of FASD. A hierarchical approach based on findings from the evidence review allows

consideration for the consideration of associated features and conditions to support targeted supports and future research.

10.1.7 Minimum prenatal alcohol exposure threshold for diagnosis

A comprehensive review of the best available evidence led to the development of a minimum prenatal alcohol exposure (PAE) threshold for diagnosis. This threshold provides guidance for practitioners and increases the certainty that observed impairments can be attributed to PAE. While PAE is a risk factor for FASD, not every exposure results in FASD.

In developing the PAE criterion and associated guidance, the Guidelines Development Group aimed to balance the available evidence, the limitations of the evidence, and how best to apply the evidence at an individual level. While these guidelines and other international guidelines (e.g., Aotearoa [NZ] FASD Guidelines Development Team, 2024; Cook et al., 2016; Kable et al., 2016) specify a PAE threshold for diagnosis, public health recommendations in Australia and many other countries recommend that people should not drink alcohol when planning a pregnancy or when pregnant to prevent adverse health outcomes, including subtle effects that can occur through the teratogenic effects of alcohol.

10.1.8 Assessment of PAE both before and after pregnancy recognition

The previous guide included assessment of PAE for the entire pregnancy. To improve accuracy, it is recommended that PAE is assessed separately for pre-recognition and post-recognition of the pregnancy. This is important as people are likely to have different alcohol use behaviours prior to awareness of their pregnancy.

10.1.9 Neurodevelopmental domains

Neurodevelopmental domains were selected based on a systematic review and meta-analyses of the best available evidence. Areas 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 a review of the literature on sensory processing. The limited available evidence did not support including sensory processing in the diagnostic criteria at this time. However, these aspects of neurodevelopment that are not included in the diagnostic criteria can still be considered in the broader assessment process to inform tailored supports.

10.1.10 Approach for determining the presence of clinically significant neurodevelopmental impairments

To support practitioners in identifying clinically significant neurodevelopmental impairments, percentile ranges and other information is included. Given the lack of evidence showing differences in important life outcomes between people above or below a particular cut-off, interpretation of standardised tests and how these scores are used to inform clinical decision-making is based on expert guidance or ‘best practices.’

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

10.1.11 Conceptualisation of the affect regulation domain

Based on the evidence review findings, this domain has been reconceptualised to focus on emotional and/or behavioural regulation symptoms, rather than requiring diagnoses of specific mental health conditions. Detailed assessment considerations are provided to support practitioners in assessing this domain.

10.1.12 Terminology of the cognition, language, and academic achievement domains

Feedback from the Advisory Groups led to amendments in the terminology used to describe some of the neurodevelopmental domains, better reflecting current practices and/or better describing the neurodevelopmental assessment process.

Chapter 11
Evidence Underpinning the Guidelines

Chapter 11: Evidence Underpinning the Guidelines

11.1 Systematic review of the association between prenatal alcohol exposure and physical size, dysmorphology and neurodevelopment.

11.1.1 Overview of literature search

Six electronic bibliographic databases (CINAHL, the Cochrane Library, EMBASE, PsychINFO, PubMed and Web of Science Core Collection) were searched from inception to February 2023. Criteria for inclusion in the review included: case-controls or cohort studies examining associations between participants with/without PAE or a FASD diagnosis, and the domains of physical size, dysmorphology, functional neurodevelopment and/or brain structure/neurology were included. Studies were excluded if they were non-empirical, sample size <10, determined PAE via biological markers, or lacked suitable comparison group. Summary data were extracted, and associations between outcomes and standardised levels of PAE or FASD diagnosis were determined using random-effects meta-analyses. Certainty of the evidence was assessed using GRADE.

11.1.2 Overview of the body of available evidence

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

For physical size, a negative association was found between heavy, very heavy, and confirmed but unquantified levels of PAE, with the quality of the evidence ranging from very low to moderate certainty. For major dysmorphology, a positive association found between moderate, heavy, and confirmed but unquantified levels of PAE, with very low to low certainty in the evidence. For functional neurodevelopmental outcomes an association was found between heavy, very heavy and confirmed unquantified levels of PAE, with very low to moderate certainty in the evidence. For structural and neurological neurodevelopmental outcomes, an association was found between all available levels of PAE, with very low to moderate certainty. The evidence for these domains consistently indicated adverse effects associated with PAE, although the quality of the evidence varied considerably.

11.1.3 Overview of the strengths and limitations

This systematic review comprehensively summarises the available evidence on the association between PAE and key diagnostic components of FASD. A strength of this review is the standardisation of PAE categories, enabling synthesis and comparison of evidence across studies at equivalent PAE levels, rather than comparing studies based on their author-defined levels.

For dysmorphology outcomes, there was a substantial lack of reporting of normative charts used and variability in reporting of data, which limited comparisons across available studies. For functional

neurodevelopmental outcomes, there was considerable diversity in the assessment instruments used, as well as the reporting methods. Further, there was a paucity of research available that had utilised contemporary clinical assessment tools, with many studies using out-dated test versions no longer used in clinical practice. For structural and neurological outcomes, besides head circumference, there was a general lack of studies available. Due to limited data available, the evidence review was unable to examine the potential influence of timing and type of PAE exposure (e.g., binge vs. chronic exposure) on the association with outcomes.

11.1.4 Overview of the connection between the evidence and the recommendations

Results of this systematic review informed the development of the GRADE-based recommendations. For further details see the association between prenatal alcohol exposure, physical size, dysmorphology and neurodevelopment: systematic review report, supplemental evidence summary files (Supplemental File A: Study exclusion list; Supplemental File B: Risk of bias assessment; Supplemental File C: Physical size GRADE ratings and forest plots; Supplemental File D: Regression summaries; Supplemental File E: Dysmorphology GRADE ratings and forest plots; Supplemental File F: Functional neurodevelopmental GRADE ratings and forest plots; Supplemental File G: Structural and neurological GRADE ratings and forest plots) and the associated publication (Akison, Hayes et al., 2024).

Summarised evidence-to-decision frameworks are included for each GRADE-based recommendation in the Administrative and Technical Report. The overarching evidence-to-decision framework for the diagnostic criteria is included in Appendix B.

11.2 Systematic review and qualitative synthesis of lived experiences of the assessment and diagnostic process.

11.2.1 Overview of the search

Six electronic bibliographic databases (CINAHL, the Cochrane Library, EMBASE, PsychINFO, PubMed and Web of Science Core Collection) were searched from inception to December 2022. Criteria for inclusion in the review included: qualitative or mixed methods studies reporting lived experiences of the diagnostic assessment process for FASD. Data from included studies were synthesised using a thematic analysis approach. GRADE-CERQual was used to assess confidence in the review findings.

11.2.2 Overview of the body of available evidence

Ten studies were included in the review. Thematic analysis identified 10 first-level themes relating to four over-arching topics, including pre-assessment concerns and challenges, the diagnostic assessment process, receipt of the diagnosis, and post-assessment adaptations and needs. GRADE-CERQual confidence ratings for each of the review themes were moderate to high.

Themes regarding pre-assessment concerns and challenges included that:

1. The assessment journey typically commenced when caregivers recognised behavioural challenges that prompted them to seek help.

2. caregivers reported accessing numerous services for their child's behavioural concerns but perceived these to be unhelpful and in some cases negative, including not feeling listened to and having their concerns dismissed by health professionals.
3. Caregivers reported that FASD was not considered as a possible diagnostic outcome, even when caregivers raised the topic of PAE/FASD with health professionals.

Themes related to the diagnostic assessment process included:

1. Caregivers described frustrations with accessing assessment services for FASD due to the limited number of providers and long waitlists when services were available.
2. Caregivers reported positive experiences with high levels of satisfaction and feelings of empowerment when attending a specialist FASD service.
3. The diagnostic reports were noted by caregivers as a valuable resource to help them and others working with their child to understand strengths and areas of vulnerability.

Themes related to receiving the diagnosis included:

1. Both adults with FASD and caregivers reported that while mixed feelings were experienced when receiving a FASD diagnosis, including a sense of relief, hope and confidence, as well as grief, hopelessness, guilt and shame, the diagnosis also provided improved understanding and insight.
2. Adults with FASD and caregivers perceived the benefits of the diagnosis as a means to access appropriate support and services tailored to their and their child's needs.

Themes related to post-assessment adaptations and needs included:

1. Caregivers describing both aspirations and apprehensions for their child's future following the assessment.
2. Caregivers describing service- and family-level barriers to accessing support.

11.2.3 Overview of the strengths and limitations

Confidence ratings for most review themes were high, indicating that these themes are a reasonable representation of people's experiences of the assessment and diagnostic process. Although the moderate confidence ratings for some themes reflected concerns about the adequacy of the data and indicate that further research is needed. Only a small number of studies discerned the perspective of biological caregivers, Indigenous caregivers, and adult clients, with no studies examining perspectives of children/adolescents who undertook an assessment. There was limited geographical representation with most included studies conducted in Australia and Canada.

11.2.4 Overview of the connection between the evidence and the recommendations

Results of this review informed the development of the lived experience statements. For further details see the lived experiences of the assessment and diagnostic process: systematic review and qualitative synthesis report and associated publication (Hayes et al., 2023).

11.3 Scoping review of factors to be considered as part of a holistic assessment.

11.3.1 Overview of the search

Six electronic bibliographic databases (CINAHL, the Cochrane Library, EMBASE, PsychINFO, PubMed and Web of Science Core Collection) were searched from inception to September 2022. Criteria for inclusion in the review included: systematic reviews and original research (inclusive of quantitative, qualitative and mixed method designs) that included a focus on any broader elements that could be considered as part of a holistic assessment process. This included: health, social, psychological, occupational, or other behavioural/mental health factors not typically considered as part of diagnostic criteria. Data charting and content analysis was utilised to synthesise the results.

11.3.2 Overview of the body of available evidence

One hundred and twenty-one studies were included, spanning 12 areas of interest. The studies indicated a wide range of factors that may influence long-term health development, and wellbeing for individuals with FASD. These included:

1. **Physical health:** including bone/teeth health, eye/ear health, cardiovascular/renal health, metabolic health, nervous system development/function, respiratory/immune system health, reproductive health, and health service utilization.
2. **Sleep**: including prevalence/type of sleep difficulties in children with PAE, associations between sleep difficulties and daytime functioning, and infant sleep-wake regulation as an early indicator of PAE.
3. **Adverse postnatal experiences**: including risk of multiple adverse experiences, the postnatal environment in the mitigation of the effects of FASD, socioeconomic effects and how adverse postnatal experiences in children with FASD affect attachment style and behavior.
4. **Substance use and other risk-taking behaviours**: including alcohol use in children/adolescents with PAE, alcohol use problems in adults with PAE, effects of other variables on alcohol use problems, and other risk-taking behaviour excluding alcohol use in individuals with PAE.
5. **Mental health:** including suicide/self-harm, medications/hospitalizations intra-individual variability and Tourette Syndrome/tic disorders.
6. **Contact with the criminal justice system**: including the effects of PAE on contact with the criminal justice system (CJS), interactions between risky AOD and CJS contact, and other factors related to CJS contact.
7. **First Nations cultural considerations**: including trauma/stigmatization, communication barriers, and cultural differences/the importance of culture and family.
8. **Transition to adult roles**: including vulnerability, independence and challenges in education and employment.
9. **Out-of-home care** (OOHC): including misdiagnosed/undiagnosed children in adoptive/foster care, and adverse outcomes associated with children with PAE/FASD living in adoptive/foster care.

10. **Feeding/eating**: including effects of PAE on general eating behaviors, nutrient intake in children with FASD and the opportunity for dietary intervention to improve outcomes, and sex-specific effects of PAE on BMI and obesity prevalence.
11. **Incontinence:** including urinary incontinent, fecal incontinence, and nocturnal enuresis).
12. **Strengths/interests/external resources:** including personal (internal strengths), personal (internal) interests and external supports (i.e., supportive environmental factors) and connection to culture.

11.3.3 Overview of the strengths and limitations

This scoping review provided a comprehensive overview of many studies across a diverse range of areas relating to PAE/FASD. The significant diversity of outcomes within key study areas limits the ability to undertake quantitative synthesis. Additionally, the review was limited to peer-reviewed publications, excluding other types of clinical publications and grey literature.

11.3.4 Overview of how this evidence was used in the guidelines

Findings from this scoping review were used to inform the development of good practice statements and practitioner templates for the medical, holistic, developmental, functional and wellbeing assessments, and for the holistic profile, formulation, and strengths-based pathways sections of the guidelines document.

See the factors to be considered as part of a holistic assessment: scoping review report and associated publication (Reid et al., 2023) for further details.

11.4 Scoping review exploring resource implications and models of care

11.4.1 Overview of the search

Six electronic bibliographic databases (CINAHL, the Cochrane Library, EMBASE, PsychINFO, PubMed and Web of Science Core Collection) were searched from inception to December 2022. Criteria for inclusion in the review included: peer-reviewed studies focused on the potential costs and/or resources associated with undertaking diagnostic assessments for FASD. Studies focused on direct costs of assessment and diagnostic service provision, resource considerations in development or delivery of services, and development and/or comparison of different types of models of care/clinical models of service delivery specific to assessment and diagnosis of FASD. Data charting and content analysis was utilised to synthesise results.

11.4.2 Overview of the body of available evidence

A total of 11 studies were included in the final qualitative synthesis. The primary patient costs were attributed to the lengthy time required for diagnosis, which could be translated to time taken off work leading to loss of income (if employed), and time required for child-care. The estimates of time required by patients for diagnosis ranged between 0.5 hours and 47 hours. The primary service costs were attributed to the costs of practitioners and support personnel, and the involvement of multi-

disciplinary teams in the assessment process. Estimates of the diagnostic costs were limited and varied between studies. Several models of care were explored, primarily in Canadian clinics, which aimed to capitalise on available services to improve patient care and reduce service costs.

11.4.3 Overview of the strengths and limitations

This review provides preliminary insights into the available evidence regarding resource implications and models of care for assessment and diagnosis of FASD. A key limitation of the evidence is the small number and predominately descriptive nature of the studies identified. Additionally, most included studies were conducted in Canada, with only one study identified from Australia.

11.4.4 Overview of how this evidence was used in the guidelines

Findings from this scoping review informed the assessment process recommended in these guidelines. See the exploring resource implications and models of care: scoping review report and associated publication (Kent et al., 2023) for further details.

11.5 Summary of key evidence gaps

11.5.1 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 is the pregnancy/birth cohort study. These studies recruit pregnant individuals, 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 outcomes, such as dysmorphology, were not examined as often in these types of studies.

Future research would greatly benefit from exposure-specific pregnancy cohorts, which could examine all prenatal and postnatal exposures and events, including all relevant FASD 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 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.

11.5.2 Local tools and norms to support assessment of facial features

Feedback from the Advisory Groups indicated that this is an important area for future Australian 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).
- Clinical, diagnostic utility, and accessibility of 3D photos.

11.5.3 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 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.

11.5.4 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 to examine the complex interplay between genetics and a wider range of environmental prenatal and postnatal factors, including adverse and protective experiences 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 by allowing the review of all genetic testing results completed through VCGS.

11.5.5. Application of the diagnostic criteria in clinical practice

Research is lacking regarding the clinical application of diagnostic criteria in Australia. While 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. 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 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, while also adhering to data sovereignty principles.

References

General references

Agency for Clinical Innovation. *Shared decision-making*. https://aci.health.nsw.gov.au/shared-decision-making

Akison LK, Hayes N, Vanderpeet C, Logan J, Munn Z, Middleton P, Moritz KM, Reid N & The Australian FASD Guidelines Development Group on behalf of the Australian FASD Guidelines Consortium. (2024). Prenatal alcohol exposure and associations with physical size, dysmorphology and neurodevelopment: A systematic review and meta-analysis. *BMC Medicine.*

American Psychological Association, APA Task Force on Psychological Assessment and Evaluation Guidelines. (2020). *APA Guidelines for Psychological Assessment and Evaluation.* https://www.apa.org/about/policy/guidelines-psychological-assessment-evaluation.pdf

Andre QR, McMorris CA, Kar P, Ritter C, Gibbard WB, Tortorelli C, & Lebel C. (2020). Different brain profiles in children with prenatal alcohol exposure with or without early adverse exposures. *Hum Brain Mapp*, *41*(15), 4375-4385.

Angelopoulou E & Drigas A. (2021). Working memory, attention and their relationship: A theoretical overview. *Res Society Dev*, *10*(5), e46410515288-e46410515288.

Aotearoa (NZ) FASD Guidelines Development Project Team. (2024). *The Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Guidelines for Aotearoa (NZ).* Hāpai te Hauora.

Astley S. (2004). *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-digit diagnostic code*. https://depts.washington.edu/fasdpn/htmls/4-digit-code.htm

Astley Hemingway SJ, Davies JK, Jirikowic T, & Olson EM. (2020). What proportion of the brain structural and functional abnormalities observed among children with fetal alcohol spectrum disorder is explained by their prenatal alcohol exposure and their other prenatal and postnatal risks? *Adv Pediatr Res*, *7*(41).

Australian Psychological Society. (2014). *Ethical guidelines for psychological assessment and use of psychological tests.* https://static1.squarespace.com/static/5cd240fc94d71aaa497cbe7f/t/5cd3af328f383d000197d453/1557376819371/EG-Psychological-tests.pdf

Baidawi S, Ball R, Kembhavi-Tam G, Avery S, Newitt R, Turnbull L, & Sheehan R. (2022). *Research Report - Care criminalisation of children with disability in child protection systems. Part 1: Scoping and policy review.* A. Royal Comission into Vploiolience, Neglect and Exploitation of People with Disability.

Bishop DVM, Snowling MJ, Thompson PA, & Greenhalgh T. (2016). CATALISE: A Multinational and Multidisciplinary Delphi Consensus Study. Identifying Language Impairments in Children. *PLoS One*, *11*(7), e0158753.

Bishop DV, Snowling MJ, Thompson PA, & Greenhalgh T. (2017). Phase 2 of CATALISE: a multinational and multidisciplinary Delphi consensus study of problems with language development: Terminology. *J Child Psychol Psychiatry*, *58*(10), 1068-1080.

Blank R, Barnett AL, Cairney J, Green D, Kirby A, Polatajko H, Rosenblum S, Smits-Engelsman B, Sugden D, Wilson P, & Vincon S. (2019). International clinical practice recommendations on the definition,

diagnosis, assessment, intervention and psychological assessments of developmental coordination disorder. *Dev Med Child Neurol*, 61(3), 242-285.

Bower C & Elliott EJ. (2016). On behalf of the Steering Group. Report to the Australian Government Department of Health: "Australian Guide to the Diagnosis of Fetal Alcohol Spectrum Disorder (FASD) ISBN. 978-0-6481297-4-5.

Cicchetti D. (1990). A historical perspective on the discipline of developmental psychopathology. In *Risk and protective factors in the development of psychopathology.* (pp. 2-28). Cambridge University Press.

Cicchetti D & Toth SL. (2009). The past achievements and future promises of developmental psychopathology: the coming of age of a discipline. *J Child Psychol Psychiatry*, *50*(1-2), 16-25.

Coles CD, Bandoli G, Kable JA, Del Campo M, Suttie M, Chambers CD. (2023). Comparison of three systems for the diagnosis of fetal alcohol spectrum disorders in a community sample. *Alcohol Clin Exp Res, 47(2)*, 370-381.

Cook JL, Green CR, Lilley CM, Anderson SM, Baldwin ME, Chudley AE, Conry JL, LeBlanc N, Loock C. A, Lutke J, Mallon BF, McFarlane AA, Temple VK, & Rosales T. (2016). Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *CMAJ*, *188*(3), 191-197.

Crawford JR, Garthwaite PH, & Slick DJ. (2009). On percentile norms in neuropsychology: Proposed reporting standards and methods for quantifying the uncertainty over the percentile ranks of test scores. *J Child Psychol Psychiatry*, *23*(7), 1173-1195.

Daly P. (2022). A New Approach to Disease, Risk, and Boundaries Based on Emergent Probability. *Journal Med Philos*, *47*(3), 457-481.

First MB. (2017). The DSM revision process: needing to keep an eye on the empirical ball: A commentary on 'Expert consensus v. evidence-based approaches in the revision of the DSM' by Kendler & Solomon (2016). *Psychol Med*, *47*(1), 19-22.

Garvey G, Anderson K, Gall A, Butler TL, Cunningham J, Whop LJ, Dickson M, Ratcliffe J, Cass A, Tong A, Arley B, & Howard K. (2021). What Matters 2 Adults (WM2Adults): Understanding the Foundations of Aboriginal and Torres Strait Islander Wellbeing. *Int J Environ Res Public Health*, *18*(12).

GRADE Working Group. (2013). *Handbook for grading the quality of evidence and strength of recommendation using the GRADE approach*. https://gdt.gradepro.org/app/handbook/handbook.html

Guilmette TJ, Sweet JJ, Hebben N, Koltai D, Mahone EM, Spiegler BJ, Stucky K, & Westerveld M. (2020). American Academy of Clinical Neuropsychology consensus conference statement on uniform labeling of performance test scores. *Clinl Neuropsychol*, *34*(3), 437-453.

Hamilton S, Maslen S, Watkins R, Conigrave K, Freeman J, O'Donnell M, Mutch RC, & Bower C. (2020). 'That thing in his head': Aboriginal and non-Aboriginal Australian caregiver responses to neurodevelopmental disability diagnoses. *Sociol of Health Ill*, *42*(7), 1581-1596.

Hamilton S, Reibel T, Maslen S, Watkins R, Jacinta F, Passmore H, Mutch R, O'Donnell M, Braithwaite V, & Bower C. (2020). Disability "In-Justice": The Benefits and Challenges of "Yarning" With Young People Undergoing Diagnostic Assessment for Fetal Alcohol Spectrum Disorder in a Youth Detention Center. *Qual Health Res*, *30*(2), 314-327.

Hayes N, Akison LK, Goldsbury S, Hewlett N, Elliott E J, Finlay-Jones A, Shanley DC, Bagley K, Crawford A, Till H, Crichton A, Friend R, Moritz KM, Mutch R, Harrington S, Webster A, & Reid N. (2022). Key Stakeholder

Priorities for the Review and Update of the Australian Guide to Diagnosis of Fetal Alcohol Spectrum Disorder: A Qualitative Descriptive Study. *Int J Environ Res Public Health*, *19*(10).

Hayes N, Bagley K, Hewlett N, Elliott EJ, Pestell CF, Gullo MJ, Munn Z, Middleton P, Walker P, Till H, Shanley DC, Young SL, Boaden N, Hutchinson D, Kippin NR, Finlay-Jones A, Friend R, Shelton D, Crichton A, & Reid N. (2023). Lived experiences of the diagnostic assessment process for fetal alcohol spectrum disorder: A systematic review of qualitative evidence. *Alcohol Clin Exp Res, 47*(7), 1209-1223.

