

Lived Experience of FASD Diagnostic Assessment

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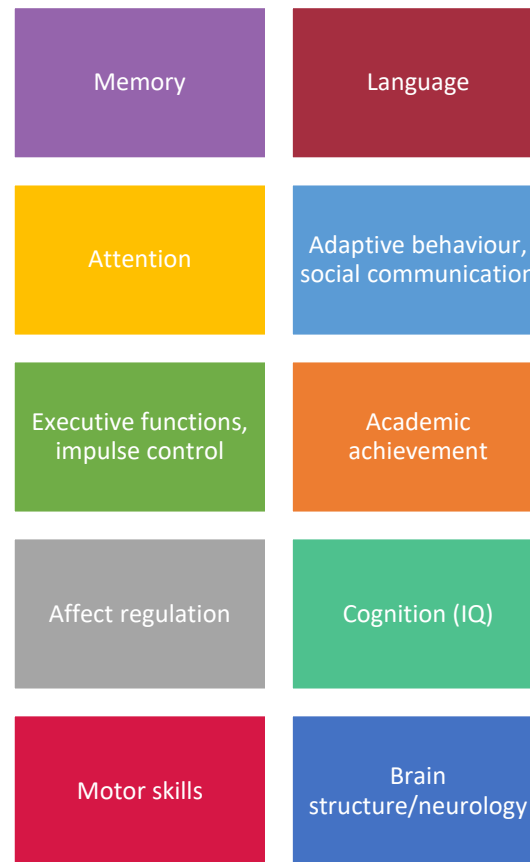
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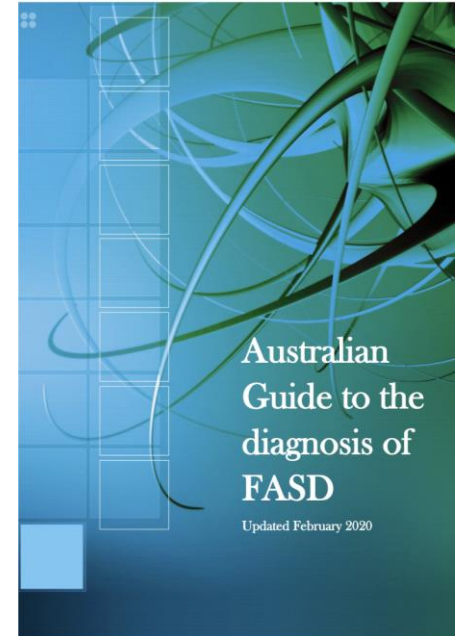
What is FASD?

- Fetal Alcohol Spectrum Disorder (FAS-D) is a lifelong cognitive disability
- Alcohol can impact the developing brain and body in lots of different ways.
- Some (not all) people with FASD have an intellectual disability
- Affects 2-5% of the population
- No blame, no shame



This presentation

- A systematic review on the lived experience of FASD diagnosis.
- Project- to review, revise and update the **Australian Guide to the Diagnosis of FASD**
- This guide is what Australian health professionals use when assessing for a diagnosis of FASD
- A FASD assessment requires a Multidisciplinary team
- The project team includes FASD researchers and health professionals across Australia



The project brings together a range of knowledge, experience and evidence:



Lived Experience Voices



Cultural knowledge



Clinical Wisdom

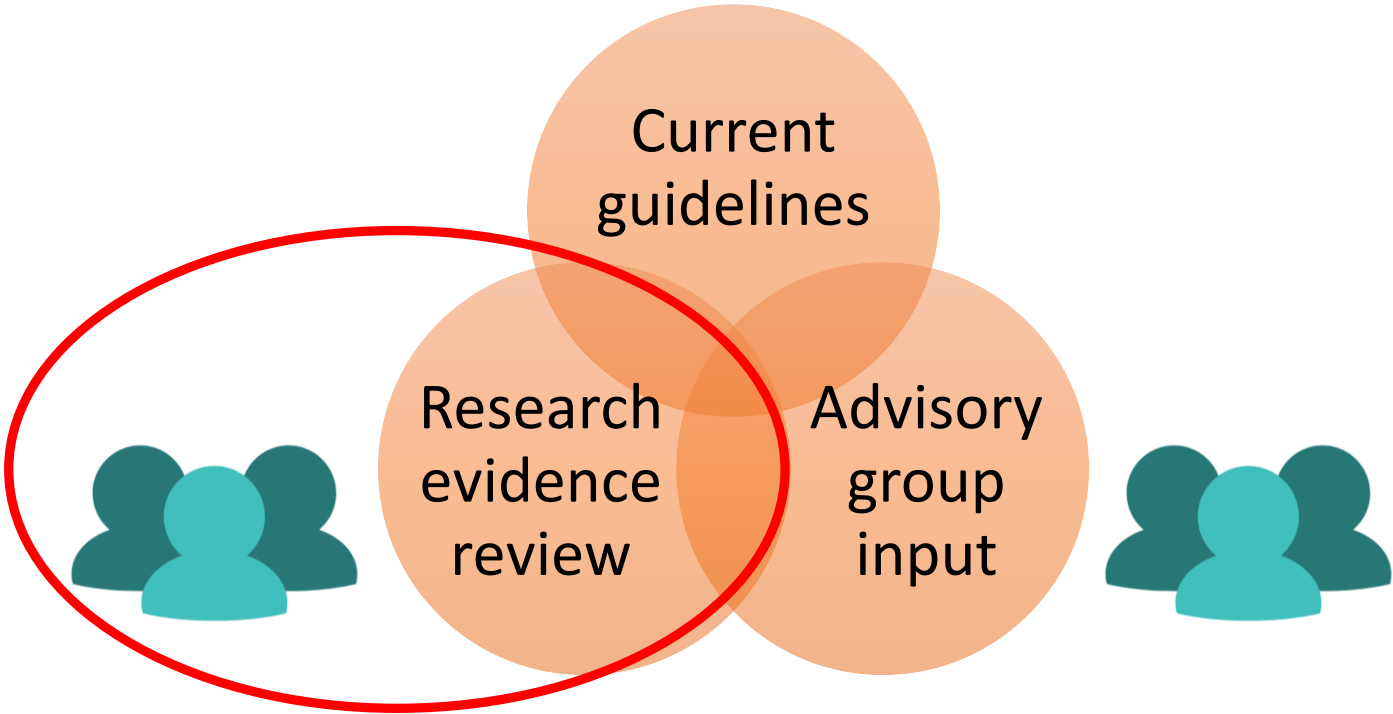


Research evidence

Key Review Components



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Systematic Review on lived experience

Aim: To identify and understand the lived experience of the diagnostic assessment for FASD.

Purpose: To inform the update of the Australian Guide to the Diagnosis of FASD

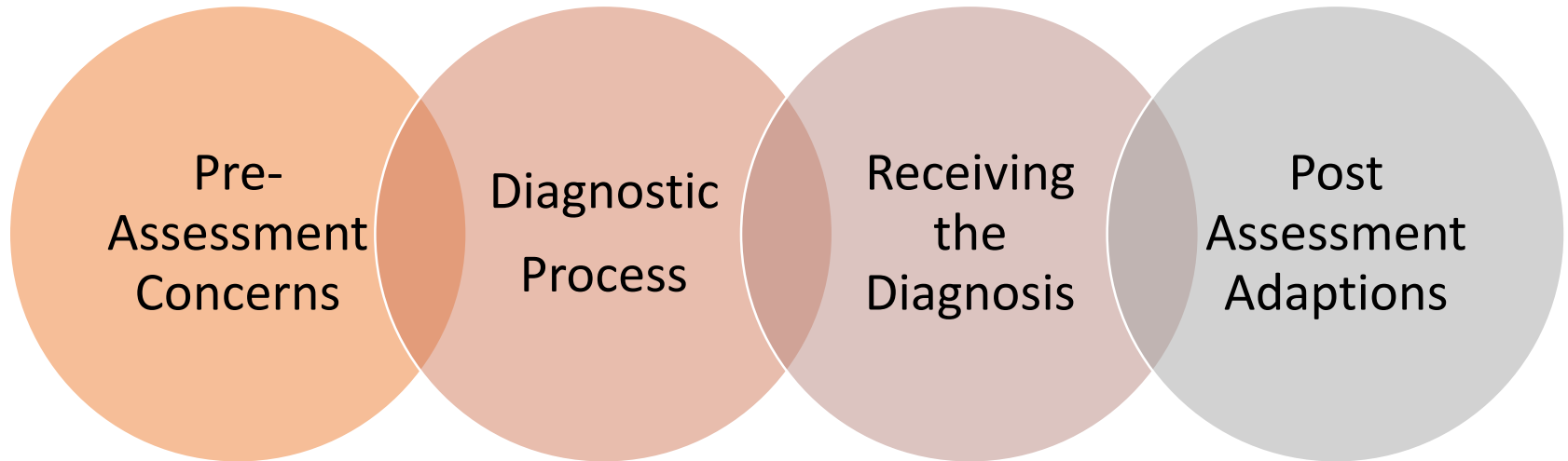
Systematic search of databases: PubMed, the Cochrane Library, CINAHL, EMBASE, PsychINFO, Web of Science

Criteria: (1) were published in English; (2) reported qualitative or mixed methods primary research; (3) reported lived experiences of individuals and/or caregivers of individuals with FASD; (4) reported experiences of diagnostic assessment for FASD or receipt of a diagnosis of FASD.

