

*FASD HUB AUSTRALIA: SUBMISSION TO
THE INQUIRY INTO THE HEALTH
IMPACTS OF ALCOHOL AND OTHER
DRUGS IN AUSTRALIA*

FASD Hub Australia

The [FASD Hub Australia](#) (FASD Hub) is the leading source of evidence-based content about the prevention, assessment, diagnosis, and management of Fetal Alcohol Spectrum Disorder (FASD) and alcohol use in pregnancy in Australia.

Core content hosted on the FASD Hub website includes *The Australian Guide to the Diagnosis of FASD* and its associated eLearning course, over 150 resources, over 400 Australian research papers and reports, and the FASD Hub Service Directory, which links families with FASD-informed clinicians across Australia.

Identified as a key priority by the FASD Technical Network and included in the *Strategy to address diagnosis, management and prevention of FASD 2013-2016*, the FASD Hub was funded by the Federal Department of Health in 2016, launching in September 2017 under the leadership of Professor Elizabeth Elliott AM and Professor Carol Bower AC.

A critical piece of digital infrastructure, the Hub is relied upon by health professionals, researchers, policymakers, educators, people living with FASD and their families, Aboriginal and Torres Strait Islander Communities, and women who are pregnant, planning pregnancy or breastfeeding. Our recently published User Evaluation showed that the FASD Hub is widely utilised and accessible and that 92% of respondents agreed that the information on the website is trustworthy and authoritative.

In the past reporting year, the FASD Hub attracted 177,820 views and 55,263 users; 1,300 webinar registrants; and the mailing list of users now exceeds 2,700 people, providing an exceptional return on investment, despite significant underfunding compared to other websites of similar calibre.

The FASD Hub is funded by the Australian Department of Health and Aged Care until July 2026.



This submission to the 'Inquiry into the health impacts of alcohol and other drugs in Australia' was prepared by [Professor Elizabeth Elliott](#) and [Ms Kate Harford](#).

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Professor Elliott is available to be a witness to the Committee, if required

We acknowledge Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of the land and waters of Australia, and pay our respects to Elders past, present and emerging.

Executive Summary

The focus of this submission is to demonstrate the role of the FASD Hub Australia in addressing alcohol harms in pregnancy and FASD in Australia.

Alcohol is a teratogen (toxic to the developing embryo and fetus). When alcohol is consumed during pregnancy it readily crosses the placenta and may disrupt the normal growth and development of the baby's brain and other organs. Prenatal alcohol exposure (PAE) can cause miscarriage, stillbirth, premature birth, low birth weight, birth defects and Fetal Alcohol Spectrum Disorder.

FASD is the diagnostic term for the severe neurodevelopmental impairments due to the brain damage caused by PAE. Critically under recognised and often misdiagnosed, it is estimated that between 2-4% of people in Australia have FASD – a higher prevalence than Autism Spectrum Disorder, Down Syndrome or Cerebral Palsy.

FASD occurs in all parts of Australian society – wherever alcohol is consumed. Whilst prevention of FASD must remain the primary goal – and gains are being made because of successful health promotion campaigns and changing social norms – it is important to note that FASD will likely never be eliminated.

The FASD Hub provides evidence-based information and resources to enable health professionals to recognise and manage alcohol use in pregnancy and FASD; inform service development and prevention policy; showcase Australian research; and facilitate access to FASD-informed services.

The recent response by the Australian Government to *the Senate Community Affairs References Committee report: Effective approaches to prevention, diagnosis and support for FASD (2020)*, acknowledges the FASD Hub as a critical piece of established infrastructure to support ongoing work to address FASD nationally.

The FASD Hub fulfils the following roles in relation to the four terms of reference of this inquiry:

- A) *Assess whether current services across the alcohol and other drugs sector are delivering equity for all Australians, value for money, and the best outcomes for individuals, their families, and society.*

The FASD Hub is freely available to all Australians, represents exceptional value for money, and promotes the best health outcomes for individuals, their families and society through its work to host and disseminate the latest evidence-based research, resources and professional development opportunities about alcohol and pregnancy and FASD in Australia.