Hewlett N, Hayes L, Williams R, Hamilton S, Holland L, Gall A, Doyle M, Goldsbury S, Boaden N, & Reid, N. (2023). Development of an Australian FASD Indigenous Framework: Aboriginal Healing-Informed and Strengths-Based Ways of Knowing, Being and Doing. *Int J Environ Res Public Health*, *20*(6).

Himmelreich, M, Lutke C, & Hargrove ET. (2020). Fetal alcohol spectrum disorder (FASD) as a whole-body diagnosis. *The Routledge handbook of social work and addictive behaviors*.

International Test Commission. (2011). International Guidelines for Test Use. *International Journal of Testing*, 1(2), 93-114. https://www.intestcom.org/files/guideline_test_use.pdf

Ji L Zhao Q, Gu H Chen Y, Zhao J, Jiang X, & Wu L. (2021) Effect of Executive Function on Event-Based Prospective Memory for Different Forms of Learning Disabilities. *Front. Psychol.* 12:528883. https://doi.org/10.3389/fpsyg.2021.528883

Joffe S. (2003). Rethink "affirmative agreement," but abandon "assent". *Am J Bioeth*, *3*(4), 9-11.

Kable JA, O'Connor MJ, Olson HC, Paley B, Mattson SN, Anderson SM, & Riley EP. (2016). Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE): Proposed DSM-5 Diagnosis. *Child Psychiatry Hum Dev*. 47(2), 335-46.

Kendler, K. S., & Solomon, M. (2016). Expert consensus v. evidence-based approaches in the revision of the DSM. *Psychological Medicine*, *46*(11), 2255-2262.

Kent N, Hayes N, Young S, Vanderpeet C, Shanley D, Harris K, Pestell C, Elliott E, & Reid N. (2023). Exploring resource implications and models of care for assessment and diagnosis of fetal alcohol spectrum disorder: A scoping review. *Alcohol Clin Exp Res*, *47*(11), 2022-2032.

Kully-Martens K, McNeil A, Pei J, & Rasmussen C. (2022). Toward a Strengths-Based Cognitive Profile of Children with Fetal Alcohol Spectrum Disorders: Implications for Intervention. *Curr Dev Disord Rep*, *9*(2), 53-62.

Lotfi T, Hajizadeh A, Moja L, Akl EA, Piggott T, Kredo T, Langendam MW, Iorio A, Klugar M, Klugarová J, Neumann I, Wiercioch W, Leontiadis GI, Mbuagbaw L, Turgeon AF, Meerpohl J, Stevens A, Brozek J, Santesso N., . . . Schünemann H J. (2022). A taxonomy and framework for identifying and developing actionable statements in guidelines suggests avoiding informal recommendations. *J Clin Epidemiol*, *141*, 161-171.

Masotti P, Longstaffe S, Gammon H, Isbister J, Maxwell B, & Hanlon-Dearman A. (2015). Integrating care for individuals with FASD: results from a multi-stakeholder symposium. *BMC Health Serv Res*, *15*(1), 457.

May PA, Gossage JP. (2011). Maternal risk factors for fetal alcohol spectrum disorders: not as simple as it might seem. *Alcohol Res* Health, 34(1), 15-26.

McDowd JM. (2007) An overview of attention: behavior and brain. *J Neurol Phys Ther*, 31(3), 98-103.

McLachlan K, Rasmussen C, Oberlander TF, Loock C, Pei J, Andrew G, Reynolds J, & Weinberg J. (2016). Dysregulation of the cortisol diurnal rhythm following prenatal alcohol exposure and early life adversity. *Alcohol*, *53*, 9-18.

Mesulam, M.M. (2000) Principles of Behavioral and Cognitive Neurology (Second Edition). Oxford University Press.

Mujawar S, Patil J, Chaudhari B, & Saldanha D. (2021). Memory: Neurobiological mechanisms and assessment. *Ind Psychiatry J*, *30*(Suppl 1), S311.

Mukherjee RAS. (2021). Diagnosing FASD in the Context of Other Overlapping Neurodevelopmental Presentations. In R. A. S. Mukherjee & N. Aiton (Eds.), *Prevention, Recognition and Management of Fetal Alcohol Spectrum Disorders* (pp. 157-170). Springer International Publishing.

Mukherjee RAS, Cook PA, Norgate SH, & Price AD. (2019). Neurodevelopmental outcomes in individuals with fetal alcohol spectrum disorder (FASD) with and without exposure to neglect: Clinical cohort data from a national FASD diagnostic clinic. *Alcohol*, *76*, 23-28.

Mutch RC, Watkins R, & Bower C. (2015). Fetal alcohol spectrum disorders: Notifications to the Western Australian Register of Developmental Anomalies. *J Paediatr Child Health*, *51*(4), 433-436.

National Health and Medical Research Council. (2020). *Procedures and requirements for meeting the NHMRC standards for clinical practice guidelines*.

National Health and Medical Research Council. (2018). *Guidelines for Guidelines Handbook*. www.nhmrc.gov.au/guidelinesforguidelines

Pei J, Poth C, Tremblay M, & Walker M. (2021). An Integrative Systems Approach to Enhancing Service Delivery for Individuals with Complex Needs. *Curr Dev Disord Rep*, *8*(2), 57-68.

Popova S, Lange S, Shield K, Mihic A, Chudley A, Mukherjee RAS, Bekmuradov D, & Rehm J. (2016). Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis. *Lancet*, *387*(10022), 978-987.

Price A, Cook PA, Norgate S, & Mukherjee RAS. (2017). Prenatal alcohol exposure and traumatic childhood experiences: A systematic review. *Neurosci Biobehav Rev*, *80*, 89-98.

Reid N, Crawford A, Petrenko C, Kable J, & Olson HC. (2022). A Family-Directed Approach for Supporting Individuals with Fetal Alcohol Spectrum Disorders. *Curr Dev Disord Rep*, *9*(1), 9-18.

Reid N, Hayes N, Young SB, Akison LK, & Moritz KM. (2021). Caregiver-reported physical health status of children and young people with fetal alcohol spectrum disorder. *J Dev Orig Health Dis*, *12*(3), 420-427.

Reid N, Kent N, Hewlett N, Bagley K, Tsang TW, Goldsbury S, Williams R, Akison L, Holland L, Vanderpeet C, Doyle M, Boaden N, & Hayes N. (2023). Factors to be considered as part of a holistic assessment for fetal alcohol spectrum disorder: A scoping review. *Alcohol Clin Exp Res*, *47*(11), 2007-2021.

Reid N & Petrenko CLM (2018). Applying a Developmental Framework to the Self-Regulatory Difficulties of Young Children with Prenatal Alcohol Exposure: A Review. *Alcohol Clin Exp Res*, *42*(6), 987-1005.

Salehinejad MA, Ghanavati E, Rashid MHA, & Nitsche MA. (2021). Hot and cold executive functions in the brain: A prefrontal-cingular network. *Brain Neurosci Adv*, *5*, 23982128211007769.

Scölin L & Heenan M. (2022). No alcohol, no risk. #FASD – twitter activity on alcohol and pregnancy among Australian organisations. *Subst Use Misuse, 57(14), 2021-2030.*

Schwartz PH. (2007). Decision and discovery in defining 'disease'. In *Establishing medical reality: Essays in the metaphysics and epistemology of biomedical science* (pp. 47-63). Springer.

Sira CS & Mateer CA. (2014). Executive Function. In M. J. Aminoff & R. B. Daroff (Eds.), *Encyclopedia of the Neurological Sciences (Second Edition)* (pp. 239-242). Academic Press.

Spriggs M. (2023). Children and bioethics: clarifying consent and assent in medical and research settings. *Br Med Bull*, *145*(1), 110-119.

Strömland K, Chen Y, Norberg T, Wennerström K, & Michael G. (1999). Reference values of facial features in Scandinavian children measured with a range-camera technique. *Scand J Plast Reconstr Surg Hand Surg*, *33*(1), 59-65.

Thompson AL. (2021). What is normal, healthy growth? Global health, human biology, and parental perspectives. *American Journal of Human Biology*, *33*(5), e23597.

Tsang TW, Laing-Aiken Z, Latimer J, Fitzpatrick J, Oscar J, Carter M, & Elliott E. (2017). Digital assessment of the fetal alcohol syndrome facial phenotype: reliability and agreement study. *BMJ Paediatr Open*, *1*(1), e000137.

Uban KA, Kan E, Wozniak JR, Mattson SN, Coles CD, & Sowell ER. (2020). The Relationship Between Socioeconomic Status and Brain Volume in Children and Adolescents With Prenatal Alcohol Exposure. *Front Hum Neurosci*, *14*, 85.

United Nations. (1989). *Convention on the rights of the child*. Treaty Series, Issue.

United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. Treaty Series, Issue. U. G. Assembly.

United Nations. (2007). *Declaration on the rights of Indigenous Peoples*. U. G. Assembly.

United Nations. (2017). *Leaving no one behind: Equaltiy and non-discrimination at the heart of sustainable development*.

Waddington L & Priestley M. (2021). A human rights approach to disability assessment. *J Int Comp Soc Policy*, *37*(1), 1-15.

Walker MJ & Rogers WA. (2018). A New Approach to Defining Disease. *J Med Philos*, *43*(4), 402-420.

Wickens C. (2021). Attention: Theory, Principles, Models and Applications, Int. J. Hum. Comput. 37(5), 403-417.

World Health Organization. (2001). *International classification of functioning, disability and health*. Geneva

World Health Organisation. (2004). *The ICD-10 classification of mental and behavioural disorders:*

clinical descriptions and diagnostic guidelines. Geneva ISBN 92 4 154422 8

Yumoto C, Jacobson SW, & Jacobson JL. (2008). Fetal Substance Exposure and Cumulative Environmental Risk in an African American Cohort. *Child Dev*, *79*(6), 1761-1776.

References: Systematic review of the association between prenatal alcohol exposure and physical size, dysmorphology and neurodevelopment

Addila AE, Azale T, Gete YK & Yitayal M. (2021). The effects of maternal alcohol consumption during pregnancy on adverse fetal outcomes among pregnant women attending antenatal care at public health facilities

in Gondar town, Northwest Ethiopia: a prospective cohort study. *Subst Abuse Treat Prev Policy*, 16, 64.

Adnams CM, Kodituwakku PW, Hay A, Molteno CD, Viljoen D & May PA. (2001). Patterns of cognitive-motor development in children with fetal alcohol syndrome from a community in South Africa. *Alcohol Clin Exp Res*, 25, 557-562.

Aghamohammadi-Sereshki A, McMorris CA, Ben Gibbard W, Tortorelli C, Pike GB & Lebel C. (2022). Effects of prenatal alcohol exposure on neurobehavioural development and volume of rostral cingulate cortex subregions. *J Psychiatry Neurosci*, 47, E272-E282.

Agnihotri S, Subramaniapillai S, Keightley M, Rasmussen C, Cameron D, Ryan J & Rovet J. (2019). Everyday memory difficulties in children and adolescents with Fetal Alcohol Spectrum Disorder. *Dev Neurorehabil*, 22, 462-469.

Alati R, Davey Smith G, Lewis SJ, Sayal K, Draper ES, Golding J, Fraser R & Gray R. (2013). Effect of prenatal alcohol exposure on childhood academic outcomes: contrasting maternal and paternal associations in the ALSPAC study. *PLoS One*, 8, e74844.

Alati R, Macleod J, Hickman M, Sayal K, May M, Smith GD & Lawlor DA. (2008). Intrauterine exposure to alcohol and tobacco use and childhood IQ: findings from a parental-offspring comparison within the Avon Longitudinal Study of Parents and Children. *Pediatr Res*, 64, 659-666.

Alati R, Najman JM, O'Callaghan M, Bor W, Williams GM & Clavarino A. (2009). Fetal growth and behaviour problems in early adolescence: findings from the Mater University Study of Pregnancy. *Int J Epidemiol*, 38, 1390-1400.

Aragón AS, Coriale G, Fiorentino D, Kalberg WO, Buckley D, Gossage JP, Ceccanti M, Mitchell ER & May PA. (2008). Neuropsychological characteristics of Italian children with fetal alcohol spectrum disorders. *Alcohol Clin Exp Res*, 32, 1909-1919.

Aragón AS, Kalberg WO, Buckley D, Barela-Scott LM, Tabachnick BG & May PA. (2008). Neuropsychological study of FASD in a sample of American Indian children: processing simple versus complex information. *Alcohol Clin Exp Res*, 32, 2136-2148.

Astley SJ, Aylward EH, Olson HC, Kerns K, Brooks A, Coggins TE, Davies J, Dorn S, Gendler B, et al. (2009). Magnetic resonance imaging outcomes from a comprehensive magnetic resonance study of children with fetal alcohol spectrum disorders. *Alcohol Clin Exp Res*, 33, 1671-1689.

Astley SJ, Olson HC, Kerns K, Brooks A, Aylward EH, Coggins TE, Davies J, Dorn S, Gendler B, et al. (2009). Neuropyschological and behavioral outcomes from a comprehensive magnetic resonance study of children with fetal alcohol spectrum disorders. *Can J Clin Pharmacol*, 16, e178-201.

Autti-Rämö I, Gaily E & Granström ML. (1992). Dysmorphic features in offspring of alcoholic mothers. *Arch Dis Child*, 67, 712-716.

Autti-Ramo I & Granstrom ML. (1991). The effect of intrauterine alcohol exposition in various durations on early cognitive development. *Neuropediatrics*, 22, 203-210.

Bada HS, Das A, Bauer CR, Shankaran S, Lester BM, Gard CC, Wright LL, Lagasse L & Higgins R. (2005). Low birth weight and preterm births: etiologic fraction attributable to prenatal drug exposure. *J Perinatol*, 25, 631-637.

Bagheri MM, Burd L, Martsolf JT & Klug MG. (1998). Fetal alcohol syndrome: maternal and neonatal characteristics. *J Perinat Med*, 26, 263-269.

Bakhireva LN, Lowe J, Garrison LM, Cano S, Leyva Y, Qeadan F & Stephen JM. (2018). Role of caregiver-reported outcomes in identification of children with prenatal alcohol exposure during the first year of life. *Pediatr Res*, 84, 362-370.

Bandoli G, Coles CD, Kable JA, Wertelecki W, Yevtushok L, Zymak-Zakutnya N, Wells A, Granovska IV, Pashtepa AO, et al. (2019). Patterns of Prenatal Alcohol Use That Predict Infant Growth and Development. *Pediatrics*, 143,

Bandoli G, Jones K, Wertelecki W, Yevtushok L, Zymak-Zakutnya N, Granovska I, Plotka L & Chambers C. (2020). Patterns of Prenatal Alcohol Exposure and Alcohol-Related Dysmorphic Features. *Alcohol Clin Exp Res*, 44, 2045-2052.

Bandoli G, Kable JA, Coles CD, Del Campo M, Suttie M & Chambers CD. (2022). Trajectories of prenatal alcohol exposure and behavioral outcomes: Findings from a community-based sample. *Drug Alcohol Depend*, 233, 109351.

Barrett CE, Kable JA, Madsen TE, Hsu CC & Coles CD. (2019). The Use of Functional Near-Infrared Spectroscopy to Differentiate Alcohol-Related Neurodevelopmental Impairment. *Dev Neuropsychol*, 44, 203-219.

Bay B, Stovring H, Wimberley T, Denny CH, Mortensen EL, Eriksen HL & Kesmodel US. (2012). Low to moderate alcohol intake during pregnancy and risk of psychomotor deficits. *Alcohol Clin Exp Res*, 36, 807-814.

Beauchamp KG, Lowe J, Schrader RM, Shrestha S, Aragón C, Moss N, Stephen JM & Bakhireva LN. (2020). Self-regulation and emotional reactivity in infants with prenatal exposure to opioids and alcohol. *Early Hum Dev*, 148, 105119.

Ben-Shachar MS, Shmueli M, Jacobson SW, Meintjes EM, Molteno CD, Jacobson JL & Berger A. (2020). Prenatal Alcohol Exposure Alters Error Detection During Simple Arithmetic Processing: An Electroencephalography Study. *Alcohol Clin Exp Res*, 44, 114-124.

Berger A, Shmueli M, Lisson S, Ben-Shachar MS, Lindinger NM, Lewis CE, Dodge NC, Molteno CD, Meintjes EM, et al. (2019). Deficits in arithmetic error detection in infants with prenatal alcohol exposure: An ERP study. *Dev Cogn Neurosci*, 40, 100722.

Bernes GA, Villodas M, Coles CD, Kable JA, May PA, Kalberg WO, Sowell ER, Jones KL, Riley EP, et al. (2021). Validity and Reliability of Executive Function Measures in Children with Heavy Prenatal Alcohol Exposure: Correspondence Between Multiple Raters and Laboratory Measures. *Alcohol Clin Exp Res*,

Biffen SC, Warton CMR, Lindinger NM, Randall SR, Lewis CE, Molteno CD, Jacobson JL, Jacobson SW & Meintjes EM. (2017). Reductions in Corpus Callosum Volume Partially Mediate Effects of Prenatal Alcohol Exposure on IQ. *Front Neuroanat*, 11, 132.

Bjorkquist OA, Fryer SL, Reiss AL, Mattson SN & Riley EP. (2010). Cingulate gyrus morphology in children and adolescents with fetal alcohol spectrum disorders. *Psychiatry Res*, 181, 101-107.

Blanck-Lubarsch M, Dirksen D, Feldmann R, Sauerland C & Hohoff A. (2019). 3D-Analysis of Mouth, Nose and Eye Parameters in Children with Fetal Alcohol Syndrome (FAS). *Int J Environ Res Public Health*, 16,

Blanck-Lubarsch M, Dirksen D, Feldmann R, Sauerland C, Kirschneck C & Hohoff A. (2019). 3D Analysis of Philtrum Depth in Children with Fetal Alcohol Syndrome. *Alcohol Alcohol*, 54, 152-158.

Borges G, Lopez-Cervantes M, Medina-Mora ME, Tapia-Conyer R & Garrido F. (1993). Alcohol consumption, low birth weight, and preterm delivery in the National Addiction Survey (Mexico). *Int J Addict*, 28, 355-368.

Breiner P, Nulman I & Koren G. (2013). Identifying the neurobehavioral phenotype of fetal alcohol spectrum disorder in young children. *J Popul Ther Clin Pharmacol*, 20, e334-339.

Brown CW, Olson HC & Croninger RG. (2010). Maternal Alcohol Consumption During Pregnancy and Infant Social, Mental, and Motor Development. *Journal of Early Intervention*, 32, 110-126.

Brown RT, Coles CD, Smith IE, Platzman KA, Silverstein J, Erickson S & Falek A. (1991). Effects of prenatal alcohol exposure at school age. II. Attention and behavior. *Neurotoxicol Teratol*, 13, 369-376.

Burden MJ, Jacobson SW, Sokol RJ & Jacobson JL. (2005). Effects of prenatal alcohol exposure on attention and working memory at 7.5 years of age. *Alcohol Clin Exp Res*, 29, 443-452.

Burden MJ, Westerlund A, Muckle G, Dodge N, Dewailly E, Nelson CA, Jacobson SW & Jacobson JL. (2011). The effects of maternal binge drinking during pregnancy on neural correlates of response inhibition and memory in childhood. *Alcohol Clin Exp Res*, 35, 69-82.

Candelaria-Cook FT, Schendel ME, Flynn L, Hill DE & Stephen JM. (2021). Altered Resting-State Neural Oscillations and Spectral Power in Children with Fetal Alcohol Spectrum Disorder. *Alcohol Clin Exp Res*, 45, 117-130.

Cardenas VA, Price M, Infante MA, Moore EM, Mattson SN, Riley EP & Fein G. (2014). Automated cerebellar segmentation: Validation and application to detect smaller volumes in children prenatally exposed to alcohol. *Neuroimage Clin*, 4, 295-301.

Carter RC, Dodge NC, Molteno CD, Meintjes EM, Jacobson JL & Jacobson SW. (2022). Mediating and Moderating Effects of Iron Homeostasis Alterations on Fetal Alcohol-Related Growth and Neurobehavioral Deficits. *Nutrients*, 14,

Carter RC, Jacobson JL, Molteno CD, Jiang H, Meintjes EM, Jacobson SW & Duggan C. (2012). Effects of heavy prenatal alcohol exposure and iron deficiency anemia on child growth and body composition through age 9 years. *Alcohol Clin Exp Res*, 36, 1973-1982.

Carter RC, Jacobson SW, Molteno CD & Jacobson JL. (2007). Fetal alcohol exposure, iron-deficiency anemia, and infant growth. *Pediatrics*, 120, 559-567.

Chambers CD, Coles C, Kable J, Akshoomoff N, Xu R, Zellner JA, Honerkamp-Smith G, Manning MA, Adam MP, et al. (2019). Fetal Alcohol Spectrum Disorders in a Pacific Southwest City: Maternal and Child Characteristics. *Alcohol Clin Exp Res*, 43, 2578-2590.

Chandran S, Sreeraj VS, Venkatasubramanian G, Sathyaprabha TN & Murthy P. (2021). Corpus callosum morphometry in children with prenatal alcohol exposure. *Psychiatry Res Neuroimaging*, 318, 111405.

Cheng DT, Meintjes EM, Stanton ME, Dodge NC, Pienaar M, Warton CMR, Desmond JE, Molteno CD, Peterson BS, et al. (2017). Functional MRI of Human Eyeblink Classical Conditioning in Children with Fetal Alcohol Spectrum Disorders. *Cereb Cortex*, 27, 3752-3767.

Chiaffarino F, Parazzini F, Chatenoud L, Ricci E, Sandretti F, Cipriani S, Caserta D & Fedele L. (2006). Alcohol drinking and risk of small for gestational age birth. *Eur J Clin Nutr*, 60, 1062-1066.

Chiodo LM, da Costa DE, Hannigan JH, Covington CY, Sokol RJ, Janisse J, Greenwald M, Ager J & Delaney-Black V. (2010). The impact of maternal age on the effects of prenatal alcohol exposure on attention. *Alcohol Clin Exp Res*, 34, 1813-1821.

Chiodo LM, Janisse J, Delaney-Black V, Sokol RJ & Hannigan JH. (2009). A metric of maternal prenatal risk drinking predicts neurobehavioral outcomes in preschool children. *Alcohol Clin Exp Res*, 33, 634-644.

Cho K, Kobayashi S, Araki A, Miyashita C, Itoh S, Saijo Y, Ito Y, Sengoku K, Baba T, et al. (2021). Prenatal alcohol exposure and adverse fetal growth restriction: findings from the Japan Environment and Children's Study. *Pediatr Res*,

Colby JB, Smith L, O'Connor MJ, Bookheimer SY, Van Horn JD & Sowell ER. (2012). White matter microstructural alterations in children with prenatal methamphetamine/polydrug exposure. *Psychiatry Res*, 204, 140-148.

Coles CD, Brown RT, Smith IE, Platzman KA, Erickson S & Falek A. (1991). Effects of prenatal alcohol exposure at school age. I. Physical and cognitive development. *Neurotoxicol Teratol*, 13, 357-367.