The systematic review:

- 10 studies met inclusion criteria
- Countries covered: Australia (3), Canada (4), USA (1), NZ (1), UK (1)
- The studies reported on the lived experiences of:
 - Parents and carers of children and young people (7)
 - Biological mothers (2)
 - Indigenous caregivers (1)
 - Adults with FASD (1)

Overarching themes



1. Pre-Assessment Concerns and Challenges

Sub theme: Caregiver* recognition and help seeking for child's challenges

- Assessment journey typically commenced when caregivers recognised behavioural differences and challenges that prompted them to seek help
- In younger children: delayed developmental milestones and sleep problems

*Caregiver includes parents and/or carers.

Sub theme: Dismissal of caregiver's concerns by health professionals

- Caregivers reported accessing numerous services for their child's behavioural concerns but perceived these to be unhelpful and in some cases negative
- Caregivers reported that their concerns about FASD were dismissed by health professionals.
- Caregivers reported feeling judged about their parenting style and said their child's difficulties were often attributed to family or environmental factors

Sub theme: FASD not considered or acknowledged

- Carers reported that FASD was often not considered as a possible diagnostic outcome, even when prenatal alcohol exposure was reported.
- They often received assessments for other conditions.
- Biological mothers who reported alcohol consumption during pregnancy said that health professionals refused to acknowledge FASD and described the label as associated with guilt and stigma for families.

2. Diagnostic Assessment Process

Sub theme: Limited availability of diagnostic assessment services

- Accessing assessment and diagnostic services was difficult due to limited providers and long wait-lists.
- Caregivers reported limited access to health professionals skilled in FASD Diagnosis.

Sub theme: A safe and supportive environment without judgement is validating and empowering

- Caregivers reported positive experiences and feelings of empowerment when attending a specialist FASD service.
- Clinicians from specialist FASD Clinics were described as, welcoming, helpful, reassuring, and respectful without being judgmental or stigmatizing.
- Biological mothers reported feeling accepted and did not feel blame from staff.

Sub theme: Strengths-based diagnostic reports are a valuable resource

- Diagnostic reports were noted as a valuable resource to help caregivers and others working with their child to understand strengths and challenges.
- Practical strengths-based strategies were particularly valued
- Caregivers also reported benefits of a feedback session to schools provided by FASD diagnostic clinic staff

3. Receiving the Diagnosis

Sub theme: Mixed emotions and improved insight

- Caregivers had mixed feelings including a sense of relief, hope, and confidence, as well as grief, hopelessness, guilt, and shame.
- The diagnosis also provided improved understanding and insight
- Adults said diagnosis allowed them to have fewer negative feelings about themselves, because in the past they had experienced guilt and sometimes blamed themselves for the problems they experienced.

Sub Theme: Diagnosis is a means to receive appropriate and tailored support

- A means to financial and therapeutic and social support.
- The diagnosis was important in promoting advocacy for and access to additional support within the education system for school aged children.
- Adults with FASD reported receiving greater support from family members and employers.
- There were cultural differences. Non-Aboriginal Australian caregivers spoke of hope for more institutional assistance from schools and the healthcare system. Aboriginal Australian caregivers anticipated support needs would be met within the context of family and community.

4. Post assessment adaptations and needs

Sub theme: Aspirations and apprehensions about the future

- Caregivers reported that the diagnosis helped them to understand their child's capabilities and be more empathic and make accommodations to assist their child.
- They expressed aspirations for a fulfilling life for their child with appropriate support from family, friends and services.
- At the same time, caregivers expressed apprehension about their child's future, acknowledging uncertainties related to ongoing difficulties.

Sub theme: Accessing supports and services

- Identified barriers to getting support included a lack of FASD informed services providers, and family work commitments, financial strain and stress.
- Some caregivers reported feeling stigmatised and isolated from their community due to a lack of understanding about their child's behaviours leading to social exclusion (e.g. playdates).
- Caregivers reported accessing helpful supports for themselves such as parent/carer support groups and ADHD medication and help with sleep problems for their children.

Where to from here?

The results from this systematic review will be fed back to the Guideline Development Group.

This evidence will contribute to recommendations regarding:

- Screening and referrals
- Intake
- The assessment process
- Post diagnostic support

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Hayes, N., Bagley, K., Hewlett, N., Elliott, E.J., Pestell, C.F., Gullo, M.J. et al. (2023) Lived experiences of the diagnostic assessment process for fetal alcohol spectrum disorder: A systematic review of qualitative evidence. *Alcohol: Clinical and Experimental Research*, 47, 1209–1223.



Thank you!