- B) *Examine the effectiveness of current programs and initiatives across all jurisdictions to improve prevention and reduction of alcohol and other drug-related health, social and economic harms, including in relation to identified priority populations and ensuring equity of access for all Australians to relevant treatment and prevention services.*

The FASD Hub hosts information about the harms and lifelong consequences of FASD and evidence-based prevention strategies for health professionals, researchers, policymakers, educators, people living with FASD and their families, Aboriginal and Torres Strait Islander Communities, justice professionals, and women who are pregnant, planning pregnancy or breastfeeding.

- C) *Examine how sectors beyond health, including for example education, employment, justice, social services and housing can contribute to prevention, early intervention, recovery and reduction of alcohol and other drug-related harms in Australia.*

The FASD Hub provides tailored content relevant to educators, justice professionals, alcohol and other drug workers, and allied health professionals aimed at the prevention and management of FASD. These stakeholders have expressed demand for more tailored content and learning opportunities such as webinars.

- D) *Draw on domestic and international policy experiences and best practice, where appropriate.*

The FASD Hub primarily provides a repository of Australian policy documents, but also links to key international documents such as the World Health Organisation's *Guidelines for identification and management of substance use and substance use disorders in pregnancy*.

Recommendations

1. That the Department of Health and Aged Care provide secure, ongoing and enhanced funding for the FASD Hub Australia infrastructure to enable it to:
 - Continue to increase capacity of the health workforce to screen for and identify FASD and provide early intervention to improve long term outcomes.
 - Disseminate the revised Australian guidelines for the diagnosis of FASD and its associated eLearning course and update relevant content on the web.
 - Showcase and disseminate Australian research, resources and reports.
 - Increase the number of FASD-informed health professionals listed on the FASD Hub Service Directory, to improve access to assessment, diagnostic and management services for families and people with FASD.
 - Amplify prevention messaging to key stakeholders including health and other professionals and people planning a pregnancy, who are pregnant, or breastfeeding.
2. That the relevant federal and state governments ensure that funding is provided at appropriate levels and enhanced as required for other critical Australian infrastructure including the FASD Australian Registry (FASDAR) (fasdregistry.org.au), the National Organisation for FASD (NOFASD) Australia (nofasd.org.au), the Every Moment Matters and Strong Born national public health campaigns (everymomentmatters.org.au), and Learning with FASD (learningwithfasd.org.au).

Introduction

There is no known 'safe' level or time for alcohol consumption during pregnancy, which is why the NHMRC's *Australian guidelines to reduce health risks from drinking alcohol* recommend that 'women who are pregnant or planning a pregnancy should *not* drink alcohol.'

In Australia, about 60% of pregnant women report consuming alcohol. Although most stop drinking once they know they are pregnant, some continue to consume alcohol for a variety of reasons including societal expectations, socio-economic disadvantage, alcohol dependency, historic trauma and mental ill-health.

The goal of governments, communities, health and other professionals, researchers and teachers should be to educate and support women (and their families) to have alcohol-free pregnancies. Although FASD is potentially preventable, it is unlikely to ever be eliminated. It is therefore imperative that the infrastructure to assess, diagnose and support individuals living with FASD and their families to thrive is expanded, adequately funded, and secured for the future.

Global WHO data estimate that about 1% of the general population has FASD, though rates are highly variable. In countries like Australia, the US and Canada, the estimated prevalence of FASD is between 2-5%, or about one child in every classroom.

In certain groups, higher rates of FASD have been documented, including people living in out of home care and institutions, justice settings, and some Aboriginal Communities.

According to data from the Australian Paediatric Surveillance Unit (APSU) and the FASDAR at 27/08/2024, the average child with FASD in Australia is:

- Confirmed to have PAE, mostly at a high level (97%)
- Diagnosed at 8.8 years of age (FASDAR data is children aged <15-years)
- Male (66%)
- Indigenous (55% compared to 3% of the general population)
- One of several affected siblings (19%)
- In contact with child protection services (75%)

There is an over-representation of children with FASD who are:

- Living in WA (26% compared to 11% of the general population)
- Living in remote or very remote regions (19% compared to 2% of the general population)
- Not living with a biological parent (78%)

The 'spectrum' of FASD includes a wide variation in the type and severity of impairments. Although use of the word 'fetal' may imply that the disorder relates only to babies, the effects of FASD may not be seen at birth. FASD is a lifelong condition that can be diagnosed in children, young people and adults.