Coles CD, Goldstein FC, Lynch ME, Chen X, Kable JA, Johnson KC, Hu X, Coles CD, Goldstein FC, et al. (2011). Memory and brain volume in adults prenatally exposed to alcohol. *Brain & Cognition*, 75, 67-77.

Coles CD, Kable JA, Granovska IV, Pashtepa AO, Plotka LD, Dolhov VB, Wertelecki W, Jones KL & Chambers CD. (2019). Gestational age and socioeconomic status as mediators for the impact of prenatal alcohol exposure on development at 6 months. *Birth Defects Res*, 111, 789-796.

Coles CD, Kable JA, Granovska IV, Pashtepa AO, Wertelecki W, Chambers CD & Cifasd. (2021). Measurement of neurodevelopmental effects of prenatal alcohol exposure in Ukrainian preschool children. *Child Neuropsychol*, 27, 1088-1103.

Coles CD, Lynch ME, Kable JA, Johnson KC & Goldstein FC. (2010). Verbal and nonverbal memory in adults prenatally exposed to alcohol. *Alcohol Clin Exp Res*, 34, 897-906.

Coles CD, Platzman KA, Lynch ME & Freides D. (2002). Auditory and visual sustained attention in adolescents prenatally exposed to alcohol. *Alcohol Clin Exp Res*, 26, 263-271.

Coles CD, Platzman KA, Raskind-Hood CL, Brown RT, Falek A & Smith IE. (1997). A comparison of children affected by prenatal alcohol exposure and attention deficit, hyperactivity disorder. *Alcohol Clin Exp Res*, 21, 150-161.

Coles CD, Smith IE & Falek A. (1987). Prenatal alcohol exposure and infant behavior: immediate effects and implications for later development. *Adv Alcohol Subst Abuse*, 6, 87-104.

Crawford A, Te Nahu LT, Peterson ER, McGinn V, Robertshaw K & Tippett L. (2020). Cognitive and social/emotional influences on adaptive functioning in children with FASD: Clinical and cultural considerations. *Child Neuropsychology*, 26, 1112-1144.

Crocker N, Riley EP & Mattson SN. (2015). Visual-spatial abilities relate to mathematics achievement in children with heavy prenatal alcohol exposure. *Neuropsychology*, 29, 108-116.

Crocker N, Vaurio L, Riley EP & Mattson SN. (2009). Comparison of adaptive behavior in children with heavy prenatal alcohol exposure or attention-deficit/hyperactivity disorder. *Alcohol Clin Exp Res*, 33, 2015-2023.

Crocker N, Vaurio L, Riley EP & Mattson SN. (2011). Comparison of verbal learning and memory in children with heavy prenatal alcohol exposure or attention-deficit/hyperactivity disorder. *Alcohol Clin Exp Res*, 35, 1114-1121.

Davies LA, Cockcroft K, Olinger L, Chersich M, Urban M, Chetty Makkan CM, Turnbull OH, Olivier L & Viljoen D. (2017). Alcohol exposure during pregnancy altered childhood developmental trajectories in a rural South African community. *Acta Paediatr*, 106, 1802-1810.

Day NL, Helsel A, Sonon K & Goldschmidt L. (2013). The association between prenatal alcohol exposure and behavior at 22 years of age. *Alcohol Clin Exp Res*, 37, 1171-1178.

Day NL, Richardson G, Robles N, Sambamoorthi U, Taylor P, Scher M, Stoffer D, Jasperse D & Cornelius M. (1990). Effect of prenatal alcohol exposure on growth and morphology of offspring at 8 months of age. *Pediatrics*, 85, 748-752.

De Guio F, Mangin JF, Rivière D, Perrot M, Molteno CD, Jacobson SW, Meintjes EM & Jacobson JL. (2014). A study of cortical morphology in children with fetal alcohol spectrum disorders. *Hum Brain Mapp*, 35, 2285-2296.

de Water E, Rockhold MN, Roediger DJ, Krueger AM, Mueller BA, Boys CJ, Schumacher MJ, Mattson SN, Jones KL, et al. (2021). Social behaviors and gray matter volumes of brain areas supporting social cognition in children and adolescents with prenatal alcohol exposure. *Brain Res*, 147388.

Dodge NC, Thomas KGF, Meintjes EM, Molteno CD, Jacobson JL & Jacobson SW. (2020). Reduced Hippocampal Volumes Partially Mediate Effects of Prenatal Alcohol Exposure on Spatial Navigation on a Virtual Water Maze Task in Children. *Alcohol Clin Exp Res*, 44, 844-855.

Donald KA, Fouche JP, Roos A, Koen N, Howells FM, Riley EP, Woods RP, Zar HJ, Narr KL, et al. (2016). Alcohol exposure in utero is associated with decreased gray matter volume in neonates. *Metab Brain Dis*, 31, 81-91.

Doney R, Lucas BR, Jirikowic T, Tsang TW, Watkins RE, Sauer K, Howat P, Latimer J, Fitzpatrick JP, et al. (2017). Graphomotor skills in children with prenatal alcohol exposure and fetal alcohol spectrum disorder: A population-based study in remote Australia. *Aust Occup Ther J*, 64, 68-78.

Doney R, Lucas BR, Watkins RE, Tsang TW, Sauer K, Howat P, Latimer J, Fitzpatrick JP, Oscar J, et al. (2016). Visual-motor integration, visual perception, and fine motor coordination in a population of children with high levels of Fetal Alcohol Spectrum Disorder. *Res Dev Disabil*, 55, 346-357.

Doney R, Lucas BR, Watkins RE, Tsang TW, Sauer K, Howat P, Latimer J, Fitzpatrick JP, Oscar J, et al. (2017). Fine motor skills in a population of children in remote Australia with high levels of prenatal alcohol exposure and Fetal Alcohol Spectrum Disorder. *BMC Pediatr*, 17, 193.

Doyle LR, Coles CD, Kable JA, May PA, Sowell ER, Jones KL, Riley EP, Mattson SN & Cifasd. (2019). Relation between adaptive function and IQ among youth with histories of heavy prenatal alcohol exposure. *Birth Defects Res*, 111, 812-821.

Doyle LR, Moore EM, Coles CD, Kable JA, Sowell ER, Wozniak JR, Jones KL, Riley EP & Mattson SN. (2018). Executive Functioning Correlates With Communication Ability in Youth With Histories of Heavy Prenatal Alcohol Exposure. *J Int Neuropsychol Soc*, 24, 1026-1037.

Dudek J, Skocic J, Sheard E & Rovet J. (2014). Hippocampal abnormalities in youth with alcohol-related neurodevelopmental disorder. *J Int Neuropsychol Soc*, 20, 181-191.

Eckstrand KL, Ding Z, Dodge NC, Cowan RL, Jacobson JL, Jacobson SW & Avison MJ. (2012). Persistent dose-dependent changes in brain structure in young adults with low-to-moderate alcohol exposure in utero. *Alcohol Clin Exp Res*, 36, 1892-1902.

Faden VB, Graubard BI & Dufour M. (1997). The relationship of drinking and birth outcome in a US national sample of expectant mothers. *Paediatr Perinat Epidemiol*, 11, 167-180.

Fagerlund A, Autti-Ramo I, Hoyme HE, Mattson SN & Korkman M. (2011). Risk factors for behavioural problems in foetal alcohol spectrum disorders. *Acta Paediatrica*, 100, 1481-1488.

Fagerlund Å, Autti-Rämö I, Kalland M, Santtila P, Hoyme HE, Mattson SN & Korkman M. (2012). Adaptive behaviour in children and adolescents with foetal alcohol spectrum disorders: a comparison with specific learning disability and typical development. *Eur Child Adolesc Psychiatry*, 21, 221-231.

Falgreen Eriksen HL, Mortensen EL, Kilburn T, Underbjerg M, Bertrand J, Støvring H, Wimberley T, Grove J, Kesmodel US, et al. (2012). The effects of low to moderate prenatal alcohol exposure in early pregnancy on IQ in 5-year-old children. *BJOG: An International Journal of Obstetrics & Gynaecology*, 119, 1191-1200.

Fan J, Jacobson SW, Taylor PA, Molteno CD, Dodge NC, Stanton ME, Jacobson JL & Meintjes EM. (2016). White matter deficits mediate effects of prenatal alcohol exposure on cognitive development in childhood. *Hum Brain Mapp*, 37, 2943-2958.

Flanigan EY, Aros S, Bueno MF, Conley M, Troendle JF, Cassorla F & Mills JL. (2008). Eye malformations in children with heavy alcohol exposure in utero. *J Pediatr*, 153, 391-395.

Foroud T, Wetherill L, Vinci-Booher S, Moore ES, Ward RE, Hoyme HE, Robinson LK, Rogers J, Meintjes EM, et al. (2012). Relation over time between facial measurements and cognitive outcomes in fetal alcohol-exposed children. *Alcohol Clin Exp Res*, 36, 1634-1646.

Forrest F, Florey CD, Taylor D, McPherson F & Young JA. (1991). Reported social alcohol consumption during pregnancy and infants' development at 18 months. *BMJ*, 303, 22-26.

Fraser SL, Muckle G, Abdous BB, Jacobson JL & Jacobson SW. (2012). Effects of binge drinking on infant growth and development in an Inuit sample. *Alcohol*, 46, 277-283.

Fryer SL, Mattson SN, Jernigan TL, Archibald SL, Jones KL & Riley EP. (2012). Caudate volume predicts neurocognitive performance in youth with heavy prenatal alcohol exposure. *Alcohol Clin Exp Res*, 36, 1932-1941.

Fryer SL, Schweinsburg BC, Bjorkquist OA, Frank LR, Mattson SN, Spadoni AD & Riley EP. (2009). Characterization of white matter microstructure in fetal alcohol spectrum disorders. *Alcohol Clin Exp Res*, 33, 514-521.

Furtado EF & Roriz ST. (2016). Inattention and impulsivity associated with prenatal alcohol exposure in a prospective cohort study with 11-years-old Brazilian children. *Eur Child Adolesc Psychiatry*, 25, 1327-1335.

Gao L, Grebogi C, Lai YC, Stephen J, Zhang T, Li Y, Ren H, Li D, Wang J, et al. (2019). Quantitative assessment of cerebral connectivity deficiency and cognitive impairment in children with prenatal alcohol exposure. *Chaos*, 29, 041101.

Gautam P, Lebel C, Narr KL, Mattson SN, May PA, Adnams CM, Riley EP, Jones KL, Kan EC, et al. (2015). Volume changes and brain-behavior relationships in white matter and subcortical gray matter in children with prenatal alcohol exposure. *Human Brain Mapping*, 36, 2318-2329.

Gautam P, Nuñez SC, Narr KL, Kan EC & Sowell ER. (2014). Effects of prenatal alcohol exposure on the development of white matter volume and change in executive function. *Neuroimage Clin*, 5, 19-27.

Glass L, Graham DM, Akshoomoff N & Mattson SN. (2015). Cognitive factors contributing to spelling performance in children with prenatal alcohol exposure. *Neuropsychology*, 29, 817-828.

Glass L, Graham DM, Deweese BN, Jones KL, Riley EP & Mattson SN. (2014). Correspondence of parent report and laboratory measures of inattention and hyperactivity in children with heavy prenatal alcohol exposure. *Neurotoxicol Teratol*, 42, 43-50.

Glass L, Moore EM, Akshoomoff N, Jones KL, Riley EP & Mattson SN. (2017). Academic Difficulties in Children with Prenatal Alcohol Exposure: Presence, Profile, and Neural Correlates. *Alcohol Clin Exp Res*, 41, 1024-1034.

Glass L, Ware AL, Crocker N, Deweese BN, Coles CD, Kable JA, May PA, Kalberg WO, Sowell ER, et al. (2013). Neuropsychological deficits associated with heavy prenatal alcohol exposure are not exacerbated by ADHD. *Neuropsychology*, 27, 713-724.

Golden NL, Sokol RJ, Kuhnert BR & Bottoms S. (1982). Maternal alcohol use and infant development. *Pediatrics*, 70, 931-934.

Goldschmidt L, Richardson GA, Stoffer DS, Geva D & Day NL. (1996). Prenatal alcohol exposure and academic achievement at age six: a nonlinear fit. *Alcohol Clin Exp Res*, 20, 763-770.

Gomez DA, May PA, Tabachnick BG, Hasken JM, Lyden ER, Kalberg WO, Hoyme HE, Manning MA, Adam MP, et al. (2020). Ocular measurements in fetal alcohol spectrum disorders. *Am J Med Genet A*, 182, 2243-2252.

Gomez MJC, Beaulieu C, McMorris CA, Gibbard B, Tortorelli C & Lebel C. (2022). Frontoparietal and temporal white matter diffusion MRI in children and youth with prenatal alcohol exposure. *Alcohol Clin Exp Res*, 46, 1808-1818.

Graham DM, Crocker N, Deweese BN, Roesch SC, Coles CD, Kable JA, May PA, Kalberg WO, Sowell ER, et al. (2013). Prenatal alcohol exposure, attention-deficit/hyperactivity disorder, and sluggish cognitive tempo. *Alcoholism: Clinical and Experimental Research*, 37, E338-E346.

Greenbaum RL, Stevens SA, Nash K, Koren G & Rovet J. (2009). Social cognitive and emotion processing abilities of children with fetal alcohol spectrum disorders: a comparison with attention deficit hyperactivity disorder. *Alcohol Clin Exp Res*, 33, 1656-1670.

Greene T, Ernhart CB, Ager J, Sokol R, Martier S & Boyd T. (1991). Prenatal alcohol exposure and cognitive development in the preschool years. *Neurotoxicol Teratol*, 13, 57-68.

Greene T, Ernhart CB, Martier S, Sokol R & Ager J. (1990). Prenatal alcohol exposure and language development. *Alcohol Clin Exp Res*, 14, 937-945.

Grisso JA, Roman E, Inskip H, Beral V & Donovan J. (1984). Alcohol consumption and outcome of pregnancy. *J Epidemiol Community Health*, 38, 232-235.

Gross LA, Moore EM, Wozniak JR, Coles CD, Kable JA, Sowell ER, Jones KL, Riley EP & Mattson SN. (2018). Neural correlates of verbal memory in youth with heavy prenatal alcohol exposure. *Brain Imaging Behav*, 12, 806-822.

Halliday JL, Muggli E, Lewis S, Elliott EJ, Amor DJ, O'Leary C, Donath S, Forster D, Nagle C, et al. (2017). Alcohol consumption in a general antenatal population and child neurodevelopment at 2 years. *J Epidemiol Community Health*, 71, 990-998.

Hannigan JH, Chiodo LM, Sokol RJ, Janisse J, Ager JW, Greenwald MK & Delaney-Black V. (2010). A 14-year retrospective maternal report of alcohol consumption in pregnancy predicts pregnancy and teen outcomes. *Alcohol*, 44, 583-594.

Hansen KD & Jirikowic T. (2013). A comparison of the sensory profile and sensory processing measure home form for children with fetal alcohol spectrum disorders. *Phys Occup Ther Pediatr*, 33, 440-452.

Hasken JM, Marais AS, de Vries M, Joubert B, Cloete M, Botha I, Symington SR, Kalberg WO, Buckley D, et al. (2021). Gestational age and birth growth parameters as early predictors of fetal alcohol spectrum disorders. *Alcohol Clin Exp Res*, 45, 1624-1638.

Hendricks G, Malcolm-Smith S, Stein DJ, Zar HJ, Wedderburn CJ, Nhapi RT, Chivese T, Adnams CM & Donald KA. (2020). Prenatal alcohol exposure is associated with early motor, but not language development in a South African cohort. *Acta Neuropsychiatr*, 32, 1-8.

Hendrickson TJ, Mueller BA, Sowell ER, Mattson SN, Coles CD, Kable JA, Jones KL, Boys CJ, Lim KO, et al. (2017). Cortical gyrification is abnormal in children with prenatal alcohol exposure. *Neuroimage Clin*, 15, 391-400.

Holzman C, Paneth N, Little R & Pinto-Martin J. (1995). Perinatal brain injury in premature infants born to mothers using alcohol in pregnancy. *Pediatrics*, 95, 66-73.

Howell KK, Lynch ME, Platzman KA, Smith GH & Coles CD. (2006). Prenatal alcohol exposure and ability, academic achievement, and school functioning in adolescence: a longitudinal follow-up. *J Pediatr Psychol*, 31, 116-126.

Hutchinson D, Youssef GJ, McCormack C, Wilson J, Allsop S, Najman J, Elliott E, Burns L, Jacobs S, et al. (2019). Prenatal alcohol exposure and infant gross motor development: a prospective cohort study. *BMC Pediatr*, 19, 149.

Ichikawa K, Fujiwara T & Kawachi I. (2018). Prenatal Alcohol Exposure and Child Psychosocial Behavior: A Sibling Fixed-Effects Analysis. *Front Psychiatry*, 9, 570.

Infante MA, Moore EM, Bischoff-Grethe A, Tapert SF, Mattson SN & Riley EP. (2017). Altered functional connectivity during spatial working memory in children with heavy prenatal alcohol exposure. *Alcohol*, 64, 11-21.

Inkelis SM, Moore EM, Bischoff-Grethe A & Riley EP. (2020). Neurodevelopment in adolescents and adults with fetal alcohol spectrum disorders (FASD): A magnetic resonance region of interest analysis. *Brain Res*, 1732, 146654.

Jackson DJ, Batiste E & Rendall-Mkosi K. (2007). Effect of smoking and alcohol use during pregnancy on the occurrence of low birthweight in a farming region in South Africa. *Paediatr Perinat Epidemiol*, 21, 432-440.

Jacobson JL, Dodge NC, Burden MJ, Klorman R & Jacobson SW. (2011). Number processing in adolescents with prenatal alcohol exposure and ADHD: differences in the neurobehavioral phenotype. *Alcohol Clin Exp Res*, 35, 431-442.

Jacobson JL, Jacobson SW & Sokol RJ. (1994). Effects of prenatal exposure to alcohol, smoking, and illicit drugs on postpartum somatic growth. *Alcohol Clin Exp Res*, 18, 317-323.

Jacobson JL, Jacobson SW, Sokol RJ & Ager JW, Jr. (1998). Relation of maternal age and pattern of pregnancy drinking to functionally significant cognitive deficit in infancy. *Alcohol Clin Exp Res*, 22, 345-351.

Jacobson SW, Jacobson JL, Molteno CD, Warton CMR, Wintermark P, Hoyme HE, De Jong G, Taylor P, Warton F, et al. (2017). Heavy Prenatal Alcohol Exposure is Related to Smaller Corpus Callosum in Newborn MRI Scans. *Alcohol Clin Exp Res*, 41, 965-975.

Jacobson SW, Jacobson JL, Sokol RJ, Chiodo LM & Corobana R. (2004). Maternal age, alcohol abuse history, and quality of parenting as moderators of the effects of prenatal alcohol exposure on 7.5-year intellectual function. *Alcohol Clin Exp Res*, 28, 1732-1745.

Jacobson SW, Jacobson JL, Sokol RJ, Martier SS & Ager JW. (1993). Prenatal alcohol exposure and infant information processing ability. *Child Dev*, 64, 1706-1721.

Jaddoe VW, Bakker R, Hofman A, Mackenbach JP, Moll HA, Steegers EA & Witteman JC. (2007). Moderate alcohol consumption during pregnancy and the risk of low birth weight and preterm birth. The generation R study. *Ann Epidemiol*, 17, 834-840.

Jirikowic T, Kartin D & Olson HC. (2008). Children with fetal alcohol spectrum disorders: a descriptive profile of adaptive function. *Can J Occup Ther*, 75, 238-248.

Jirikowic T, Olson HC & Kartin D. (2008). Sensory processing, school performance, and adaptive behavior of young school-age children with fetal alcohol spectrum disorders. *Phys Occup Ther Pediatr*, 28, 117-136.

Joseph J, Warton C, Jacobson SW, Jacobson JL, Molteno CD, Eicher A, Marais P, Phillips OR, Narr KL, et al. (2014). Three-dimensional surface deformation-based shape analysis of hippocampus and caudate nucleus in children with fetal alcohol spectrum disorders. *Hum Brain Mapp*, 35, 659-672.

Kable JA, Coles CD, Jones KL, Yevtushok L, Kulikovsky Y, Zymak-Zakutnya N, Dubchak I, Akhmedzhanova D, Wertelecki W, et al. (2021). Infant Cardiac Orienting Responses Predict Later FASD in the Preschool Period. *Alcohol Clin Exp Res*, 45, 386-394.

Kaemingk KL & Halverson PT. (2000). Spatial memory following prenatal alcohol exposure: more than a material specific memory deficit. *Child Neuropsychol*, 6, 115-128.

Kaemingk KL, Mulvaney S & Halverson PT. (2003). Learning following prenatal alcohol exposure: performance on verbal and visual multitrial tasks. *Arch Clin Neuropsychol*, 18, 33-47.

Kalberg WO, May PA, Blankenship J, Buckley D, Gossage JP & Adnams CM. (2013). A Practical Testing Battery to Measure Neurobehavioral Ability among Children with FASD. *Int J Alcohol Drug Res*, 2, 51-60.

Kelly Y, Sacker A, Gray R, Kelly J, Wolke D & Quigley MA. (2009). Light drinking in pregnancy, a risk for behavioural problems and cognitive deficits at 3 years of age? *Int J Epidemiol*, 38, 129-140.

Kerns KA, Siklos S, Baker L & Müller U. (2016). Emotion recognition in children with Fetal Alcohol Spectrum Disorders. *Child Neuropsychol*, 22, 255-275.

Kesmodel US, Bertrand J, Stovring H, Skarpness B, Denny CH, Mortensen EL & Lifestyle During Pregnancy Study G. (2012). The effect of different alcohol drinking patterns in early to mid pregnancy on the child's intelligence, attention, and executive function. *BJOG*, 119, 1180-1190.

Kodituwakku P, Coriale G, Fiorentino D, Aragón AS, Kalberg WO, Buckley D, Gossage JP, Ceccanti M & May PA. (2006). Neurobehavioral characteristics of children with fetal alcohol spectrum disorders in communities from Italy: Preliminary results. *Alcohol Clin Exp Res*, 30, 1551-1561.

Kodituwakku PW, Adnams CM, Hay A, Kitching AE, Burger E, Kalberg WO, Viljoen DL & May PA. (2006). Letter and category fluency in children with fetal alcohol syndrome from a community in South Africa. *J Stud Alcohol*, 67, 502-509.

Kodituwakku PW, May PA, Clericuzio CL & Weers D. (2001). Emotion-related learning in individuals prenatally exposed to alcohol: an investigation of the relation between set shifting, extinction of responses, and behavior. *Neuropsychologia*, 39, 699-708.

Kooistra L, Ramage B, Crawford S, Cantell M, Wormsbecker S, Gibbard B & Kaplan BJ. (2009). Can attention deficit hyperactivity disorder and fetal alcohol spectrum disorder be differentiated by motor and balance deficits? *Hum Mov Sci*, 28, 529-542.

Korkman M, Autti-Ramo I, Koivulehto H & Granstrom MJ. (1998). Neuropsychological effects at early school age of fetal alcohol exposure of varying duration. *Child Neuropsychology*, 4, 199-212.

Krueger AM, Roediger DJ, Mueller BA, Boys CA, Hendrickson TJ, Schumacher MJ, Mattson SN, Jones KL, Riley EP, et al. (2020). Para-limbic Structural Abnormalities Are Associated With Internalizing Symptoms in Children With Prenatal Alcohol Exposure. *Alcohol Clin Exp Res*, 44, 1598-1608.

Kuehn D, Aros S, Cassorla F, Avaria M, Unanue N, Henriquez C, Kleinsteuber K, Conca B, Avila A, et al. (2012). A prospective cohort study of the prevalence of growth, facial, and central nervous system abnormalities in children with heavy prenatal alcohol exposure. *Alcohol Clin Exp Res*, 36, 1811-1819.

Kyllerman M, Aronson M, Sabel KG, Karlberg E, Sandin B & Olegård R. (1985). Children of alcoholic mothers. Growth and motor performance compared to matched controls. *Acta Paediatr Scand*, 74, 20-26.

Lane KA, Stewart J, Fernandes T, Russo N, Enns JT & Burack JA. (2014). Complexities in understanding attentional functioning among children with fetal alcohol spectrum disorder. *Front Hum Neurosci*, 8, 119.

Larroque B & Kaminski M. (1998). Prenatal alcohol exposure and development at preschool age: main results of a French study. *Alcohol Clin Exp Res*, 22, 295-303.

Lazzaroni F, Bonassi S, Magnani M, Calvi A, Repetto E, Serra F, Podesta F & Pearce N. (1993). Moderate maternal drinking and outcome of pregnancy. *Eur J Epidemiol*, 9, 599-606.

Lebel C, Mattson SN, Riley EP, Jones KL, Adnams CM, May PA, Bookheimer SY, O'Connor MJ, Narr KL, et al. (2012). A longitudinal study of the long-term consequences of drinking during pregnancy: heavy in utero alcohol exposure disrupts the normal processes of brain development. *J Neurosci*, 32, 15243-15251.

Lee KT, Mattson SN & Riley EP. (2004). Classifying children with heavy prenatal alcohol exposure using measures of attention. *J Int Neuropsychol Soc*, 10, 271-277.

Lees B, Mewton L, Jacobus J, Valadez EA, Stapinski LA, Teesson M, Tapert SF & Squeglia LM. (2020). Association of Prenatal Alcohol Exposure With Psychological, Behavioral, and Neurodevelopmental Outcomes in Children From the Adolescent Brain Cognitive Development Study. *Am J Psychiatry*, 177, 1060-1072.

Lewis CE, Thomas KG, Dodge NC, Molteno CD, Meintjes EM, Jacobson JL & Jacobson SW. (2015). Verbal learning and memory impairment in children with fetal alcohol spectrum disorders. *Alcohol Clin Exp Res*, 39, 724-732.

Li L, Coles CD, Lynch ME & Hu X. (2009). Voxelwise and skeleton-based region of interest analysis of fetal alcohol syndrome and fetal alcohol spectrum disorders in young adults. *Hum Brain Mapp*, 30, 3265-3274.

Lidstone DE, Miah FZ, Poston B, Beasley JF & Dufek JS. (2020). Manual dexterity in children with autism spectrum disorder: A cross-syndrome approach. *Research in Autism Spectrum Disorders*, 73,

Lindinger NM, Malcolm-Smith S, Dodge NC, Molteno CD, Thomas KG, Meintjes EM, Jacobson JL & Jacobson SW. (2016). Theory of Mind in Children with Fetal Alcohol Spectrum Disorders. *Alcohol Clin Exp Res*, 40, 367-376.

Little BB, Snell LM, Rosenfeld CR, Gilstrap Iii LC & Gant NF. (1990). Failure to recognize fetal alcohol syndrome in newborn infants. *American Journal of Diseases of Children*, 144, 1142-1146.

Little G & Beaulieu C. (2020). Multivariate models of brain volume for identification of children and adolescents with fetal alcohol spectrum disorder. *Hum Brain Mapp*, 41, 1181-1194.

Long X, Kar P, Gibbard B, Tortorelli C & Lebel C. (2019). The brain's functional connectome in young children with prenatal alcohol exposure. *Neuroimage Clin*, 24, 102082.

Long X & Lebel C. (2022). Evaluation of Brain Alterations and Behavior in Children With Low Levels of Prenatal Alcohol Exposure. *JAMA Netw Open*, 5, e225972.

Lucas BR, Doney R, Latimer J, Watkins RE, Tsang TW, Hawkes G, Fitzpatrick JP, Oscar J, Carter M, et al. (2016). Impairment of motor skills in children with fetal alcohol spectrum disorders in remote Australia: The Lililwan Project. *Drug Alcohol Rev*, 35, 719-727.

Lucas BR, Latimer J, Doney R, Watkins RE, Tsang TW, Hawkes G, Fitzpatrick JP, Oscar J, Carter M, et al. (2016). Gross motor performance in children prenatally exposed to alcohol and living in remote Australia. *J Paediatr Child Health*, 52, 814-824.

Lucas BR, Latimer J, Fitzpatrick JP, Doney R, Watkins RE, Tsang TW, Jirikowic T, Carmichael Olson H, Oscar J, et al. (2016). Soft neurological signs and prenatal alcohol exposure: a population-based study in remote Australia. *Dev Med Child Neurol*, 58, 861-867.

Lumley J, Correy JF, Newman NM & Curran JT. (1985). Cigarette smoking, alcohol consumption and fetal outcome in Tasmania 1981-82. *Aust N Z J Obstet Gynaecol*, 25, 33-40.

Lundsberg LS, Bracken MB & Saftlas AF. (1997). Low-to-moderate gestational alcohol use and intrauterine growth retardation, low birthweight, and preterm delivery. *Ann Epidemiol*, 7, 498-508.

Lundsberg LS, Illuzzi JL, Belanger K, Triche EW & Bracken MB. (2015). Low-to-moderate prenatal alcohol consumption and the risk of selected birth outcomes: a prospective cohort study. *Ann Epidemiol*, 25, 46-54.e43.

Lynch ME, Kable JA & Coles CD. (2015). Prenatal alcohol exposure, adaptive function, and entry into adult roles in a prospective study of young adults. *Neurotoxicol Teratol*, 51, 52-60.

Lynch ME, Kable JA & Coles CD. (2017). Effects of prenatal alcohol exposure in a prospective sample of young adults: Mental health, substance use, and difficulties with the legal system. *Neurotoxicol Teratol*, 64, 50-62.

Maher GM, Khashan AS, O'Byrne L, Flanagan S, Mortimer RM, Kiely M, J OBH, Kenny LC, Murray D, et al. (2022). Periconceptual and prenatal alcohol consumption and neurodevelopment at age two and five years. *Eur J Obstet Gynecol Reprod Biol*, 274, 197-203.

Malisza KL, Buss JL, Bolster RB, de Gervai PD, Woods-Frohlich L, Summers R, Clancy CA, Chudley AE & Longstaffe S. (2012). Comparison of spatial working memory in children with prenatal alcohol exposure and those diagnosed with ADHD; A functional magnetic resonance imaging study. *J Neurodev Disord*, 4, 12.

Marbury MC, Linn S, Monson R, Schoenbaum S, Stubblefield PG & Ryan KJ. (1983). The association of alcohol consumption with outcome of pregnancy. *Am J Public Health*, 73, 1165-1168.

Marianian A, Atalyan A, Bohora S, Darenskaya M, Grebenkina L, Kolesnikova L, Kolesnikov S, Mikhaylevich I, Protopopova N, et al. (2020). The effect of low alcohol consumption during pregnancy on the lipid

peroxidation-antioxidant defense system of women, their alcohol-exposed infants, and growth, health, and developmental outcomes. *Birth Defects Res*, 112, 40-53.

Mariscal M, Palma S, Llorca J, Perez-Iglesias R, Pardo-Crespo R & Delgado-Rodriguez M. (2006). Pattern of alcohol consumption during pregnancy and risk for low birth weight. *Ann Epidemiol*, 16, 432-438.

Mattson SN, Jones KL, Chockalingam G, Wozniak JR, Hyland MT, Courchesne-Krak NS, Del Campo M, Riley EP & Cifasd. (2023). Validation of the FASD-Tree as a screening tool for fetal alcohol spectrum disorders. *Alcohol Clin Exp Res (Hoboken)*, 47, 263-272.

Mattson SN & Riley EP. (1999). Implicit and explicit memory functioning in children with heavy prenatal alcohol exposure. *J Int Neuropsychol Soc*, 5, 462-471.

Mattson SN & Riley EP. (2000). Parent ratings of behavior in children with heavy prenatal alcohol exposure and IQ-matched controls. *Alcohol Clin Exp Res*, 24, 226-231.

Mattson SN, Riley EP, Gramling L, Delis DC & Jones KL. (1997). Heavy prenatal alcohol exposure with or without physical features of fetal alcohol syndrome leads to IQ deficits. *J Pediatr*, 131, 718-721.

Mattson SN & Roebuck TM. (2002). Acquisition and retention of verbal and nonverbal information in children with heavy prenatal alcohol exposure. *Alcohol Clin Exp Res*, 26, 875-882.

Mattson SN, Roesch SC, Fagerlund A, Autti-Rämö I, Jones KL, May PA, Adnams CM, Konovalova V & Riley EP. (2010). Toward a neurobehavioral profile of fetal alcohol spectrum disorders. *Alcohol Clin Exp Res*, 34, 1640-1650.

Mattson SN, Roesch SC, Glass L, Deweese BN, Coles CD, Kable JA, May PA, Kalberg WO, Sowell ER, et al. (2013). Further development of a neurobehavioral profile of fetal alcohol spectrum disorders. *Alcohol Clin Exp Res*, 37, 517-528.

May PA, Baete A, Russo J, Elliott AJ, Blankenship J, Kalberg WO, Buckley D, Brooks M, Hasken J, et al. (2014). Prevalence and characteristics of fetal alcohol spectrum disorders. *Pediatrics*, 134, 855-866.

May PA, Blankenship J, Marais AS, Gossage JP, Kalberg WO, Barnard R, De Vries M, Robinson LK, Adnams CM, et al. (2013). Approaching the prevalence of the full spectrum of fetal alcohol spectrum disorders in a South African population-based study. *Alcohol Clin Exp Res*, 37, 818-830.

May PA, Brooke L, Gossage JP, Croxford J, Adnams C, Jones KL, Robinson L & Viljoen D. (2000). Epidemiology of fetal alcohol syndrome in a South African community in the Western Cape Province. *Am J Public Health*, 90, 1905-1912.

May PA, de Vries MM, Marais AS, Kalberg WO, Adnams CM, Hasken JM, Tabachnick B, Robinson LK, Manning MA, et al. (2016). The continuum of fetal alcohol spectrum disorders in four rural communities in South Africa: Prevalence and characteristics. *Drug Alcohol Depend*, 159, 207-218.

May PA, De Vries MM, Marais AS, Kalberg WO, Buckley D, Adnams CM, Hasken JM, Tabachnick B, Robinson LK, et al. (2017). Replication of High Fetal Alcohol Spectrum Disorders Prevalence Rates, Child Characteristics, and Maternal Risk Factors in a Second Sample of Rural Communities in South Africa. *Int J Environ Res Public Health*, 14,

May PA, Fiorentino D, Phillip Gossage J, Kalberg WO, Eugene Hoyme H, Robinson LK, Coriale G, Jones KL, del Campo M, et al. (2006). Epidemiology of FASD in a province in Italy: Prevalence and characteristics of children in a random sample of schools. *Alcohol Clin Exp Res*, 30, 1562-1575.

May PA, Gossage JP, Marais AS, Adnams CM, Hoyme HE, Jones KL, Robinson LK, Khaole NC, Snell C, et al. (2007). The epidemiology of fetal alcohol syndrome and partial FAS in a South African community. *Drug Alcohol Depend*, 88, 259-271.

May PA, Gossage JP, Smith M, Tabachnick BG, Robinson LK, Manning M, Cecanti M, Jones KL, Khaole N, et al. (2010). Population differences in dysmorphic features among children with fetal alcohol spectrum disorders. *J Dev Behav Pediatr*, 31, 304-316.

May PA, Hasken JM, Baete A, Russo J, Elliott AJ, Kalberg WO, Buckley D, Brooks M, Ortega MA, et al. (2020). Fetal Alcohol Spectrum Disorders in a Midwestern City: Child Characteristics, Maternal Risk Traits, and Prevalence. *Alcohol Clin Exp Res*, 44, 919-938.

May PA, Hasken JM, Bozeman R, Jones JV, Burns MK, Goodover J, Kalberg WO, Buckley D, Brooks M, et al. (2020). Fetal Alcohol Spectrum Disorders in a Rocky Mountain Region City: Child Characteristics, Maternal Risk Traits, and Prevalence. *Alcohol Clin Exp Res*, 44, 900-918.

May PA, Hasken JM, Hooper SR, Hedrick DM, Jackson-Newsom J, Mullis CE, Dobyns E, Kalberg WO, Buckley D, et al. (2021). Estimating the community prevalence, child traits, and maternal risk factors of fetal alcohol spectrum disorders (FASD) from a random sample of school children. *Drug Alcohol Depend*, 227, 108918.

May PA, Hasken JM, Stegall JM, Mastro HA, Kalberg WO, Buckley D, Brooks M, Hedrick DM, Ortega MA, et al. (2020). Fetal Alcohol Spectrum Disorders in a Southeastern County of the United States: Child Characteristics and Maternal Risk Traits. *Alcohol Clin Exp Res*, 44, 939-959.

May PA, Keaster C, Bozeman R, Goodover J, Blankenship J, Kalberg WO, Buckley D, Brooks M, Hasken J, et al. (2015). Prevalence and characteristics of fetal alcohol syndrome and partial fetal alcohol syndrome in a Rocky Mountain Region City. *Drug Alcohol Depend*, 155, 118-127.

McCarthy FP, O'Keeffe LM, Khashan AS, North RA, Poston L, McCowan LME, Baker PN, Dekker GA, Roberts CT, et al. (2013). Association between maternal alcohol consumption in early pregnancy and pregnancy outcomes. *Obstet Gynecol*, 122, 830-837.

McCormack C, Hutchinson D, Burns L, Youssef G, Wilson J, Elliott E, Allsop S, Najman J, Jacobs S, et al. (2018). Maternal and partner prenatal alcohol use and infant cognitive development. *Drug Alcohol Depend*, 185, 330-338.

McDonald AD, Armstrong BG & Sloan M. (1992). Cigarette, alcohol, and coffee consumption and prematurity. *Am J Public Health*, 82, 87-90.

McGee CL, Bjorkquist OA, Riley EP & Mattson SN. (2009). Impaired language performance in young children with heavy prenatal alcohol exposure. *Neurotoxicol Teratol*, 31, 71-75.

McGee CL, Fryer SL, Bjorkquist OA, Mattson SN & Riley EP. (2008). Deficits in social problem solving in adolescents with prenatal exposure to alcohol. *Am J Drug Alcohol Abuse*, 34, 423-431.

McGee CL, Schonfeld AM, Roebuck-Spencer TM, Riley EP & Mattson SN. (2008). Children with heavy prenatal alcohol exposure demonstrate deficits on multiple measures of concept formation. *Alcohol Clin Exp Res*, 32, 1388-1397.

McLachlan K, Vavasour I, MacKay A, Brain U, Oberlander T, Loock C, Reynolds JN & Beaulieu C. (2019). Myelin Water Fraction Imaging of the Brain in Children with Prenatal Alcohol Exposure. *Alcohol Clin Exp Res*, 43, 833-841.

McLachlan K, Zhou D, Little G, Rasmussen C, Pei J, Andrew G, Reynolds JN & Beaulieu C. (2020). Current Socioeconomic Status Correlates With Brain Volumes in Healthy Children and Adolescents but Not in Children With Prenatal Alcohol Exposure. *Front Hum Neurosci*, 14, 223.

Meintjes EM, Narr KL, van der Kouwe AJ, Molteno CD, Pirnia T, Gutman B, Woods RP, Thompson PM, Jacobson JL, et al. (2014). A tensor-based morphometry analysis of regional differences in brain volume in relation to prenatal alcohol exposure. *Neuroimage Clin*, 5, 152-160.

Migliorini R, Moore EM, Glass L, Infante MA, Tapert SF, Jones KL, Mattson SN & Riley EP. (2015). Anterior cingulate cortex surface area relates to behavioral inhibition in adolescents with and without heavy prenatal alcohol exposure. *Behav Brain Res*, 292, 26-35.

Miles M, Warton FL, Meintjes EM, Molteno CD, Jacobson JL, Jacobson SW & Warton CMR. (2021). Effects of Prenatal Alcohol Exposure on the Volumes of the Lateral and Medial Walls of the Intraparietal Sulcus. *Front Neuroanat*, 15, 639800.

Mills JL, Graubard BI, Harley EE, Rhoads GG & Berendes HW. (1984). Maternal alcohol consumption and birth weight. How much drinking during pregnancy is safe? *JAMA*, 252, 1875-1879.

Mitchell JM, Jeffri FJ, Maher GM, Khashan AS & McCarthy FP. (2020). Prenatal alcohol exposure and risk of attention deficit hyperactivity disorder in offspring: A retrospective analysis of the millennium cohort study. *Journal of Affective Disorders*, 269, 94-100.

Miyake Y, Tanaka K, Okubo H, Sasaki S & Arakawa M. (2014). Alcohol consumption during pregnancy and birth outcomes: the Kyushu Okinawa Maternal and Child Health Study. *BMC Pregnancy Childbirth*, 14, 79.

Moore EM, Glass L, Infante MA, Coles CD, Kable JA, Jones KL, Riley EP & Mattson SN. (2021). Cross-Sectional Analysis of Spatial Working Memory Development in Children with Histories of Heavy Prenatal Alcohol Exposure. *Alcohol Clin Exp Res*, 45, 215-223.

Moore ES, Ward RE, Jamison PL, Morris CA, Bader PI & Hall BD. (2002). New perspectives on the face in fetal alcohol syndrome: what anthropometry tells us. *Am J Med Genet*, 109, 249-260.

Muggli E, Matthews H, Penington A, Claes P, O'Leary C, Forster D, Donath S, Anderson PJ, Lewis S, et al. (2017). Association Between Prenatal Alcohol Exposure and Craniofacial Shape of Children at 12 Months of Age. *JAMA Pediatr*, 171, 771-780.

Naidoo S, Chikte U, Laubscher R & Lombard C. (2005). Fetal alcohol syndrome: anthropometric and oral health status. *J Contemp Dent Pract*, 6, 101-115.

Nakhid D, McMorris C, Sun H, Gibbard WB, Tortorelli C & Lebel C. (2022). Brain volume and magnetic susceptibility differences in children and adolescents with prenatal alcohol exposure. *Alcohol Clin Exp Res*, 46, 1797-1807.

Nardelli A, Lebel C, Rasmussen C, Andrew G & Beaulieu C. (2011). Extensive deep gray matter volume reductions in children and adolescents with fetal alcohol spectrum disorders. *Alcohol Clin Exp Res*, 35, 1404-1417.

Nayak R, Murthy P, Girimaji S & Navaneetham J. (2012). Fetal Alcohol Spectrum Disorders-a Case-Control Study from India. *J Trop Pediatr*, 58, 19-24.

Nguyen TT, Glass L, Coles CD, Kable JA, May PA, Kalberg WO, Sowell ER, Jones KL, Riley EP, et al. (2014). The clinical utility and specificity of parent report of executive function among children with prenatal alcohol exposure. *J Int Neuropsychol Soc*, 20, 704-716.

Niclasen J, Nybo Andersen AM, Teasdale TW & Strandberg-Larsen K. (2014). Prenatal exposure to alcohol, and gender differences on child mental health at age seven years. *J Epidemiol Community Health*, 68, 224-232.

Noland JS, Singer LT, Arendt RE, Minnes S, Short EJ & Bearer CF. (2003). Executive functioning in preschool-age children prenatally exposed to alcohol, cocaine, and marijuana. *Alcohol Clin Exp Res*, 27, 647-656.

Nykjaer C, Alwan NA, Greenwood DC, Simpson NA, Hay AW, White KL & Cade JE. (2014). Maternal alcohol intake prior to and during pregnancy and risk of adverse birth outcomes: evidence from a British cohort. *J Epidemiol Community Health*, 68, 542-549.

O'Callaghan FV, O'Callaghan M, Najman JM, Williams GM & Bor W. (2007). Prenatal alcohol exposure and attention, learning and intellectual ability at 14 years: a prospective longitudinal study. *Early Hum Dev*, 83, 115-123.

O'Conaill CR, Malisza KL, Buss JL, Bolster RB, Clancy C, de Gervai PD, Chudley AE & Longstaffe S. (2015). Visual search for feature conjunctions: an fMRI study comparing alcohol-related neurodevelopmental disorder (ARND) to ADHD. *J Neurodev Disord*, 7, 10.

O'Hare ED, Lu LH, Houston SM, Bookheimer SY, Mattson SN, O'Connor MJ & Sowell ER. (2009). Altered frontal-parietal functioning during verbal working memory in children and adolescents with heavy prenatal alcohol exposure. *Hum Brain Mapp*, 30, 3200-3208.

O'Leary C, Lawrence D, Hafekost K, Zubrick SR & Bower C. (2020). Maternal Alcohol-Use Disorder and Child Outcomes. *Pediatrics*, 145,

O'Leary C, Zubrick SR, Taylor CL, Dixon G & Bower C. (2009). Prenatal alcohol exposure and language delay in 2-year-old children: the importance of dose and timing on risk. *Pediatrics*, 123, 547-554.

O'Leary CM & Bower C. (2012). Guidelines for pregnancy: what's an acceptable risk, and how is the evidence (finally) shaping up? *Drug Alcohol Rev*, 31, 170-183.

O'Leary CM, Nassar N, Kurinczuk JJ & Bower C. (2009). The effect of maternal alcohol consumption on fetal growth and preterm birth. *Bjog*, 116, 390-400.

O'Leary CM, Nassar N, Zubrick SR, Kurinczuk JJ, Stanley F & Bower C. (2010). Evidence of a complex association between dose, pattern and timing of prenatal alcohol exposure and child behaviour problems. *Addiction*, 105, 74-86.

O'Leary CM, Taylor C, Zubrick SR, Kurinczuk JJ & Bower C. (2013). Prenatal alcohol exposure and educational achievement in children aged 8-9 years. *Pediatrics*, 132, e468-475.

Oberlander TF, Jacobson SW, Weinberg J, Grunau RE, Molteno CD & Jacobson JL. (2010). Prenatal alcohol exposure alters biobehavioral reactivity to pain in newborns. *Alcoholism: Clinical and Experimental Research*, 34, 681-692.