People with FASD have a range of health, mental health, learning and behavioural problems associated with PAE. These include intellectual disability, a variety of birth defects (renal and congenital heart defects, cleft lip and palate, problems with hearing and vision) and sleep disorder.

FASD may co-occur with other diagnoses, including intellectual disability, conduct disorder, Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), specific learning disorders and mental health problems (e.g. anxiety and depression). These may be a direct result of PAE but may also have a genetic component or be secondary to the challenges faced by people with FASD.

People with FASD have many hopes and dreams and families and friends who want the best for them. As a society we must prioritise FASD assessment, diagnosis and ongoing support to ensure people with FASD and their families are given all they require to thrive.

Why is a FASD diagnosis important?

Making a diagnosis of FASD is a complex and time-consuming process, and a limited number of Australian health professionals feel competent or confident to complete an assessment. Some people question why a diagnosis for FASD is important when there is a potential for stigma for the mother and child; there are too few services and supports for people with FASD; and children may already have alternative diagnoses such as ADHD or ASD.

However, people living with FASD and their families say that an accurate diagnosis is important because it helps them understand their unique challenges and strengths, and to access the services and supports needed to achieve the best outcomes. Without early diagnosis, intervention, and tailored support, people with FASD are at risk of school disengagement, drug and alcohol use, mental ill-health, unemployment, and engagement with the justice system, as both victims and offenders.

An early diagnosis may also help prevent another alcohol-exposed pregnancy.

Addressing the *Submission to the Inquiry into the health impacts of alcohol and other drugs in Australia*'s Terms of Reference:

A) Assess whether current services across the alcohol and other drugs sector is delivering equity for all Australians, value for money, and the best outcomes for individuals, their families, and society.

The FASD Hub offers a strong return on investment

The FASD Hub is freely available to all Australians, represents value for money and promotes the best health outcomes for individuals, their families and society.

The FASD Hub is a valued and trusted source of information about FASD in Australia. It is used by a wide range of health professionals, researchers and policy makers and by people living with FASD.

In the last reporting year, the FASD Hub attracted 177,820 views with 55,263 users, demonstrating continued growth from previous years. At present the FASD Hub has over 2,700 engaged newsletter subscribers, strong organic search engine optimisation and brand recognition.

Core content hosted on the FASD Hub website includes:

- *The Australian Guide to the Diagnosis of FASD.*
- 150+ educational resources on different topics and catering to different audiences.
- 400+ Australian research publications and reports.
- *The FASD Hub Service Directory* which links families with FASD-informed clinicians across Australia.
- *The FASD Hub eLearning course* which aligns to *The Australian Guide to Diagnosis of FASD.*

Given the reliance by health professionals and the general public on the internet for the latest information about alcohol and pregnancy and FASD, it is important that websites like the FASD Hub are easily accessible, and that content is relevant, trusted and evidence-based.

An evaluation of the FASD Hub published in *Drug and Alcohol Review* in May 2024 found that the FASD Hub is widely utilised and accessible. Of survey respondents, 92% agreed that information on the website was trustworthy and authoritative. Most participants in the survey were from Australia (95%) and were likely or very likely to recommend the FASD Hub to colleagues (92%), friends (74%) and patients (72%).

The FASD Hub fills a critical role as a one-stop-shop for information about alcohol harms in pregnancy and FASD

Before the FASD Hub was established, many resources and publications related to FASD and PAE were available only in hard copy, came from overseas, or were limited to certain jurisdictions. The Hub has bridged this information gap, providing a centralised location for information relevant to Australia.

The FASD Hub also acts as a central resource and amplifier to other infrastructure projects that are funded by the Australian Government. For example, it connects audiences with specialist organisations and groups including the FASDAR; NOFASD Australia which provides a helpline, information and advocacy for individuals and families living with FASD; Learning with FASD, which provides resources for educators; the 'Every Moment Matters' campaign which is a public health awareness campaign run by Foundation for Alcohol Research and Education; and the 'Strong Born' campaign run by the National Aboriginal Community Controlled Health Organisation.

Over the past 12-month reporting period, 180 news articles, events, training and other content from third party, Australian run, FASD organisations were promoted via the monthly newsletter, website, social media channels and webinars.

The FASD Hub connects people with lived experience and FASD-informed professionals through the FASD Hub Service Directory

The FASD Hub Service Directory provides a platform for families and people with FASD to find FASD-informed health professionals in their local area to provide assessments or treatment. At present, 96 services are registered and the number is expected to grow significantly as more health professionals complete the FASD Hub e-learning course, become FASD-informed, and are encouraged to register their details publicly. The FASD Hub provides the only publicly facing database to assist families to identify and seek FASD-informed services in their vicinity. In the past reporting year, the Services Directory was the fourth most viewed page on the FASD Hub and was visited 13,420 times.

As well as enabling families to locate the services closest to them, the FASD Hub provides extensive information about the FASD assessment and diagnostic process for a range of stakeholders including health and other professionals and families and people with lived experience.

Australians can be proud of the FASD Hub and other existing infrastructure

In the past 25 years, Australia has made progress towards reducing FASD and better supporting people with FASD and their families to thrive by:

- Establishing the FASD Hub Australia (2016 – 2026) to collate the latest evidence-based resources and research about the prevention, assessment, diagnosis, and management of FASD in Australia.
- Developing clinical guidelines for the assessment and diagnosis of FASD (hosted on the FASD Hub).

- Funding specialist FASD clinics in certain jurisdictions to provide assessment, diagnosis and management services for people with FASD and their families.
- Rolling out the comprehensive and effective ‘Every Moment Matters’ and ‘Strong Born’ public health campaigns, aimed at supporting alcohol-free pregnancies and safe breastfeeding practices.
- Funding the development of the FASDAR to collect detailed information about children under 15 years in Australia with FASD and improve health outcomes.
- Providing funding to NOFASD Australia which provides advocacy and support for those with lived experience.
- Including FASD in the eligibility list for the NDIS.
- Naming FASD as a complex neurodevelopmental disorder for certain Medicare item numbers.

B) Examine the effectiveness of current programs and initiatives across all jurisdictions to improve prevention and reduction of alcohol and other drug-related health, social and economic harms, including in relation to identified priority populations and ensuring equity of access for all Australians to relevant treatment and prevention services.

The FASD Hub is leading work to prevent harms from prenatal alcohol exposure in Australia

A key objective of the FASD Hub is to increase health and other professionals and community knowledge and understanding of the harms and lifelong consequences of FASD, as well as to promote awareness of the ‘no safe level, no safe time’ recommendations regarding alcohol for women who are pregnant, may become pregnant, or are breastfeeding. The FASD Hub does this by:

- Prominently featuring and disseminating the NHMRC’s *Australian guidelines to reduce health risks from drinking alcohol*, the WHO and other guidelines.
- Promoting the *Every Moment Matters* and *Strong Born* campaigns across all our digital platforms.
- Providing access to prevention resources created by the FASD Hub and partners.
- Creating content for people planning a pregnancy, who are pregnant or breastfeeding.
- Promoting prevention strategies such as the mandatory alcohol warning labels.
- Hosting webinars targeting women including webinars covering alcohol and breastfeeding.
- Hosting eLearning modules that provide advice for Health Professionals asking and advising about alcohol use in pregnancy.

The FASD Hub ensures the evidence-base about alcohol harms in pregnancy is accessible for all Australians

The FASD Hub hosts information relevant to a number of different groups, including audiences who are culturally and linguistically diverse. Hosting key fact sheets about alcohol and pregnancy and FASD in ten languages other than English, as well as access to a free translator helpline, the FASD Hub is committed to ensuring the important messages about preventing FASD are accessible and culturally appropriate.

Recognising the strengths of Aboriginal and Torres Strait Islander Communities across Australia, the FASD Hub is proud to host a number of Indigenous-led resources sharing information about the prevention, assessment, diagnosis and management of FASD, including the federally funded Strong Born campaign. In a recent website redesign, ensuring the FASD Hub was culturally safe and appropriate was set as a key priority, with a working group formed to provide strategic direction to ensure this was achieved.