Okah FA, Cai J & Hoff GL. (2005). Term-gestation low birth weight and health-compromising behaviors during pregnancy. *Obstet Gynecol*, 105, 543-550.

Olsen J, Pereira Ada C & Olsen SF. (1991). Does maternal tobacco smoking modify the effect of alcohol on fetal growth? *Am J Public Health*, 81, 69-73.

Olswang LB, Svensson L & Astley S. (2010). Observation of classroom social communication: do children with fetal alcohol spectrum disorders spend their time differently than their typically developing peers? *J Speech Lang Hear Res*, 53, 1687-1703.

Panczakiewicz AL, Glass L, Coles CD, Kable JA, Sowell ER, Wozniak JR, Jones KL, Riley EP & Mattson SN. (2016). Neurobehavioral Deficits Consistent Across Age and Sex in Youth with Prenatal Alcohol Exposure. *Alcohol Clin Exp Res*, 40, 1971-1981.

Paolozza A, Rasmussen C, Pei J, Hanlon-Dearman A, Nikkel SM, Andrew G, McFarlane A, Samdup D & Reynolds JN. (2014). Deficits in response inhibition correlate with oculomotor control in children with fetal alcohol spectrum disorder and prenatal alcohol exposure. *Behav Brain Res*, 259, 97-105.

Paolozza A, Rasmussen C, Pei J, Hanlon-Dearman A, Nikkel SM, Andrew G, McFarlane A, Samdup D & Reynolds JN. (2014). Working memory and visuospatial deficits correlate with oculomotor control in children with fetal alcohol spectrum disorder. *Behav Brain Res*, 263, 70-79.

Paolozza A, Treit S, Beaulieu C & Reynolds JN. (2014). Response inhibition deficits in children with Fetal Alcohol Spectrum Disorder: relationship between diffusion tensor imaging of the corpus callosum and eye movement control. *Neuroimage Clin*, 5, 53-61.

Pei J, Job J, Kully-Martens K & Rasmussen C. (2011). Executive function and memory in children with Fetal Alcohol Spectrum Disorder. *Child Neuropsychol*, 17, 290-309.

Pfinder M & Lhachimi S. (2020). Lifestyle-related risk factors during pregnancy: even low-to-moderate drinking during pregnancy increases the risk for adolescent behavioral problems. *Journal of Substance Use*, 25, 135-140.

Pinner JFL, Coffman BA & Stephen JM. (2020). Covariation Between Brain Function (MEG) and Structure (DTI) Differentiates Adolescents with Fetal Alcohol Spectrum Disorder from Typically Developing Controls. *Neuroscience*, 449, 74-87.

Popova S, Dozet D, O'Hanlon G, Temple V & Rehm J. (2021). Maternal alcohol use, adverse neonatal outcomes and pregnancy complications in British Columbia, Canada: a population-based study. *BMC Pregnancy Childbirth*, 21, 74.

Popova S, Lange S, Poznyak V, Chudley AE, Shield KD, Reynolds JN, Murray M & Rehm J. (2019). Population-based prevalence of fetal alcohol spectrum disorder in Canada. *BMC public health*, 19, 845.

Poth LD, Love T & Mattson SN. (2023). Profiles of language and communication abilities in adolescents with fetal alcohol spectrum disorders. *J Int Neuropsychol Soc*, 29, 724-733.

Primatesta P, Del Corno G, Bonazzi MC & Waters WE. (1993). Alcohol and pregnancy: an international comparison. *J Public Health Med*, 15, 69-76.

Quattlebaum JL & O'Connor MJ. (2013). Higher functioning children with prenatal alcohol exposure: is there a specific neurocognitive profile? *Child Neuropsychol*, 19, 561-578.

Rajaprakash M, Chakravarty MM, Lerch JP & Rovet J. (2014). Cortical morphology in children with alcohol-related neurodevelopmental disorder. *Brain Behav*, 4, 41-50.

Rasmussen C, Becker M, McLennan J, Urichuk L & Andrew G. (2011). An evaluation of social skills in children with and without prenatal alcohol exposure. *Child Care Health Dev*, 37, 711-718.

Rasmussen C, Soleimani M & Pei J. (2011). Executive functioning and working memory deficits on the CANTAB among children with prenatal alcohol exposure. *J Popul Ther Clin Pharmacol*, 18, e44-53.

Rasmussen C, Tamana S, Baugh L, Andrew G, Tough S & Zwaigenbaum L. (2013). Neuropsychological impairments on the NEPSY-II among children with FASD. *Child Neuropsychol*, 19, 337-349.

Rasmussen C, Wyper K & Talwar V. (2009). The relation between theory of mind and executive functions in children with fetal alcohol spectrum disorders. *Can J Clin Pharmacol*, 16, e370-380.

Riley EP, Mattson SN, Sowell ER, Jernigan TL, Sobel DF & Jones KL. (1995). Abnormalities of the corpus callosum in children prenatally exposed to alcohol. *Alcoholism: Clinical and Experimental Research*, 19, 1198-1202.

Robertson FC, Narr KL, Molteno CD, Jacobson JL, Jacobson SW & Meintjes EM. (2016). Prenatal Alcohol Exposure is Associated with Regionally Thinner Cortex During the Preadolescent Period. *Cereb Cortex*, 26, 3083-3095.

Rockhold MN, Krueger AM, de Water E, Lindgren CW, Sandness KE, Eckerle JK, Schumacher MJ, Fink BA, Boys CJ, et al. (2021). Executive and Social Functioning Across Development in Children and Adolescents With Prenatal Alcohol Exposure. *Alcohol Clin Exp Res*, 45, 457-469.

Roediger DJ, Krueger AM, de Water E, Mueller BA, Boys CA, Hendrickson TJ, Schumacher MJ, Mattson SN, Jones KL, et al. (2021). Hippocampal subfield abnormalities and memory functioning in children with fetal alcohol Spectrum disorders. *Neurotoxicol Teratol*, 83, 106944.

Roos A, Wedderburn CJ, Fouche JP, Subramoney S, Joshi SH, Woods RP, Zar HJ, Narr KL, Stein DJ, et al. (2021). Central white matter integrity alterations in 2-3-year-old children following prenatal alcohol exposure. *Drug Alcohol Depend*, 225, 108826.

Roussotte FF, Sulik KK, Mattson SN, Riley EP, Jones KL, Adnams CM, May PA, O'Connor MJ, Narr KL, et al. (2012). Regional brain volume reductions relate to facial dysmorphology and neurocognitive function in fetal alcohol spectrum disorders. *Hum Brain Mapp*, 33, 920-937.

Salihu HM, Kornosky JL, Lynch O, Alio AP, August EM & Marty PJ. (2011). Impact of prenatal alcohol consumption on placenta-associated syndromes. *Alcohol*, 45, 73-79.

Sayal K, Draper ES, Fraser R, Barrow M, Davey Smith G & Gray R. (2013). Light drinking in pregnancy and mid-childhood mental health and learning outcomes. *Arch Dis Child*, 98, 107-111.

Sayal K, Heron J, Golding J & Emond A. (2007). Prenatal alcohol exposure and gender differences in childhood mental health problems: a longitudinal population-based study. *Pediatrics*, 119, e426-434.

Schonfeld AM, Mattson SN, Lang AR, Delis DC & Riley EP. (2001). Verbal and nonverbal fluency in children with heavy prenatal alcohol exposure. *J Stud Alcohol*, 62, 239-246.

Schonfeld AM, Mattson SN & Riley EP. (2005). Moral maturity and delinquency after prenatal alcohol exposure. *J Stud Alcohol*, 66, 545-554.

Shu XO, Hatch MC, Mills J, Clemens J & Susser M. (1995). Maternal smoking, alcohol drinking, caffeine consumption, and fetal growth: results from a prospective study. *Epidemiology*, 6, 115-120.

Skogerbo A, Kesmodel US, Denny CH, Kjaersgaard MI, Wimberley T, Landro NI & Mortensen EL. (2013). The effects of low to moderate alcohol consumption and binge drinking in early pregnancy on behaviour in 5-year-old children: a prospective cohort study on 1628 children. *BJOG*, 120, 1042-1050.

Skogerbo A, Kesmodel US, Wimberley T, Stovring H, Bertrand J, Landro NI & Mortensen EL. (2012). The effects of low to moderate alcohol consumption and binge drinking in early pregnancy on executive function in 5-year-old children. *BJOG*, 119, 1201-1210.

Sood B, Delaney-Black V, Covington C, Nordstrom-Klee B, Ager J, Templin T, Janisse J, Martier S & Sokol RJ. (2001). Prenatal alcohol exposure and childhood behavior at age 6 to 7 years: I. dose-response effect. *Pediatrics*, 108, E34.

Sood BG, Nordstrom Bailey B, Covington C, Sokol RJ, Ager J, Janisse J, Hannigan JH & Delaney-Black V. (2005). Gender and alcohol moderate caregiver reported child behavior after prenatal cocaine. *Neurotoxicol Teratol*, 27, 191-201.

Sowell ER, Johnson A, Kan E, Lu LH, Van Horn JD, Toga AW, O'Connor MJ & Bookheimer SY. (2008). Mapping white matter integrity and neurobehavioral correlates in children with fetal alcohol spectrum disorders. *J Neurosci*, 28, 1313-1319.

Sowell ER, Mattson SN, Thompson PM, Jernigan TL, Riley EP & Toga AW. (2001). Mapping callosal morphology and cognitive correlates - Effects of heavy prenatal alcohol exposure. *Neurology*, 57, 235-244.

Spottiswoode BS, Meintjes EM, Anderson AW, Molteno CD, Stanton ME, Dodge NC, Gore JC, Peterson BS, Jacobson JL, et al. (2011). Diffusion tensor imaging of the cerebellum and eyeblink conditioning in fetal alcohol spectrum disorder. *Alcohol Clin Exp Res*, 35, 2174-2183.

Stevens SA, Clairman H, Nash K & Rovet J. (2017). Social perception in children with fetal alcohol spectrum disorder. *Child Neuropsychology*, 23, 980-993.

Stevens SA, Dudek J, Nash K, Koren G & Rovet J. (2015). Social Perspective Taking and Empathy in Children with Fetal Alcohol Spectrum Disorders. *J Int Neuropsychol Soc*, 21, 74-84.

Stevens SA, Major D, Rovet J, Koren G, Fantus E, Nulman I & Desrocher M. (2012). Social problem solving in children with fetal alcohol spectrum disorders. *J Popul Ther Clin Pharmacol*, 19, e99-110.

Streissguth AP, Barr HM & Martin DC. (1984). Alcohol exposure in utero and functional deficits in children during the first four years of life. *Ciba Found Symp*, 105, 176-196.

Streissguth AP, Barr HM, Martin DC & Herman CS. (1980). Effects of maternal alcohol, nicotine, and caffeine use during pregnancy on infant mental and motor development at eight months. *Alcohol Clin Exp Res*, 4, 152-164.

Stromland K. (1985). Ocular abnormalities in the fetal alcohol syndrome. *Acta Ophthalmol Suppl (1985)*, 171, 1-50.

Subramoney S, Joshi SH, Wedderburn CJ, Lee D, Roos A, Woods RP, Zar HJ, Narr KL, Stein DJ, et al. (2022). The impact of prenatal alcohol exposure on gray matter volume and cortical surface area of 2 to 3-year-old children in a South African birth cohort. *Alcohol Clin Exp Res*, 46, 1233-1247.

Sullivan EV, Moore EM, Lane B, Pohl KM, Riley EP & Pfefferbaum A. (2020). Graded Cerebellar Lobular Volume Deficits in Adolescents and Young Adults with Fetal Alcohol Spectrum Disorders (FASD). *Cereb Cortex*, 30, 4729-4746.

Sun Y, Strandberg-Larsen K, Vestergaard M, Christensen J, Nybo Andersen AM, Grønbaek M & Olsen J. (2009). Binge drinking during pregnancy and risk of seizures in childhood: a study based on the Danish National Birth Cohort. *Am J Epidemiol*, 169, 313-322.

Suttie M, Foroud T, Wetherill L, Jacobson JL, Molteno CD, Meintjes EM, Hoyme HE, Khaole N, Robinson LK, et al. (2013). Facial dysmorphism across the fetal alcohol spectrum. *Pediatrics*, 131, e779-788.

Suttie M, Wozniak JR, Parnell SE, Wetherill L, Mattson SN, Sowell ER, Kan E, Riley EP, Jones KL, et al. (2018). Combined Face-Brain Morphology and Associated Neurocognitive Correlates in Fetal Alcohol Spectrum Disorders. *Alcohol Clin Exp Res*, 42, 1769-1782.

Taggart TC, Simmons RW, Thomas JD & Riley EP. (2017). Children with Heavy Prenatal Alcohol Exposure Exhibit Atypical Gait Characteristics. *Alcohol Clin Exp Res*, 41, 1648-1655.

Tamura N, Hanaoka T, Ito K, Araki A, Miyashita C, Ito S, Minakami H, Cho K, Endo T, et al. (2018). Different Risk Factors for Very Low Birth Weight, Term-Small-for-Gestational-Age, or Preterm Birth in Japan. *Int J Environ Res Public Health*, 15,

Taylor PA, Jacobson SW, van der Kouwe A, Molteno CD, Chen G, Wintermark P, Alhamud A, Jacobson JL & Meintjes EM. (2015). A DTI-based tractography study of effects on brain structure associated with prenatal alcohol exposure in newborns. *Hum Brain Mapp*, 36, 170-186.

Thorne JC. (2017). Accentuate the Negative: Grammatical Errors During Narrative Production as a Clinical Marker of Central Nervous System Abnormality in School-Aged Children With Fetal Alcohol Spectrum Disorders. *J Speech Lang Hear Res*, 60, 3523-3537.

Treit S, Chen Z, Zhou D, Baugh L, Rasmussen C, Andrew G, Pei J & Beaulieu C. (2017). Sexual dimorphism of volume reduction but not cognitive deficit in fetal alcohol spectrum disorders: A combined diffusion tensor imaging, cortical thickness and brain volume study. *Neuroimage Clin*, 15, 284-297.

Treit S, Jeffery D, Beaulieu C & Emery D. (2020). Radiological Findings on Structural Magnetic Resonance Imaging in Fetal Alcohol Spectrum Disorders and Healthy Controls. *Alcohol Clin Exp Res*, 44, 455-462.

Treit S, Zhou D, Chudley AE, Andrew G, Rasmussen C, Nikkel SM, Samdup D, Hanlon-Dearman A, Loock C, et al. (2016). Relationships between Head Circumference, Brain Volume and Cognition in Children with Prenatal Alcohol Exposure. *PLoS One*, 11, e0150370.

Uecker A & Nadel L. (1996). Spatial locations gone awry: object and spatial memory deficits in children with fetal alcohol syndrome. *Neuropsychologia*, 34, 209-223.

Underbjerg M, Kesmodel US, Landro NI, Bakketeig L, Grove J, Wimberley T, Kilburn TR, Svaerke C, Thorsen P, et al. (2012). The effects of low to moderate alcohol consumption and binge drinking in early pregnancy on selective and sustained attention in 5-year-old children. *BJOG*, 119, 1211-1221.

Vaurio L, Riley EP & Mattson SN. (2011). Neuropsychological comparison of children with heavy prenatal alcohol exposure and an IQ-matched comparison group. *J Int Neuropsychol Soc*, 17, 463-473.

Verkerk PH, van Noord-Zaadstra BM, Florey CD, de Jonge GA & Verloove-Vanhorick SP. (1993). The effect of moderate maternal alcohol consumption on birth weight and gestational age in a low risk population. *Early Hum Dev*, 32, 121-129.

Viljoen DL, Gossage JP, Brooke L, Adnams CM, Jones KL, Robinson LK, Hoyme HE, Snell C, Khaole NC, et al. (2005). Fetal alcohol syndrome epidemiology in a South African community: a second study of a very high prevalence area. *J Stud Alcohol*, 66, 593-604.

Virji SK. (1991). The relationship between alcohol consumption during pregnancy and infant birthweight. An epidemiologic study. *Acta Obstet Gynecol Scand*, 70, 303-308.

Walthall JC, O'Connor MJ & Paley B. (2008). A comparison of psychopathology in children with and without prenatal alcohol exposure. *Mental Health Aspects of Developmental Disabilities*, 11, 69-78.

Ware AL, Crocker N, O'Brien JW, Deweese BN, Roesch SC, Coles CD, Kable JA, May PA, Kalberg WO, et al. (2012). Executive function predicts adaptive behavior in children with histories of heavy prenatal alcohol exposure and attention-deficit/hyperactivity disorder. *Alcohol Clin Exp Res*, 36, 1431-1441.

Ware AL, Long X & Lebel C. (2021). Functional connectivity of the attention networks is altered and relates to neuropsychological outcomes in children with prenatal alcohol exposure. *Dev Cogn Neurosci*, 48, 100951.

Ware AL, O'Brien JW, Crocker N, Deweese BN, Roesch SC, Coles CD, Kable JA, May PA, Kalberg WO, et al. (2013). The effects of prenatal alcohol exposure and attention-deficit/hyperactivity disorder on psychopathology and behavior. *Alcohol Clin Exp Res*, 37, 507-516.

Way EL & Rojahn J. (2012). Psycho-Social Characteristics of Children with Prenatal Alcohol Exposure, Compared to Children with Down Syndrome and Typical Children. *J Dev Phys Disabil*, 24, 247-268.

Whaley SE, O'Connor, Mj & Gunderson B. (2001). Comparison of the adaptive functioning of children prenatally exposed to alcohol to a nonexposed clinical sample. *Alcohol Clin Exp Res*, 25, 1018-1024.

Wheeler SM, Stevens SA, Sheard ED & Rovet JF. (2012). Facial memory deficits in children with fetal alcohol spectrum disorders. *Child Neuropsychol*, 18, 339-346.

Whitehead N & Lipscomb L. (2003). Patterns of alcohol use before and during pregnancy and the risk of small-for-gestational-age birth. *Am J Epidemiol*, 158, 654-662.

Willford J, Leech S & Day N. (2006). Moderate prenatal alcohol exposure and cognitive status of children at age 10. *Alcohol Clin Exp Res*, 30, 1051-1059.

Willoughby KA, Sheard ED, Nash K & Rovet J. (2008). Effects of prenatal alcohol exposure on hippocampal volume, verbal learning, and verbal and spatial recall in late childhood. *J Int Neuropsychol Soc*, 14, 1022-1033.

Windham GC, Fenster L, Hopkins B & Swan SH. (1995). The association of moderate maternal and paternal alcohol consumption with birthweight and gestational age. *Epidemiology*, 6, 591-597.

Wozniak JR, Mueller BA, Bell CJ, Muetzel RL, Hoecker HL, Boys CJ & Lim KO. (2013). Global functional connectivity abnormalities in children with fetal alcohol spectrum disorders. *Alcohol Clin Exp Res*, 37, 748-756.

Wozniak JR, Mueller BA, Chang PN, Muetzel RL, Caros L & Lim KO. (2006). Diffusion tensor imaging in children with fetal alcohol spectrum disorders. *Alcohol Clin Exp Res*, 30, 1799-1806.

Wozniak JR, Muetzel RL, Mueller BA, McGee CL, Freerks MA, Ward EE, Nelson ML, Chang PN & Lim KO. (2009). Microstructural corpus callosum anomalies in children with prenatal alcohol exposure: an extension of previous diffusion tensor imaging findings. *Alcohol Clin Exp Res*, 33, 1825-1835.

Yang Q, Witkiewicz BB, Olney RS, Liu Y, Davis M, Khoury MJ, Correa A & Erickson JD. (2001). A case-control study of maternal alcohol consumption and intrauterine growth retardation. *Ann Epidemiol*, 11, 497-503.

Yang Y, Phillips OR, Kan E, Sulik KK, Mattson SN, Riley EP, Jones KL, Adnams CM, May PA, et al. (2012). Callosal thickness reductions relate to facial dysmorphology in fetal alcohol spectrum disorders. *Alcohol Clin Exp Res*, 36, 798-806.

Yang Y, Roussotte F, Kan E, Sulik KK, Mattson SN, Riley EP, Jones KL, Adnams CM, May PA, et al. (2012). Abnormal cortical thickness alterations in fetal alcohol spectrum disorders and their relationships with facial dysmorphology. *Cereb Cortex*, 22, 1170-1179.

Yoshida S, Wilunda C, Kimura T, Takeuchi M & Kawakami K. (2018). Prenatal Alcohol Exposure and Suspected Hearing Impairment Among Children: A Population-based Retrospective Cohort Study. *Alcohol Alcohol*, 53, 221-227.

Zhou DM, Lebel C, Lepage C, Rasmussen C, Evans A, Wyper K, Pei J, Andrew G, Massey A, et al. (2011). Developmental cortical thinning in fetal alcohol spectrum disorders. *Neuroimage*, 58, 16-25.

Zuccolo L, DeRoo LA, Wills AK, Davey Smith G, Suren P, Roth C, Stoltenberg C & Magnus P. (2016). Pre-conception and prenatal alcohol exposure from mothers and fathers drinking and head circumference: results from the Norwegian Mother-Child Study (MoBa). *Sci Rep*, 7, 39535.

References: Systematic review and qualitative synthesis of lived experiences of the assessment and diagnostic process

Chamberlain K, Reid N, Warner J, Shelton D & Dawe S. (2017). A qualitative evaluation of caregivers' experiences, understanding and outcomes following diagnosis of FASD. *Res Dev Disabil*, 63, 99-106.

Doak J, Katsikitis M, Webster H & Wood A. (2019). A fetal alcohol spectrum disorder diagnostic service and beyond: Outcomes for families. *Res Dev Disabil*, 93, 103428.

Duquette C & Stodel EJ. (2005). School experiences of students with fetal alcohol spectrum disorder. *Exceptionality Educ Canada*, 15, 51-75.

Hamilton SL, Maslen S, Watkins R, Conigrave K, Freeman J, O'Donnell M, Mutch RC & Bower C. (2020). 'That thing in his head': Aboriginal and non-Aboriginal Australian caregiver responses to neurodevelopmental disability diagnoses. *Sociol Health Illn*, 42, 1581-1596.

Petrenko CL, Tahir N, Mahoney EC & Chin NP. (2014). Prevention of secondary conditions in fetal alcohol spectrum disorders: identification of systems-level barriers. *Matern Child Health J*, 18, 1496-1505.

Salmon J. (2008). Fetal alcohol spectrum disorder: New Zealand birth mothers' experiences. *Can J Clin Pharmacol*, 15, e191-213.

Sanders JL & Buck G. (2010). A long journey: Biological and non-biological parents' experiences raising children with FASD. *Journal of Population Therapeutics and Clinical Pharmacology*, 17, e308-e322.

Temple VK, Prasad S, Popova S & Lindsay A. (2021). Long-term outcomes following Fetal Alcohol Spectrum Disorder (FASD) diagnosis in adulthood. *Journal of Intellectual & Developmental Disability*, 46, 272-280.