FASD occurs in all parts of Australian society where alcohol is consumed, and the experiences of those with lived and living experience is unique to each individual. Through ensuring a lived experience lens is applied to all content created, and by sharing individual and family stories across our channels, the FASD Hub aims to increase awareness and understanding of the diversity of experiences people with FASD have, in order to improve outcomes for people with FASD and their families.

C) Examine how sectors beyond health, including for example education, employment, justice, social services and housing can contribute to prevention, early intervention, recovery and reduction of alcohol and other drug-related harms in Australia.

The primary audience of the FASD Hub is health professionals but the FASD Hub also provides information tailored to justice professionals, educators, social workers and policy makers on specialised landing pages.

Feedback from webinars aimed at these audience groups has been very positive, with many requests for additional webinars and learning opportunities specifically targeting these groups.

In particular, the FASD Hub has worked closely with *Learning with FASD* to amplify their resources created for those working within the learning environment, with a webinar co-hosted between the two organisations aimed at teachers attracting over 700 registrants.

D) Draw on domestic and international policy experiences and best practice, where appropriate.

Preventing FASD requires organisations and professional groups across Australia to contribute to policy development and knowledge and translation activities. The FASD Hub aims to facilitate this by providing access to all papers, reports, policies and calls for submissions related to alcohol harms in pregnancy from across Australian jurisdictions, in one centralised location.

Whilst the primary goal of the FASD Hub is to provide access to Australian research and resources to inform an evidence-base for local policy, the FASD Hub also links to key international documents including the WHO 'Guidelines for identification and management of substance use and substance use disorders in pregnancy.'

Recommendations

1. We request the Department of Health and Aged Care provides secure, ongoing and expanded funding to the FASD Hub Australia to enable it to:
 - Continue to increase capacity of the health workforce to screen for and identify FASD and provide early intervention to improve long term outcomes.
 - Disseminate the revised Australian guidelines for the diagnosis of FASD and its associated eLearning course and update relevant content on the web.
 - Showcase and disseminate Australian research, resources and reports.

- Increase the number of FASD-informed health professionals listed on the FASD Hub Service Directory, to improve access to assessment, diagnostic and management services for families and people with FASD.
 - Amplify prevention messaging to key stakeholders including health and other professionals and people planning a pregnancy, who are pregnant, or breastfeeding.
2. That the relevant federal and state governments ensure that funding is provided at appropriate levels and enhanced as required for other critical Australian infrastructure including the FASD Australian Registry, the National Organisation for FASD Australia, the Every Moment Matters and Strong Born national public health campaigns, and Learning with FASD.

Conclusion

Since its launch in 2017, the FASD Hub has been a critical pillar of Australia’s world-leading work to address alcohol harms in pregnancy and support people with FASD to thrive, however much is left to do. Ensuring sustainable and expanded funding for the FASD Hub infrastructure must be prioritised, with additional continuing funding allocated beyond 2026 to ensure the biggest gains in addressing FASD.

Preventing FASD must be the ultimate goal of governments, communities and services, however work to support people living with FASD and their families must also be a priority. Living and lived experience and First Nations voices must inform and be at the heart of these strategies.

With the right funding and prioritisation of resources, much more can be done to ensure alcohol harms are prevented in the future, and people living with FASD are supported for the best possible life outcomes.

References

Bower C, Elliott EJ, The Steering Group. Report to the Australian Government Department of Health: Australian Guide to the diagnosis of FASD (2016; updated 2020).

Cheung, M.M.Y., Jones, H., Eastwell, N., Zhang, T., Harford, K., Bower, C. and Elliott, E.J., 2024. Evaluation of the Fetal Alcohol Spectrum Disorder Hub Australia website. *Drug and Alcohol Review*.

Elliott, Elizabeth J., and Carol Bower. Fetal alcohol spectrum disorder in Australia: from fiction to fact and to the future. In *Fetal alcohol spectrum disorder: advances in research and practice*, pp. 263-310. New York, NY: Springer US, 2022.

Popova, S., Charness, M.E., Burd, L., Crawford, A., Hoyme, H.E., Mukherjee, R.A., Riley, E.P. and Elliott, E.J., 2023. Fetal alcohol spectrum disorders. *Nature reviews Disease primers*, 9(1), p.11.