Thomas R & Mukherjee R. (2019). Exploring the experiences of birth mothers whose children have been diagnosed with fetal alcohol spectrum disorders: a qualitative study. *Adv Dual Diagn*, 12, 27-35.

Watson SL, Hayes SA, Coons KD & Radford-Paz E. (2013). Autism spectrum disorder and fetal alcohol spectrum disorder. Part II: A qualitative comparison of parenting stress. *J Intellect Dev Disabil*, 38, 105-113.

References: Scoping review of factors to be considered as part of a holistic assessment .

Physical Health

Akison LK, Moritz KM, Reid N. Adverse reproductive outcomes associated with fetal alcohol exposure: a systematic review. Reproduction. 2019;157(4):329-43.

Akison LK, Reid N, Wyllie M, Moritz KM. Adverse health outcomes in offspring associated with fetal alcohol exposure: a systematic review of clinical and preclinical studies with a focus on metabolic and body composition outcomes. Alcoholism, Clinical and Experimental Research. 2019;43(7):1324-43.

Avaria Mde L, Mills JL, Kleinsteuber K, Aros S, Conley MR, Cox C, et al. Peripheral nerve conduction abnormalities in children exposed to alcohol in utero. The Journal of Pediatrics. 2004;144(3):338-43.

Blanck-Lubarsch M, Dirksen D, Feldmann R, Sauerland C, Hohoff A. Tooth malformations, DMFT index, speech impairment and oral habits in patients with fetal alcohol syndrome. International Journal of Environmental Research and Public Health. 2019;16(22).

Brownell MD, Hanlon-Dearman A, Macwilliam LR, Chudley AE, Roos NP, Yallop LP, et al. Use of health, education, and social services by individuals with fetal alcohol spectrum disorder. Journal of Population Therapeutics and Clinical Pharmacology. 2013;20(2):e95-e106.

Carter RC, Jacobson SW, Molteno CD, Jacobson JL. Fetal alcohol exposure, iron-deficiency anemia, and infant growth. Pediatrics. 2007;120(3):559-67.

Cheung MMY, Tsang TW, Watkins R, Birman C, Popova S, Elliott EJ. Ear abnormalities among children with fetal alcohol spectrum disorder: A systematic review and meta-analysis. The Journal of Pediatrics. 2022;242:113-20 e16.

Cook JC, Lynch ME, Coles CD. Association analysis: Fetal alcohol spectrum disorder and hypertension status in children and adolescents. Alcoholism, Clinical and Experimental Research. 2019;43(8):1727-33.

Flannigan K, Tremblay M, Potts S, Nelson M, Brintnell S, O'Riordan T, et al. Understanding the needs of justice-involved adults with fetal alcohol spectrum disorder in an Indigenous community. Behavioral Sciences & the Law. 2022;40(1):129-43.

Gummel K, Ygge J. Ophthalmologic findings in Russian children with fetal alcohol syndrome. European Journal of Ophthalmology. 2013;23(6):823-30.

Habbick BF, Blakley PM, Houston CS, Snyder RE, Senthilselvan A, Nanson JL. Bone age and growth in fetal alcohol syndrome. Alcoholism, Clinical and Experimental Research. 1998;22(6):1312-6.

Kable JA, Mehta PK, Coles CD. Alterations in insulin levels in adults with prenatal alcohol exposure. Alcoholism, Clinical and Experimental Research. 2021;45(3):500-6.

Loney EA, Habbick BF, Nanson JL. Hospital utilization of Saskatchewan people with fetal alcohol syndrome. Canadian Journal of Public Health. 1998;89(5):333-6.

Naidoo S, Chikte U, Laubscher R, Lombard C. Fetal alcohol syndrome: anthropometric and oral health status. The Journal of Contemporary Dental Practice. 2005;6(4):101-15.

Naidoo S, Norval G, Swanevelder S, Lombard C. Foetal alcohol syndrome: a dental and skeletal age analysis of patients and controls. European Journal of Orthodontics. 2006;28(3):247-53.

Popova S, Lange S, Shield K, Mihic A, Chudley AE, Mukherjee RAS, et al. Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis. Lancet. 2016;387(10022):978-87.

Reid N, Moritz KM, Akison LK. Adverse health outcomes associated with fetal alcohol exposure: A systematic review focused on immune-related outcomes. Pediatric Allergy and Immunology. 2019;30(7):698-707.

Reid N, Akison LK, Hoy W, Moritz KM. Adverse health outcomes associated with fetal alcohol exposure: A systematic review focused on cardio-renal outcomes. Journal of Studies on Alcohol and Drugs. 2019;80(5):515-23.

Reid N, Hayes N, Young SB, Akison LK, Moritz KM. Caregiver-reported physical health status of children and young people with fetal alcohol spectrum disorder. Journal of Developmental Origins of Health and Disease. 2021;12(3):420-7.

Tsang TW, Finlay-Jones A, Perry K, Grigg JR, Popova S, Cheung MMY, et al. Eye abnormalities in children with fetal alcohol spectrum disorders: A systematic review. Ophthalmic Epidemiol. 2022:1-12.

Young SL, Gallo LA, Brookes DSK, Hayes N, Maloney M, Liddle K, et al. Altered bone and body composition in children and adolescents with confirmed prenatal alcohol exposure. Bone. 2022;164:116510.

Sleep

Alvik A, Torgersen AM, Aalen OO, Lindemann R. Binge alcohol exposure once a week in early pregnancy predicts temperament and sleeping problems in the infant. Early Hum Dev. 2011;87(12):827-33.

Chandler-Mather N, Occhipinti S, Donovan C, Shelton D, Dawe S. An investigation of the link between prenatal alcohol exposure and sleep problems across childhood. Drug and alcohol dependence. 2021;218:108412.

Chen ML, Olson HC, Picciano JF, Starr JR, Owens J. Sleep problems in children with fetal alcohol spectrum disorders. J Clin Sleep Med. 2012;8(4):421-9.

Chernick V, Childiaeva R, Ioffe S. Effects of maternal alcohol intake and smoking on neonatal electroencephalogram and anthropometric measurements. Am J Obstet Gynecol. 1983;146(1):41-7.

Dylag KA, Bando B, Baran Z, Dumnicka P, Kowalska K, Kulaga P, et al. Sleep problems among children with fetal alcohol spectrum sisorders (FASD)- an explorative study. Ital J Pediatr. 2021;47(1):113.

Goril S, Zalai D, Scott L, Shapiro CM. Sleep and melatonin secretion abnormalities in children and adolescents with fetal alcohol spectrum disorders. Sleep Medicine. 2016;23:59-64.

Havlicek V, Childiaeva R, Chernick V. EEG frequency spectrum characteristics of sleep states in infants of alcoholic mothers. Neuropadiatrie. 1977;8(4):360-73.

Hayes N, Moritz KM, Reid N. Parent-reported sleep problems in school-aged children with fetal alcohol spectrum disorder: association with child behaviour, caregiver, and family functioning. Sleep Medicine. 2020;74:307-14.

Ioffe S, Chernick V. Development of the EEG between 30 and 40 weeks gestation in normal and alcohol-exposed infants. Developmental Medicine and Child Neurology. 1988;30(6):797-807.

Ipsiroglu OS, McKellin WH, Carey N, Loock C. "They silently live in terror…" why sleep problems and night-time related quality-of-life are missed in children with a fetal alcohol spectrum disorder. Soc Sci Med. 2013;79:76-83.

Mughal R, Joyce A, Hill C, Dimitriou D. Sleep disturbance as a predictor of anxiety in children with fetal alcohol spectrum disorders and typically developing children. Research in Developmental Disabilities. 2020;101:103610.

Mughal R, Hill CM, Joyce A, Dimitriou D. Sleep and cognition in children with fetal alcohol spectrum disorders (FASD) and children with autism spectrum disorders (ASD). Brain Science. 2020;10(11).

Mughal R, Wong SS, Dimitriou D, Halstead E. Nightmares in children with foetal alcohol spectrum disorders, autism spectrum disorders, and their typically developing peers. Clocks Sleep. 2021;3(3):465-81.

Rosett HL, Louis PS, Sander W, Lee A, Cook P, Weiner L, et al. Effects of maternal drinking on neonate state regulation. Developmental Medicine & Child Neurology. 1979;21(4):464-73.

Scher MS, Richardson GA, Coble PA, Day NL, Stoffer DS. The Effects of Prenatal Alcohol and Marijuana Exposure: Disturbances in Neonatal Sleep Cycling and Arousal. Pediatric Research. 1988;24(1):101-5.

Scher MS, Richardson GA, Day NL. Effects of prenatal cocaine/crack and other drug exposure on electroencephalographic sleep studies at birth and one year. Pediatrics. 2000;105(1 Pt 1):39-48.

Spruyt K, Ipsiroglu O, Stockler S, Reynolds JN. Challenging sleep-wake behaviors reported in informal, conversational interviews of caregivers of children with fetal alcohol spectrum disorder. Int J Dev Disabil. 2016;64(2):65-74.

Troese M, Fukumizu M, Sallinen BJ, Gilles AA, Wellman JD, Paul JA, et al. Sleep fragmentation and evidence for sleep debt in alcohol-exposed infants. Early Hum Dev. 2008;84(9):577-85.

Wengel T, Hanlon-Dearman AC, Fjeldsted B. Sleep and sensory characteristics in young children with fetal alcohol spectrum disorder. J Dev Behav Pediatr. 2011;32(5):384-92.

Adverse Postnatal Experiences

Andre QR, McMorris CA, Kar P, Ritter C, Gibbard WB, Tortorelli C, et al. Different brain profiles in children with prenatal alcohol exposure with or without early adverse exposures. Human Brain Mapping. 2020;41(15):4375-85.

Bingol N, Schuster C, Fuchs M, Iosub S, Turner G, Stone RK, et al. The influence of socioeconomic factors on the occurrence of fetal alcohol syndrome. Adv Alcohol Subst Abuse. 1987;6(4):105-18.

Flannigan K, Kapasi A, Pei J, Murdoch I, Andrew G, Rasmussen C. Characterizing adverse childhood experiences among children and adolescents with prenatal alcohol exposure and fetal alcohol spectrum disorder. Child Abuse and Neglect. 2021;112:104888.

Hemingway SJA, Davies JK, Jirikowic T, Olson EM. What proportion of the brain structural and functional abnormalities observed among children with fetal alcohol spectrum disorder is explained by their prenatal alcohol exposure and their other prenatal and postnatal risks? Advances in Pediatric Research. 2020;7.

Jacobson SW, Jacobson JL, Sokol RJ, Chiodo LM, Corobana R. Maternal age, alcohol abuse history, and quality of parenting as moderators of the effects of prenatal alcohol exposure on 7.5-year intellectual function. Alcoholism, Clinical and Experimental Research. 2004;28(11):1732-45.

Kambeitz C, Klug MG, Greenmyer J, Popova S, Burd L. Association of adverse childhood experiences and neurodevelopmental disorders in people with fetal alcohol spectrum disorders (FASD) and non-FASD controls. BMC Pediatrics. 2019;19(1):498.

Lebel CA, McMorris CA, Kar P, Ritter C, Andre Q, Tortorelli C, et al. Characterizing adverse prenatal and postnatal experiences in children. Birth Defects Research. 2019;111(12):848-58.

McLachlan K, Rasmussen C, Oberlander TF, Loock C, Pei J, Andrew G, et al. Dysregulation of the cortisol diurnal rhythm following prenatal alcohol exposure and early life adversity. Alcohol. 2016;53:9-18.

Mukherjee RAS, Cook PA, Norgate SH, Price AD. Neurodevelopmental outcomes in individuals with fetal alcohol spectrum disorder (FASD) with and without exposure to neglect: Clinical cohort data from a national FASD diagnostic clinic. Alcohol. 2019;76:23-8.

O'Connor MJ, Sigman M, Brill N. Disorganization of attachment in relation to maternal alcohol consumption. Journal of Consulting and Clinical Psychology. 1987;55(6):831-6.

O'Connor MJ, Sigman M, Kasari C. Attachment behavior of infants exposed prenatally to alcohol: Mediating effects of infant affect and mother-infant interaction. Development and Psychopathology. 1992;4(2):243-56.

O'Connor MJ, Kogan N, Findlay R. Prenatal alcohol exposure and attachment behavior in children. Alcoholism, Clinical and Experimental Research. 2002;26(10):1592-602.

Pfinder M, Liebig S, Feldmann R. Explanation of social inequalities in hyperactivity/inattention in children with prenatal alcohol exposure. Klinische Padiatrie. 2012;224(5):303-8.

Price A, Cook PA, Norgate S, Mukherjee R. Prenatal alcohol exposure and traumatic childhood experiences: A systematic review. Neuroscience and Biobehavioral Reviews. 2017;80:89-98.

Uban KA, Kan E, Wozniak JR, Mattson SN, Coles CD, Sowell ER. The Relationship Between Socioeconomic Status and Brain Volume in Children and Adolescents with Prenatal Alcohol Exposure. Frontiers in Human Neuroscience. 2020;14:85.

Yumoto C, Jacobson SW, Jacobson JL. Fetal substance exposure and cumulative environmental risk in an African American cohort. Child Development. 2008;79(6):1761-76.

Substance Use and Other Risk-Taking Behaviours

Alati R, Al Mamun A, Williams GM, O'Callaghan M, Najman JM, Bor W. In utero alcohol exposure and prediction of alcohol disorders in early adulthood: a birth cohort study. Archives of General Psychiatry. 2006;63(9):1009-16.

Alati R, Clavarino A, Najman JM, O'Callaghan M, Bor W, Mamun AA, et al. The developmental origin of adolescent alcohol use: findings from the Mater University Study of Pregnancy and its outcomes. Drug and alcohol dependence. 2008;98(1-2):136-43.

Baer JS, Barr HM, Bookstein FL, Sampson PD, Streissguth AP. Prenatal alcohol exposure and family history of alcoholism in the etiology of adolescent alcohol problems. Journal of Studies on Alcohol. 1998;59(5):533-43.

Baer JS, Sampson PD, Barr HM, Connor PD, Streissguth AP. A 21-year longitudinal analysis of the effects of prenatal alcohol exposure on young adult drinking. Archives of General Psychiatry. 2003;60(4):377-85.

Cornelius MD, De Genna NM, Goldschmidt L, Larkby C, Day NL. Prenatal alcohol and other early childhood adverse exposures: Direct and indirect pathways to adolescent drinking. Neurotoxicology and Teratology. 2016;55:8-15.

Cornelius MD, Goldschmidt L, Day NL. Gestational alcohol exposure and other factors associated with continued teenage drinking. Health Education & Behavior. 2016;43(4):428-33.

De Genna NM, Cornelius MD. Maternal drinking and risky sexual behavior in offspring. Health Education & Behavior. 2014;42(2):185-93.

Flannigan K, Tremblay M, Potts S, Nelson M, Brintnell S, O'Riordan T, et al. Understanding the needs of justice-involved adults with fetal alcohol spectrum disorder in an Indigenous community. Behavioral Sciences & the Law. 2022;40(1):129-43.

Goldschmidt L, Richardson GA, De Genna NM, Cornelius MD, Day NL. Prenatal alcohol exposure and offspring alcohol use and misuse at 22 years of age: A prospective longitudinal study. Neurotoxicology and Teratology. 2019;71:1-5.

Hannigan JH, Chiodo LM, Sokol RJ, Janisse J, Delaney-Black V. Prenatal alcohol exposure selectively enhances young adult perceived pleasantness of alcohol odors. Physiology & Behavior. 2015;148:71-7.

Lees B, Mewton L, Stapinski LA, Teesson M, Squeglia LM. Association of prenatal alcohol exposure with preadolescent alcohol sipping in the ABCD study®. Drug and Alcohol Dependence. 2020;214:108187.

Lynch ME, Kable JA, Coles CD. Effects of prenatal alcohol exposure in a prospective sample of young adults: Mental health, substance use, and difficulties with the legal system. Neurotoxicology and Teratology. 2017;64:50-62.

McLachlan K, Flannigan K, Temple V, Unsworth K, Cook JL. Difficulties in daily living experienced by adolescents, transition-aged youth, and adults with fetal alcohol spectrum disorder. Alcoholism, Clinical and Experimental Research. 2020;44(8):1609-24.

O'Brien JW, Hill SY. Effects of prenatal alcohol and cigarette exposure on offspring substance use in multiplex, alcohol-dependent families. Alcoholism, Clinical and Experimental Research. 2014;38(12):2952-61.

Rangmar J, Hjern A, Vinnerljung B, Strömland K, Aronson M, Fahlke C. Psychosocial outcomes of fetal alcohol syndrome in adulthood. Pediatrics. 2015;135(1):e52-8.

Streissguth AP, Bookstein FL, Barr HM, Sampson PD, O'Malley K, Young JK. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. J Dev Behav Pediatr. 2004;25(4):228-38.

Yates WR, Cadoret RJ, Troughton EP, Stewart M, Giunta TS. Effect of fetal alcohol exposure on adult symptoms of nicotine, alcohol, and drug dependence. Alcoholism, Clinical and Experimental Research. 1998;22(4):914-20.

Contact with the Criminal Justice System

Blagg H, Tulich T, Bush Z. Indefinite detention meets colonial dispossession: Indigenous youths with foetal alcohol spectrum disorders in a white settler justice system. Social & Legal Studies. 2017;26(3):333-58.

Brownell M, Enns JE, Hanlon-Dearman A, Chateau D, Phillips-Beck W, Singal D, et al. Health, social, education, and justice outcomes of Manitoba First Nations children diagnosed with fetal alcohol spectrum disorder: A population-based cohort study of linked administrative data. Can J Psychiatry. 2019;64(9):611-20.

Clark E, Lutke J, Minnes P, Ouellette-Kuntz H. Secondary disabilities among adults with fetal alcohol spectrum disorder in British Columbia. J FAS Int. 2004;2.

Currie BA, Hoy J, Legge L, Temple VK, Tahir M. Adults with fetal alcohol spectrum disorder: Factors associated with positive outcomes and contact with the criminal justice system. Journal of Population Therapeutics and Clinical Pharmacology. 2016;23(1):e37-52.

Flannigan K, Tremblay M, Potts S, Nelson M, Brintnell S, O'Riordan T, et al. Understanding the needs of justice-involved adults with fetal alcohol spectrum disorder in an Indigenous community. Behavioral Sciences & the Law. 2022;40(1):129-43.

Hamilton S, Maslen S, Best D, Freeman J, O'Donnell M, Reibel T, et al. Putting 'justice' in recovery capital: Yarning about hopes and futures with young people in detention. International Journal for Crime, Justice, and Social Democracy. 2020;8.

Lynch ME, Coles CD, Corley T, Falek A. Examining delinquency in adolescents differentially prenatally exposed to alcohol: the role of proximal and distal risk factors. Journal of Studies on Alcohol. 2003;64(5):678-86.

Lynch ME, Kable JA, Coles CD. Effects of prenatal alcohol exposure in a prospective sample of young adults: Mental health, substance use, and difficulties with the legal system. Neurotoxicology and Teratology. 2017;64:50-62.

McLachlan K, Flannigan K, Temple V, Unsworth K, Cook JL. Difficulties in daily living experienced by adolescents, transition-aged youth, and adults with fetal alcohol spectrum disorder. Alcoholism, Cinical and Experimental Research. 2020;44(8):1609-24.

Pei J, Leung W, Jampolsky F, Alsbury B (2016) Experiences in the Canadian criminal justice system for individuals with fetal alcohol spectrum disorders: Double jeopardy?. Can J Criminol 58**:** 56-86.

Rangmar J, Hjern A, Vinnerljung B, Strömland K, Aronson M, Fahlke C. Psychosocial outcomes of fetal alcohol syndrome in adulthood. Pediatrics. 2015;135(1):e52-8.

Rangmar J, Dahlgren Sandberg A, Aronson M, Fahlke C. Self-reported health, use of alcohol and illicit drugs, and criminality among adults with foetal alcohol syndrome. Nordisk Alkohol- & Narkotikatidskrift. 2017;34(3):255-66.

Rogers B, McLachlan K, Roesch R. Resilience and enculturation: Strengths among young offenders with fetal alcohol spectrum disorder. First Peoples Child & Family Review. 2013;8(1):62-80.

Schonfeld AM, Mattson SN, Riley EP. Moral maturity and delinquency after prenatal alcohol exposure. Journal of Studies on Alcohol. 2005;66(4):545-54.

Streissguth AP, Bookstein FL, Barr HM, Sampson PD, O'Malley K, Young JK. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. J Dev Behav Pediatr. 2004;25(4):228-38.

Mental Health

Ali S, Kerns KA, Mulligan BP, Olson HC, Astley SJ. An investigation of intra-individual variability in children with fetal alcohol spectrum disorder (FASD). Child Neuropsychol. 2018;24(5):617-37.

Baldwin MR. Fetal alcohol spectrum disorders and suicidality in a healthcare setting. International journal of circumpolar health. 2007;66 Suppl 1:54-60.

Brownell M, Enns JE, Hanlon-Dearman A, Chateau D, Phillips-Beck W, Singal D, et al. Health, social, education, and justice outcomes of Manitoba First Nations children diagnosed with fetal alcohol spectrum disorder: A population-based cohort study of linked administrative data. Can J Psychiatry. 2019;64(9):611-20.

Burns J, Badry DE, Harding KD, Roberts N, Unsworth K, Cook JL. Comparing outcomes of children and youth with fetal alcohol spectrum disorder (FASD) in the child welfare system to those in other living situations in Canada: Results from the Canadian National FASD Database. Childcare, Health and Development. 2021;47(1):77-84.

Flannigan K, Tremblay M, Potts S, Nelson M, Brintnell S, O'Riordan T, et al. Understanding the needs of justice-involved adults with fetal alcohol spectrum disorder in an Indigenous community. Behavioral Sciences & the Law. 2022;40(1):129-43.

Harding KD, Turner K, Howe SJ, Bagshawe MJ, Flannigan K, Mela M, et al. Caregivers' experiences and perceptions of suicidality among their children and youth with fetal alcohol spectrum disorder. Front Psychiatry. 2022;13:931528.

Mathews CA, Scharf JM, Miller LL, Macdonald-Wallis C, Lawlor DA, Ben-Shlomo Y. Association between pre- and perinatal exposures and Tourette syndrome or chronic tic disorder in the ALSPAC cohort. Br J Psychiatry. 2014;204(1):40-5.

O'Connor MJ, Portnoff LC, Lebsack-Coleman M, Dipple KM. Suicide risk in adolescents with fetal alcohol spectrum disorders. Birth defects research. 2019;111(12):822-8.

Rangmar J, Hjern A, Vinnerljung B, Strömland K, Aronson M, Fahlke C. Psychosocial outcomes of fetal alcohol syndrome in adulthood. Pediatrics. 2015;135(1):e52-8.

Rangmar J, Dahlgren Sandberg A, Aronson M, Fahlke C. Self-reported health, use of alcohol and illicit drugs, and criminality among adults with foetal alcohol syndrome. Nordisk Alkohol- & Narkotikatidskrift : NAT. 2017;34(3):255-66.

Streissguth AP, Bookstein FL, Barr HM, Sampson PD, O'Malley K, Young JK. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. J Dev Behav Pediatr. 2004;25(4):228-38.

Temple VK, Cook JL, Unsworth K, Rajani H, Mela M. Mental health and affect regulation impairment in fetal alcohol spectrum disorder (FASD): Results from the Canadian National FASD Database. Alcohol and Alcoholism. 2019;54(5):545-50.

First Nations Cultural Considerations

Blagg H, Tulich T and Bush Z. Diversionary pathways for Indigenous youth with FASD in Western Australia: Decolonising alternatives. Alternative Law Journal 2015; 40: 257-260.

Brownell M, Enns JE, Hanlon-Dearman A, Chateau D, Phillips-Beck W, Singal D, et al. Health, Social, Education, and Justice Outcomes of Manitoba First Nations Children Diagnosed with Fetal Alcohol Spectrum

Disorder: A Population-Based Cohort Study of Linked Administrative Data. Can J Psychiatry. 2019;64(9):611-20.

Crawford A, Te Nahu LTH, Peterson ER, McGinn V, Robertshaw K, Tippett L. Cognitive and social/emotional influences on adaptive functioning in children with FASD: Clinical and cultural considerations. Child Neuropsychology. 2020;26(8):1112-44.

Flannigan K, Tremblay M, Potts S, Nelson M, Brintnell S, O'Riordan T, et al. Understanding the needs of justice-involved adults with fetal alcohol spectrum disorder in an Indigenous community. Behavioral sciences & the Law. 2022;40(1):129-43.

Gonzales K, Jacob M, Mercier A, Heater H, Behind L, Joseph J, et al. An indigenous framework of the cycle of fetal alcohol spectrum disorder risk and prevention across the generations: historical trauma, harm and healing. Ethnicity & Health. 2018;26:1-19.

Hamilton SL, Reibel T, Watkins R, Mutch RC, Kippin NR, Freeman J, et al. 'He has problems; he is not the problem . . .' a qualitative study of non-custodial staff providing services for young offenders assessed for foetal alcohol spectrum disorder in an Australian youth detention centre. Youth Justice. 2019;19(2):137-57.

Hamilton SL, Maslen S, Watkins R, Conigrave K, Freeman J, O'Donnell M, et al. 'That thing in his head': Aboriginal and non-Aboriginal Australian caregiver responses to neurodevelopmental disability diagnoses. Sociology of Health & Illness. 2020;42(7):1581-96.

Hamilton S, Maslen S, Best D, Freeman J, O'Donnell M, Reibel T, et al. Putting 'justice' in recovery capital: Yarning about hopes and futures with young people in detention. International Journal for Crime, Justice and Social Democracy. 2020;8.

Hayes LG. Aboriginal women, alcohol and the road to fetal alcohol spectrum disorder. Med J Aust. 2012;197(1):21-3.

Miller L, Shanley DC, Page M, Webster H, Liu W, Reid N, et al. Preventing drift through continued co-design with a First Nations community: Refining the prototype of a tiered FASD assessment. International Journal of Environmental Research and Public Health. 2022;19(18).

Reid N, Hawkins E, Liu W, Page M, Webster H, Katsikitis M, et al. Yarning about fetal alcohol spectrum disorder: Outcomes of a community-based workshop. Research in Developmental Disabilities. 2021;108:103810.

Rogers B, McLachlan K, Roesch R. Resilience and enculturation: Strengths among young offenders with fetal alcohol spectrum disorder. First Peoples Child & Family Review. 2013;8(1):62-80.

Transition To Adult Roles

Brownell M, Enns JE, Hanlon-Dearman A, Chateau D, Phillips-Beck W, Singal D, et al. Health, Social, Education, and Justice Outcomes of Manitoba First Nations Children Diagnosed with Fetal Alcohol Spectrum Disorder: A Population-Based Cohort Study of Linked Administrative Data. Can J Psychiatry. 2019;64(9):611-20.

Clark E, Lutke J, Minnes P, Ouellette-Kuntz H. Secondary disabilities among adults with fetal alcohol spectrum disorder in British Columbia. J FAS Int. 2004;2.

Currie BA, Hoy J, Legge L, Temple VK, Tahir M. Adults with Fetal Alcohol Spectrum Disorder: Factors Associated with Positive Outcomes and Contact with the Criminal Justice System. Journal of population therapeutics and clinical pharmacology. 2016;23(1):e37-52.

Duquette C, Stodel E, Fullarton S, Hagglund K. Persistence in high school: experiences of adolescents and young adults with Fetal Alcohol Spectrum Disorder. Journal of intellectual & developmental disability. 2006;31(4):219-31.

Duquette C, Orders S. On fitting a triangle into a circle: A study on employment outcomes of adults with Fetal Alcohol Spectrum Disorder who attended postsecondary institutions. The International Journal of Alcohol and Drug Research. 2013;2:27.

Flannigan K, Tremblay M, Potts S, Nelson M, Brintnell S, O'Riordan T, et al. Understanding the needs of justice-involved adults with fetal alcohol spectrum disorder in an Indigenous community. Behavioral sciences & the law. 2022;40(1):129-43.

Freunscht I, Feldmann R. Young adults with Fetal Alcohol Syndrome (FAS): social, emotional and occupational development. Klinische Padiatrie. 2011;223(1):33-7.

Lynch ME, Kable JA, Coles CD. Prenatal alcohol exposure, adaptive function, and entry into adult roles in a prospective study of young adults. Neurotoxicology and teratology. 2015;51:52-60.

McLachlan K, Flannigan K, Temple V, Unsworth K, Cook JL. Difficulties in Daily Living Experienced by Adolescents, Transition-Aged Youth, and Adults With Fetal Alcohol Spectrum Disorder. Alcoholism, clinical and experimental research. 2020;44(8):1609-24.

Rangmar J, Hjern A, Vinnerljung B, Strömland K, Aronson M, Fahlke C. Psychosocial outcomes of fetal alcohol syndrome in adulthood. Pediatrics. 2015;135(1):e52-8.

Streissguth AP, Bookstein FL, Barr HM, Sampson PD, O'Malley K, Young JK. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. J Dev Behav Pediatr. 2004;25(4):228-38.

Temple V, Shewfelt L, Tao L, Casati J, Klevnick L. Comparing daily living skills in adults with fetal alcohol spectrum disorder (FASD) to an IQ matched clinical sample. Journal of Population Therapeutics and Clinical Pharmacology. 2011;18(2).

Out-of-home Care

Bakhireva LN, Garrison L, Shrestha S, Sharkis J, Miranda R, Rogers K. Challenges of diagnosing fetal alcohol spectrum disorders in foster and adopted children. Alcohol (Fayetteville, NY). 2018;67:37-43.

Burns J, Badry DE, Harding KD, Roberts N, Unsworth K, Cook JL. Comparing outcomes of children and youth with fetal alcohol spectrum disorder (FASD) in the child welfare system to those in other living situations in Canada: Results from the Canadian National FASD Database. Childcare, Health and Development. 2021;47(1):77-84.

Chasnoff IJ, Telford E, Wells AM, King L. Mental Health Disorders among Children within Child Welfare who have Prenatal Substance Exposure: Rural vs. Urban Populations. Child Welfare. 2015;94(4):53-70.

Chasnoff IJ, Wells AM, King L. Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. Pediatrics. 2015;135(2):264-70.

Patel M, Agnihotri S, Hawkins C, Levin L, Goodman D, Simpson A. Identifying Fetal Alcohol Spectrum Disorder and psychiatric comorbidity for Children and Youth in Care: A community approach to diagnosis and treatment. Children and Youth Services Review. 2020;108:104606.

Rangmar J, Sandberg AD, Aronson M, Fahlke C. Childhood placement in out-of-home care in relation to psychosocial outcomes in adults with fetal alcohol syndrome. European journal of public health. 2016;26(5):856-61.

Richards T, Bertrand J, Newburg-Rinn S, McCann H, Morehouse E, Ingoldsby E. Children prenatally exposed to alcohol and other drugs: what the literature tells us about child welfare information sources, policies, and practices to identify and care for children. J Public Child Welf. 2020;1(24).

Victor A, Wozniak J, Chang P-N. Environmental Correlates of Cognition and Behavior in Children with Fetal Alcohol Spectrum Disorders. Journal of Human Behavior in The Social Environment. 2008;18:288-300.

Feeding/Eating

Amos-Kroohs RM, Fink BA, Smith CJ, Chin L, Van Calcar SC, Wozniak JR, et al. Abnormal Eating Behaviors Are Common in Children with Fetal Alcohol Spectrum Disorder. The Journal of Pediatrics. 2016;169:194-200.e1.

Fuglestad AJ, Fink BA, Eckerle JK, Boys CJ, Hoecker HL, Kroupina MG, et al. Inadequate intake of nutrients essential for neurodevelopment in children with fetal alcohol spectrum disorders (FASD). Neurotoxicology and Teratology. 2013;39:128-32.

Fuglestad AJ, Boys CJ, Chang PN, Miller BS, Eckerle JK, Deling L, et al. Overweight and obesity among children and adolescents with fetal alcohol spectrum disorders. Alcoholism, clinical and experimental research. 2014;38(9):2502-8.

Hayes N, Reid N, Akison LK, Moritz KM. The effect of heavy prenatal alcohol exposure on adolescent body mass index and waist-to-height ratio at 12–13 years. International Journal of Obesity. 2021;45(9):2118-25.

Nguyen TT, Risbud RD, Chambers CD, Thomas JD. Dietary Nutrient Intake in School-Aged Children With Heavy Prenatal Alcohol Exposure. Alcoholism, Clinical and Experimental Research. 2016;40(5):1075-82.

Werts RL, Van Calcar SC, Wargowski DS, Smith SM. Inappropriate feeding behaviors and dietary intakes in children with fetal alcohol spectrum disorder or probable prenatal alcohol exposure. Alcoholism, Clinical and Experimental Research. 2014;38(3):871-8.

Strengths/Interests/External Resources

Flannigan K, Kapasi A, Pei J, Murdoch I, Andrew G, Rasmussen C. Characterizing adverse childhood experiences among children and adolescents with prenatal alcohol exposure and fetal alcohol spectrum disorder. Child Abuse and Neglect. 2021;112:104888.

Hamilton S, Maslen S, Best D, Freeman J, O'Donnell M, Reibel T, et al. Putting 'justice' in recovery capital: Yarning about hopes and futures with young people in detention. International Journal for Crime, Justice and Social Democracy. 2020;8.

Kautz-Turnbull C, Adams TR, Petrenko CLM. The Strengths and Positive Influences of Children With Fetal Alcohol Spectrum Disorders. Am J Intellect Dev Disabil. 2022;127(5):355-68.

Pei J, Leung W, Jampolsky F, Alsbury B (2016) Experiences in the Canadian criminal justice system for individuals with fetal alcohol spectrum disorders: Double jeopardy?. Can J Criminol 58**:** 56-86.

Skorka K, Copley J, McBryde C, Meredith PJ, Reid N. Lived experiences of adolescents with fetal alcohol spectrum disorder. Developmental Medicine & Child Neurology. 2022.

Incontinence

Reid N, Hayes N, Young SB, Akison LK, Moritz KM. Caregiver-reported physical health status of children and young people with fetal alcohol spectrum disorder. Journal of Developmental Origins of Health and Disease. 2021;12(3):420-7.

Roozen S, Olivier L, Niemczyk J, von Gontard A, Peters GY, Kok G, et al. Nocturnal incontinence in children with fetal alcohol spectrum disorders (FASD) in a South African cohort. Journal of pediatric urology. 2017;13(5):496.e1-.e7.

Roozen S, Dylag KA, Przybyszewska K, Niemczyk J, von Gontard A, Peters G-JY, et al. Incontinence in persons with fetal alcohol spectrum disorders: a polish cohort. Journal of Pediatric Urology. 2020;16(3):386.e1-.e11.

References: Scoping review exploring resource implications and models of care

Clarren SK and Lutke J. Building clinical capacity for fetal alcohol spectrum disorder diagnoses in western and northern Canada. *Can J Clin Pharmacol* 2008; 15: e223-237. 2008/06/12.

Clarren SK, Lutke J and Sherbuck M. The Canadian guidelines and the interdisciplinary clinical capacity of Canada to diagnose fetal alcohol spectrum disorder. *J Popul Ther Clin Pharmacol* 2011; 18: e494-499. 2011/11/30.

Dugas EN, Poirier M, Basque D, et al. Canadian clinical capacity for fetal alcohol spectrum disorder assessment, diagnosis, disclosure and support to children and adolescents: a cross-sectional study. *BMJ Open* 2022; 12: e065005. 2022/08/31. DOI: 10.1136/bmjopen-2022-065005.

Fuchs D, Burnside L, Brownell M, et al. *The economic impact of children in care with FASD and parental alcohol issues phase II: Costs and service utilization of health care, special education, and child care.* 2009.

McFarlane A. Fetal alcohol spectrum disorder in adults: diagnosis and assessment by a multidisciplinary team in a rural area *Canadian Journal of Rural Medicine* 2011; 16: 25-30.

McFarlane A and Rajani H. Rural FASD diagnostic services model: Lakeland Centre for fetal alcohol spectrum disorder. *Can J Clin Pharmacol* 2007; 14: e301-306. 2007/11/21.

Panton K, Fitzpatrick J, Jeyaseelan D, et al. Developing local Fetal Alcohol Spectrum Disorder diagnostic services and models of care in Australia. 2022; 4: e1-e15. DOI: 10.22374/jfasrp.v4i1.17.

Patel M, Agnihotri S, Hawkins C, et al. Identifying Fetal Alcohol Spectrum Disorder and psychiatric comorbidity for Children and Youth in Care: A community approach to diagnosis and treatment. *Children and Youth Services Review* 2019; 108: 104606. DOI: 10.1016/j.childyouth.2019.104606.

Peadon E, Fremantle E, Bower C, et al. International survey of diagnostic services for children with Fetal Alcohol Spectrum Disorders. *BMC Pediatrics* 2008; 8: 12. DOI: 10.1186/1471-2431-8-12.

Popova S, Lange S, Burd L, et al. Cost of Fetal Alcohol Spectrum Disorder Diagnosis in Canada. *PLOS ONE* 2013; 8: e60434. DOI: 10.1371/journal.pone.0060434.

Reid N, Shanley DC, Logan J, et al. International Survey of Specialist Fetal Alcohol Spectrum Disorder Diagnostic Clinics: Comparison of Diagnostic Approach and Considerations Regarding the Potential for Unification. *International journal of environmental research and public health 19(23)*(2022).

Temple VK, Ives J and Lindsay A. Diagnosing FASD in adults: the development and operation of an adult FASD clinic in Ontario, Canada. *J Popul Ther Clin Pharmacol* 2015; 22: e96-e105. 2015/03/06.

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
Associated features	Includes clinical features that are not represented in the criteria but occur more often in individuals with the condition that those with the condition.
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)	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.
CRPD	Convention on the Rights of Persons with Disabilities
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
Developmental and epileptic 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.

EF	Executive Function
FASD	Fetal alcohol spectrum disorder
FXS Testing	Fragile X Syndrome Testing
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).
Gestalt	A psychological approach that emphasises holistic perspective.
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.
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
IDD	Intellectual developmental disorder (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 individuals	The terminology of pregnant individuals has been used to be inclusive of transmen, who may become pregnant, but not identify as a woman.
NDIS	National Disability Insurance Scheme
SD	Standard deviation

Specifiers	Specifiers allow for a more specific diagnosis that will help understand an individual's presentation in more detail. In the specific context of FASD, physical specifiers may provide increased certainty regarding the causative role of 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: Overarching evidence-to decision-framework for the diagnostic criteria

QUESTION

What is the available evidence for the diagnostic criteria?	
POPULATION:	Individuals with prenatal alcohol exposure (PAE) or fetal alcohol spectrum disorder (FASD)
EXPOSURE:	PAE
COMPARISON:	Control (typically developing and non/minimal PAE exposure)
MAIN OUTCOMES:	Physical size, dysmorphology, neurodevelopment
SETTING:	Multidisciplinary specialist clinics; single discipline specialist clinics; primary health care
PERSPECTIVE:	Practitioner population perspective
BACKGROUND:	There are differences in diagnostic criteria used worldwide for assessment and diagnosis of FASD. This process considered all of the potential diagnostic features of FASD across all of the currently available criteria.
CONFLICT OF INTERESTS:	None

Problem/priority Is assessment and diagnosis of FASD in Australia a priority/problem?		
	Research evidence	Additional considerations
○ No ○ Probably no ○ Probably yes ○ Yes ○ Varies ○ Don't know	Previous research demonstrates high rates of prenatal alcohol use in Australia (e.g., AIHW, 2021; Young et al., 2022). Available data in Australia point to FASD being under-recognised in Australia (e.g., NDIS access data, cases reported to FASD Registry) although also noted that other potential influencing factors to these reporting rates. FASD is a preventable condition, which is expensive for the individual and family on a personal level and for society. Earlier identification and support has potential to improve long-term outcomes for individuals (e.g., Streissguth et al., 2004). The level of interest and engagement from stakeholders in the review and update process also highlights this is a priority/problem. Advisory Group input and public consultation also provided support for the importance of assessment and diagnosis of FASD in Australia. For instance, some Advisory Group members noted that FASD is likely under-recognised and diagnosed, the complex nature of impairments that individuals with FASD can experience and the significant secondary challenges that individuals can experience when not provided with assessment, diagnosis, and appropriate supports. Other Advisory Group members raised concerns regarding some current diagnostic practices that may be resulting in incorrect diagnoses of FASD in Australia. Overall, both types of feedback indicated it is a priority to improve assessment and diagnostic practices in Australia.	Guidelines Development Group (GDG) also noted the National FASD Strategic Action Plan and funding being provided from Australian Department of Health and Aged Care providing support for this being a problem and priority for Australia.

Strength of the association How substantial is the association between PAE for all of the diagnostic outcomes?		
	Research evidence	Additional considerations
○ Trivial ○ Small ○ Moderate ○ Large ○ Varies ○ Don't know	The strength of the association between prenatal alcohol exposure (PAE) and the diagnostic outcomes varied depending on the level of PAE. At higher levels of PAE, there were stronger associations seen between PAE and all of the diagnostic outcomes. Given these findings, a minimum PAE threshold has been proposed in the diagnostic criteria. In developing the minimum PAE threshold (i.e., Criterion A: PAE above a low risk level) the GDG aimed to balance the available evidence, the limitations of the evidence, and how best to apply the available evidence in practice at an individual level (i.e., benefits and harms). For example, not including a minimum PAE threshold could continue to perpetuate the misunderstanding in Australia that any level of PAE results in a diagnosis of FASD, when this is not consistent with the best available evidence. Conversely, setting a PAE threshold that is too high could miss detecting people who have experienced clinically significant adverse outcomes at moderate levels of PAE. The GDG weighed up these different perspectives in developing criterion A of the diagnostic criteria and the associated information provided to support implementation of criterion A in the guidelines.	The GDG note that FASD is just one potential adverse outcome of PAE. The evidence review supports the Australian Alcohol Guidelines that there is 'no safe level of alcohol consumption during pregnancy.' As there is the potential for adverse effects across PAE levels. The GDG also notes that Criterion A and relevant good practice statements provide information to support practitioners in collecting and assessing risk and reliability of available PAE information.
Certainty of evidence What is the overall certainty of the evidence of effects across diagnostic outcomes?		

	Research evidence	Additional considerations
○ Very low ○ Low ○ Moderate ○ High ○ No included studies ○ Varies	Certainty of the evidence varied from Very Low to High, with the most common certainty rating overall being low. Certainty was commonly impacted by risk of bias in many of the included studies, which were often rated as serious for risk of bias. The most common reasons for serious risk of bias ratings included inadequate control of confounding variables, lack of reliable PAE measurements included for control groups, and/or insufficient details regarding PAE assessment being reported. Certainty also varied based on PAE levels and outcome types. For example, sometimes there were patterns observable where there was increased certainty at the extreme ends of exposure (i.e. light and very heavy). Further well designed studies with quantified levels of PAE are needed across all PAE levels.	A range of information is included in the diagnostic criteria to increase certainty of the association between PAE and diagnostic outcomes: -Minimum PAE threshold (Criterion A); Requires evidence that the neurodevelopmental impairments are 'pervasive' (Criterion B); result in functional impacts (Criterion C); onset of the neurodevelopmental impairments are in childhood (criterion D); and an individual's presentation is not better attributed to another condition or exposure (Criterion E) and the application of any relevant physical specifiers (facial features, physical size or head circumference restriction).
Values Do key stakeholders have different values and preferences about the diagnosis of FASD?		
	RESEARCH EVIDENCE	**ADDITIONAL CONSIDERATIONS**

○ Important uncertainty or variability ○ Possibly important uncertainty or variability ○ Probably no important uncertainty or variability ○ No important uncertainty of variability	Based on some of the Advisory Group and Public Consultation feedback collected on the draft versions of the documents it is possible there is variability in values and preferences about the diagnosis of FASD. With some people placing high value on a diagnosis of FASD and others not valuing diagnosis of FASD as highly. Advisory Group members shared a range of different experiences that informed these values and preferences. Values and preferences differed both within and between different key stakeholder groups. For instance, it is important to note that people with living experience have a diverse range of values and preferences that were communicated through the Advisory Group process. The importance of shared decision making with individuals and families has emerged as a critical practice approach in navigating differing values and preferences to ensure that individuals and families are provided with information and supported to make decisions for themselves based on their values and preferences.	It was also discussed how values could differ based on different service settings and how supports are accessed (e.g., diagnostic-based access vs needs-based access).

Resources required How large are the resource requirements (costs) to implement the diagnostic criteria?		
	RESEARCH EVIDENCE	**ADDITIONAL CONSIDERATIONS**
○ Large costs ○ Moderate costs ○ Negligible costs and saving ○ Moderate savings ○ Large	Overall, the diagnostic criteria and associated information took this into consideration and presents an assessment process that aims to engage and involve practitioners across a range of different settings to support resource limitations. This was supported by the results of the scoping review exploring resource implications and models of care (Kent et al., 2023). Results of this review highlighted benefits that can be conferred through models of care that capitalise on available services to improve accessibility and reduce costs. The GDG discussed that the resource requirements may vary based on a number of factors:	GDG discussed the need for targeted dissemination and implementation strategies to support practitioners in flexible ways to address the varying resource needs across different practitioners and settings.

savings o Varies o Don't know	1. Practitioners' current level of involvement with assessment and diagnosis of FASD – with those already having move involvement would have less resource requirements and those with less involvement having larger costs (e.g., upskilling, supervision, purchasing assessment tools). 2. Practitioners' current knowledge, skills and alignment with best practice approaches to assessment – with those already with more alignment having less resource requirements in terms of upskilling and professional development. 3. Requirements may vary across different disciplines – for instance across different medical professionals who are already more involved in assessments and across the different allied health disciplines. Another resource needs discussed were: • Costs associated with general dissemination and implementation supports – discussed need for further funding to support uptake of the new criteria. • Need to update training programs and resources. • Need to update clinic data capture processes.	
Certainty of evidence of required resources What is the certainty of the evidence of resource requirements (costs)?		
JUDGEMENT	**RESEARCH EVIDENCE**	**ADDITIONAL CONSIDERATIONS**
o Very low o Low o Moderate o High o No included studies	There was a very low number of available studies and variability in data, including lack of studies with formal costings and detailed information on available models of care to inform judgements in this area. No formal certainty assessments completed through the scoping review completed.	
Equity		

What would be the impact on health equity of implementing this set of diagnostic criteria?		
JUDGEMENT	**RESEARCH EVIDENCE**	**ADDITIONAL CONSIDERATIONS**
○Reduced ○ Probably reduced ○ Probably no impact ○ Probably increased ○Increased ○ Varies ○ Don't know	The GDG and the wider project had a strong focus on health equity through these diagnostic criteria. Specifically, the input from the Cultural Advisory Group and development of the Indigenous Framework and content was key. Further some specific key considerations that are aimed at improving health equity were: 1. Level of detail provided in the diagnostic criteria and associated information 2. Flexibility provided to support application of different assessment approaches for people from different cultural backgrounds. 3. Incorporation and encouragement of shared decision-making approaches 4. Approach regarding use of standardised assessment tools. 5. Consideration of assessment across the lifespan, with inclusion of special considerations for infants and young children and adolescents and adults. 6. An assessment process aimed at supporting accessibility – including across rural, regional and remote areas. Taken together, it is hoped that these changes will support practitioners to implement the diagnostic criteria more appropriately across different population groups in Australia, increasing health equity.	GDG discussed importance of monitoring and evaluation to directly assess impacts on health equity.
Acceptability Would this set of diagnostic criteria be acceptable to key stakeholders?		
JUDGEMENT	**RESEARCH EVIDENCE**	**ADDITIONAL CONSIDERATIONS**
○ No ○ Probably no ○ Probably yes ○ Yes ○ Varies ○ Don't know	Overall, the GDG have aimed to take a nuanced approach that considers risks of over-and-under-diagnosis that has been raised by Advisory Group members, consideration of different settings (e.g., rural/remote vs metro), differences across cultural groups and different stakeholder perspectives.	GDG discussed relevance of points here also covered in the strength of the association section above. GDG discussed need for targeted implementation resources for different stakeholder groups could

	Based on some of the Advisory Group and Public Consultation feedback collected on the draft versions of the documents it is possible that there may be differences in acceptability of the diagnostic criteria. Specifically, it appears that some people have different views regarding the PAE threshold for diagnosis, believing that low levels of PAE should be included in the diagnostic criteria. Based on some of the information received during public consultation, it is possible that some of these differences in perspectives are based on differing interpretations of risk levels of PAE (i.e., some stakeholders interpreting low risk exposures that the evidence review and GDG would consider to be moderate risk exposures). The GDG have considered all the feedback that has been received throughout all phases of the project to create a risk assessment framework that is evidence-based, incorporates the AUDIT-C where possible and that is cognisant of feedback regarding wording and practicalities of the clinical context. Other Advisory Group and Public Consultation feedback highlighted how stakeholders valued the rigorous approach of the criteria, the level of detail provided, more comprehensive consideration of other exposures and considerations and increased consideration of culture and improvements regarding appropriateness of standardised assessment tools included in the diagnostic criteria. Another key area of difference in acceptability of stakeholders was regarding the use of standardised assessment tools. The GDG have heard the range of different perspectives raised through the project and have tried to balance the risks and benefits around information provided in the guidelines regarding standardised tools. The GDG have also tried to align the approaches in these guidelines with other neurodevelopmental conditions and best practice approaches in neurodevelopmental assessments. Overall, feedback collected through the Advisory Group and Public Consultation process indicates that the diagnostic criteria would probably be acceptable to key stakeholders. Revisions of the documents following Advisory Group and Public Consultation Feedback have hopefully helped to increase acceptability. However, the development of targeted implementation resources for different key stakeholder groups would be beneficial and increasing acceptability of the diagnostic criteria.	help better communicate information in different formats and help with acceptability. Also discussed need for monitoring and evaluation to directly assess acceptability.

Feasibility What would be the feasibility of using this set of criteria for practitioners?		
JUDGEMENT	**RESEARCH EVIDENCE**	**ADDITIONAL CONSIDERATIONS**
○ No ○ Probably no ○ Probably yes ○ Yes ○ Varies ○ Don't know	Overall, feedback collected through the Advisory Group and Public Consultation process indicated that the diagnostic criteria would likely be feasible to use. The GDG have undertaken a wide multi-stage consultation process and considered and responded to all the feedback that has been provided. Feedback from the majority of practitioners indicates that the criteria will be feasible to implement. The GDG took into consideration differences in ages of individuals attending for assessment, resource availability and practitioner and settings differences and issues that may influence feasibility. In line with the resource domain, it was discussed how it was evident through the feedback received through the public consultation that there are current differences in practice across practitioners, which likely influence feasibility of using the criteria. For practitioners whose approaches are already closely aligned with these criteria less changes to their practice are required compared to those who are currently less aligned with the criteria. A significant amount of additional information is provided to support practitioners in implementing the diagnostic criteria. This will also hopefully help practitioners to align their assessment practices more broadly.	As per other areas was discussed how ongoing monitoring and evaluation is required.
Adoption implications What are the downstream implications of adopting these new criteria? Likely to result in net benefit or harm? In terms of incidence/prevalence, benefits, harms, net benefit/harm.		
JUDGEMENT	**RESEARCH EVIDENCE**	**ADDITIONAL CONSIDERATIONS**

○Clear net benefit ○ Probable net benefit ○ Mixed benefit/harm ○ Clear net harm ○ No/trivial difference ○ Varies ○ Don't know	Based on feedback received through the Advisory Groups and public consultation there is currently variability in practice, making it challenging to accurately understand the adoption implications. The GDG discussed a wide range of potential risks and benefits when considering the implications of adopting these new criteria. Overall, it was decided that on the balance of these implications and additional information considerations there was a clear net benefit to implementing these guidelines over the current Guide. *Possible implications of including a minimum PAE threshold (Criterion A):* • Reduces harm of incorrect diagnosis for individuals with low levels of exposure. • Reduces harm of the distress that can currently be experienced by biological parents through messaging that any level of alcohol results in FASD. • Reduces inappropriate referrals for specialist assessments where there are low levels of PAE, leading to better use of limited health resources. • Risk that practitioners rigidly apply information regarding standard drinks as 'clinical cut offs' for referrals or diagnosis, which is not the intended use of this information. This could result in missed diagnoses, reducing incidence/prevalence. • Risk of inaccurate information regarding PAE is used for assessment of risk – for a variety of reasons could lead to increased or reduced incidence/prevalence. • Risks in terms of public health messaging – misinterpreting information to believe that the guidelines are saying it is safe to drink during pregnancy. Although this is uncertain as it is also possible that provision of evidence-based information could lead to improvements in public health messaging as some research has found some women find the current public health messages unhelpful • Discussed how it is also unknown the impacts on incidence and prevalence due to differences in current practices i.e., how many practitioners were actually diagnosing FASD at low levels of PAE vs how many practitioners were already not doing this? *Possible implications of criterion regarding facial features assessment (Criterion A):* • Wording of 'may be considered sufficient' is used to indicate that facial features assessment is not a mandatory part of the assessment. Based on concerns raised regarding the inappropriateness of currently available tools and norms for culturally diverse population groups in Australia. Hopefully leading to more client-	As highlighted above need for monitoring and evaluation. Need for further feedback from practitioners and other stakeholders. Discussed in the context of comparison to previous guide. Foundation of evidence and information included in these guidelines provides n platform for going forward. Discussed how the adoption implications will be dependent on the use of the guidelines in the way they are written and intended. Discussed how there are differences across different areas – e.g. disagreement in certain areas and not in other areas and how this may influence adoption. Discussed rigorous GRADE process and consultation process strengthened this domain.

	centred/individualised and culturally responsive assessment approaches (Hewlett et al., 2023; Indigenous Framework). • GDG discussed that it is currently unknown regarding the impacts on incidence and prevalence of this change – could lead to reductions if an individual had all three facial features and was not identified but also, we do not currently understand the impacts of current facial features assessment tools and norms for people from different cultural backgrounds – could lead to increases or reductions in incidence and prevalence. *Possible implications of criterion regarding neurodevelopmental impairments (Criterion B):* • Directions for practitioners to use standardised assessments where appropriate leading to more client-centred/individualised and culturally responsive assessment approaches and ultimately more accurate diagnostic outcomes for Australians. • GDG discussed how it is uncertain regarding the potential impacts on incidence and prevalence. For practitioners who are not currently applying confidence intervals and use of clinical judgement in diagnostic decision-making regarding diagnostic cut offs (i.e., inflexibly applying a 2SD cut off), may result in increased incidence/prevalence of diagnosis. However, other changes and additional information (e.g., how academic achievement is considered, reducing inappropriate use of standardised tools) could reduce incidence/prevalence. • A percentile range is provided to support practitioners in their diagnostic decision making, which is a more appropriate statistical approach to consideration of standardised assessment results and brings FASD more in line with best practice assessment practices more broadly. • GDG hopes that the increased level of detail provided in the diagnostic criteria and associated information leads to less false positives and increased inter-rater reliability for future evaluations. *Possible implications of criterion regarding an individual's presentation not being better attributed to another condition or exposure (Criterion E).*	

	• Improves accuracy of FASD diagnoses through rigorous consideration of other conditions or exposures. • Discussed how interactions between trauma and FASD are not unique to FASD – is a consideration across all neurodevelopmental conditions. Whilst some information is provided, there is the need for practitioners to have better understanding of trauma, which is outside the scope of these guidelines – separate upskilling required for practitioners and clinical supervision. • This criterion and associated information highlights importance of interprofessional assessments and how this supports consideration of other exposures and conditions. • This criterion highlights the importance of considering the whole person in the assessment process, not just focusing on PAE or anything else in isolation. *Possible implications of inclusion of specifiers:* • Provides detailed clinically meaningful information about physical features associated with PAE. Can help increase certainty that PAE has played a role in the outcomes. • Encourages documentation of the full range of physical features that individuals may experience. • Documentation in this way has potential to improve clinical care and research. • Risk – may lead people to believe that these are not as important part of the assessment process. Information is provided to help mitigate this risk. *Possible implications of inclusion of associated features structure:* • Allows capture of the wide range of features that may be associated with PAE, but there was currently not enough evidence to include in the diagnostic criteria. • May enable future research to better understand potential associations of these features/conditions with PAE. • Holistic perspective – whole person approach to understanding	

	Possible implications of co-occurring conditions: • Highlights the importance of assessment considering a wide range of co-occurring conditions, which are highly prevalent with FASD, which may improve recommendations and supports for individuals.	

SUMMARY OF JUDGEMENTS

	JUDGEMENT						
PROBLEM/PRIORITY	No	Probably No	Probably Yes	**Yes**		Varies	Don't know
STRENGTH OF ASSOCIATION	Trivial	Small	Moderate	Large		**Varies**	Don't know
CERTAINTY OF EVIDENCE	Very low	Low	Moderate	High		**Varies**	No included studies

	JUDGEMENT						
VALUES	Important uncertainty or variability	**Possibly important uncertainty or variability**	Probably no important uncertainty or variability	No important uncertainty or variability			
RESOURCES REQUIRED	Large costs	Moderate costs	Negligible costs and savings	Moderate savings	Large savings	**Varies**	Don't know
CERTAINTY OF EVIDENCE OF REQUIRED RESOURCES	Very low	Low	Moderate	High			**No included studies**
EQUITY	Reduced	Probably reduced	Probably no impact	**Probably increased**	Increased	Varies	Don't know
ACCEPTABILITY	No	Probably no	**Probably yes**	Yes		Varies	Don't know
FEASIBILITY	No	Probably no	Probably yes	**Yes**		Varies	Don't know
ADOPTION IMPLICATIONS	Clear net harm	No/trivial differences	Mixed benefit/harm	Probable net benefit	**Clear net benefit**	Varies	Don't know

TYPE OF RECOMMENDATION

Strong recommendation against	Conditional recommendation against the	**Conditional recommendation for**	Strong recommendation for
○	○	○	○

CONCLUSIONS

Recommendation

The Australian FASD Guidelines Development Group suggests the following key diagnostic considerations:

- evidence of prenatal alcohol exposure above a low risk level for diagnosis of FASD at any time during gestation. Or, in the absence of a confirmed history of PAE following exclusion of other causes, the presence of three sentinel facial features (short palpebral fissures, thin upper lip and smooth philtrum)
- presence of pervasive and clinically significant neurodevelopmental impairments
- the neurodevelopmental impairments result in functional impacts that necessitate significant supports across multiple areas
- the onset of neurodevelopmental impairments is evident during the developmental period
- an individual's presentation is not better attributed to another condition or exposure

any of the relevant diagnostic specifiers are applied (i.e., physical size, head circumference and/or facial features) (Variable Certainty).

Justification

This process considered all the evidence compiled through each of the individual evidence-to-decision frameworks to provide an overall recommendation regarding diagnostic features to be considered for diagnosis of FASD.

Subgroup considerations

Wording of the diagnostic criteria has been carefully considered to support equity for people from culturally and linguistically diverse backgrounds, including First Nations Australians. For example, including assessment of physical features and use of standardised tests. See the additional information section following the diagnostic criteria for detailed information regarding this.

Implementation considerations

Extensive additional information and resources and provided in the main guidelines document to support practitioners with implementing the diagnostic criteria in clinical practice.

Research priorities

Research is needed to understand all the possible adoption implications discussed above regarding these diagnostic criteria. Research is also needed to understand the long-term outcomes for individuals diagnosed with FASD.

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

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

- 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 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 ☐
Biological parent/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 six or more standard drinks on one occasion? 0 Never 1 Less than monthly 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.

Note. Question 3 of the AUDIT-C is consistent with the original AUDIT-C, which was developed in Australia where the standard drink size is 10 grams of ethanol, 6 or more standard drinks refers to an intake of 60 grams or more. Practitioners may have seen other versions of the AUDIT-C where this question is 5 or more drinks, which is based on U.S standard drink sizes of 12 to 14 grams of ethanol (Dawson et al 2005).

The AUDIT-C risk categories included here and in Figure 9 (p. 57) are based on an evidence review completed by Goldman and colleagues (2017) regarding the use of the AUDIT-C with pregnant Australian women.

References

Dawson DA, Grant BF, Stinson FS, Zhou Y. Effectiveness of the derived Alcohol Use Disorders Identification Test (AUDIT-C) in screening for alcohol use disorders and risk drinking in the US general population. Alcohol: Clinical and Experimental Research. 2005;29(5):844-54.

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 ☐
Biological parent/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

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

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

Postnatal	Date	Age	Head circumference (cm)	Percentile

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

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 & height (if available)	
Current weight & height	
Associated features	
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.

Diagnostic Criteria Summary

Criteria	**Summary**
Criterion A: More than low risk exposure or presence of three sentinel facial features.	
Criterion B: Presence of pervasive and clinically significant neurodevelopmental impairments.	
Criterion C: The neurodevelopmental impairments necessitate significant supports.	
Criterion D: Onset of neurodevelopmental impairments is in developmental period.	
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 features (i.e., 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], sensory processing challenges, social cognition impairments, social communication/pragmatics, motor speech or speech-sound impairments.	

Diagnosis

☐ Meets criteria

☐ Does not meet criteria

☐ At risk of FASD

☐ Incomplete assessment i.e., further investigations needed.

Co-occurring conditions

☐ Attention deficit hyperactivity disorder

☐ Intellectual developmental 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.

Practitioners can use locally developed resources/visuals to support meaningful collaborative engagement in a goal setting process for individuals and families attending for assessment. There are also a range of goal setting tools that can be used and adapted as appropriate to support the 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

Australian Guidelines for Assessment and Diagnosis of Fetal Alcohol Spectrum Disorder

A PLAIN ENGLISH GUIDE TO READING THE GUIDELINES

Introduction

In 2025, the **Australian FASD Guidelines Consortium** published the *Australian Guidelines for Assessment and Diagnosis of Fetal Alcohol Spectrum Disorder (FASD)*. This is a revision and update of the Australian Guide for the Diagnosis of FASD released in 2016. The ultimate goal of the new Guidelines is to improve assessment and diagnostic services for FASD in Australia.

This document aims to provide an easy-to-read summary of some of the key information in the full guidelines document.

What is FASD?

- FASD can develop from prenatal alcohol exposure.
- Prenatal alcohol exposure can occur at any time during pregnancy, even before a person realises they are pregnant.
- Prenatal alcohol can impact the development of a baby's brain and body.
- This can lead to challenges relating to:
  - Learning
  - Behaviour
  - Mental health
  - Physical health

Why are these Guidelines needed?

- Early diagnosis is crucial for individuals with FASD and their families.
- Recognition and support can help support challenges associated with FASD.
- Clear, evidence-based guidelines are needed to support accurate identification of FASD.
- Good guidelines should:
  - **Assist** healthcare workers in delivering effective care
  - **Help** clients understand complicated information
  - **Enable** practical, individualised advice and recommendations.

How were the guidelines developed?

Good guidelines are created by carefully reviewing all the latest research on a topic. The development of good guidelines also requires the opinions of a variety of people; including experts in the field, those who use the services, and those with lived experience. In Australia we have strict standards that should be followed in developing guidelines.

Our Objective?
To bring together the best available evidence, lived experience voices, cultural and clinical wisdom to develop Australian clinical practice guidelines for the assessment and diagnosis of FASD.

Review of international guidelines

- To create new Australian Guidelines, we wanted to understand how other countries diagnosed FASD.
- We reviewed existing diagnostic guidelines from Canada, Germany, Scotland, and the United States.
- We examined the reasoning and evidence that informed their decisions.

Advisory Group input: Who was involved?

- Paediatricians
- Registered Nurses
- Psychologists & Psychiatrists
- Speech Pathologists
- Occupational Therapists
- Geneticists
- Public Health Experts
- Social Workers
- Researchers
- First Nations Elders and leaders
- Carers and Parents
- Individuals with FASD

Evidence review process

We reviewed evidence from different parts of the FASD diagnostic process. This followed the strict standards of the National Health and Medical Research Council (NHMRC).

- We created four research questions relating to **current criteria**, **lived experiences, holistic considerations,** and **costs & resource implications.**
- Performed a big literature search addressing these questions.
- Determined the quality of the research.
- Assessed the findings of the evidence and their certainty.
- Developed evidence to decision frameworks to help combine science and practice.
- Developed actionable statements for clinicians (i.e., recommendations).
- Consulted with the public and received independent expert review.
- Finalised the Guidelines and submitted to the NHMRC for review.

Actionable Statements Guideline Recommendations

These statements aim to optimise assessment and diagnosis for individuals and their families.

Strong Recommendations

- The recommended course of action will benefit most individuals.
- Uses the term **'Recommends'**

Conditional Recommendations

- The recommended course of action may not apply to all individuals.
- Uses the term **'Suggests'**

1 What does the science say? (GRADE-Based Recommendations)

- Based on the review and analysis of scientific evidence.
- Provides direct links between diagnostic criteria and scientific evidence.
- Example recommendation: We **suggest** that physical size should be considered as part of the assessment for FASD.

What is GRADE?

Grading of **R**ecommendations, **A**ssessment, **D**evelopment and **E**valuation

- Framework for creating and sharing summaries of evidence.
- Helps to make clinical practice recommendations.

2 What do people with lived experience say? (Lived Experience Statements)

- Based on the review and analysis of scientific evidence.
- Provides guidance from the point-of-view of people with lived experience of FASD.
- Statements frequently relate to the need for non-judgemental and respectful care.
- Example: The concerns of parents and caregivers should be listened to and taken seriously.

3 What is Best Practice? (Good Practice Statements)

- These statements aim to support practitioners in applying the evidence-based statements.
- Created based on input from the Advisory Groups.
- Statements frequently relate to how to sensitively and accurately assess prenatal alcohol exposure, interpreting results, and coming to decisions about diagnoses.
- Example: assessments should use a family-centred approach that considers strengths and challenges. Collaborate with family members and tailor assessment plans to individual needs.

4 How can we Implement this? (Implementation, tools & tips)

- Created with advice from the Advisory Groups to help practitioners put the other recommendations into practice.
- This includes resources relating to shared-decision making, culturally responsive care, respect and communication, and information to aid with data collection and assessment.

Final Thoughts

The purpose of this summary was to help individuals with FASD and their families learn more about the new Guidelines. We hope that these new Guidelines can guide further research, promote the uptake of evidence-based care, and ultimately enable early and efficient diagnosis and support for individuals with FASD and their families.

Acknowledgments:
We would like to acknowledge all people in Australia living with FASD. We hope these guidelines respect and honour people's diverse experiences, enhance assessment and diagnostic practices, reduce stigma, and improve the quality of life for all people living with FASD in Australia.

We would also like to acknowledge everyone involved in the development of these new Guidelines. Thank you for your hard work, support and dedication throughout this process.

Want to learn more? Links to available guidelines documents

- Main Guidelines Document - Full Version
- Main Guidelines Document - Short Version

- Administrative and Technical Report
- Dissemination, Implementation, and Evaluation Report
- FASD Indigenous Framework

- Summary of Actionable Statements (Recommendations)
- Assessment Principles and Diagnostic Criteria
- Summary of Changes from the 2016 Guide to FASD Diagnosis

- Technical Report - Diagnostic Criteria Components
- Technical Report - Lived Experiences
- Technical Report - Holistic Assessment
- Technical Report - Resource Implications and Models of Care.

This summary was prepared by Chelsea Vanderpeet and Dr. Natasha Reid, Child Health Research Centre, The University of Queensland

Appendix G: Links to Associated Documents

- Indigenous Framework
- Frequently Asked Questions
- A Plan English Guide to Reading the Guidelines
- Main Guidelines Document – Brief Version
- Summary of Actionable Statements
- Summary of Changes from the 2016 Guide
- Assessment Principles and Diagnostic Criteria
- Administrative and Technical Report
- Dissemination, Implementation, and Evaluation Report
- Lived experiences of the assessment and diagnostic process: Systematic review and qualitative synthesis report
- Factors to be considered as part of a holistic assessment: Scoping review report
- Exploring resource implications and models of care: Scoping review report
- Association between prenatal alcohol exposure, physical size, dysmorphology and neurodevelopment: Systematic review report
- Supplemental File A: Study exclusion list
- Supplemental File B: Risk of bias assessment
- Supplemental File C: Physical size GRADE ratings and forest plots
- Supplemental File D: Regression summaries
- Supplemental File E: Dysmorphology GRADE ratings and forest plots
- Supplemental File F: Functional neurodevelopmental GRADE ratings and forest plots
- Supplemental File G: Structural and neurological GRADE ratings and forest plots

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