

Advocacy and recognition of Fetal Alcohol Spectrum Disorder (FASD)

Introduction

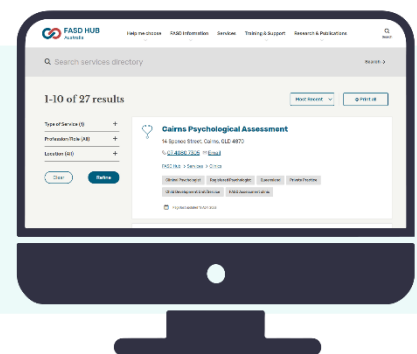
Advocacy is essential for children and adults with FASD in various areas, including health, child protection, justice, education, and allied health. Robust advocacy is necessary to reduce the potential risks of adverse social outcomes for individuals with FASD, including involvement in the child welfare and justice system. It is not only the duty of caregivers to provide support for individuals with FASD throughout their lives.

Legal advocacy, especially from lawyers who are knowledgeable about FASD, is crucial for children and adults who are involved in the legal system, including the family court. It is important to note that the age of criminal responsibility in Australia is ten years old, and the absence of early intervention and support raises the likelihood of children with FASD becoming involved in the justice system and the risk of ongoing incarceration. ⁱ

Individuals with FASD are likely to face ongoing challenges in life and will require robust advocacy to access the necessary services. It's worth noting that the responsibility of caring for children with FASD is primarily on kinship carers and caregivers, who usually receive inadequate support. Kinship carers who are Aboriginal or Torres Strait Islander people often receive less social support than foster carers, and many of them provide informal care without appropriate resources or assistance. ⁱⁱ Therefore, advocacy is essential for both the child and their kinship carers. Recognising these complex circumstances is critical in implementing strategic advocacy for better access to resources and evidence-based interventions.

Assessment Services

www.fasdhub.org.au has extensive information on [assessment and diagnosis](#) including a list of [assessment services](#) and information related to the [NDIS](#).



What we know

- Kinship carers often have their own chronic health conditions and maybe raising more than one child with FASD. Therefore, it is crucial to provide advocacy support for the entire family. ^{iii iv}
- Although Kinship carers and families are usually the best advocates for their children, caring for children with FASD can be demanding and require additional support.
- Services for children with FASD are limited, and there are reportedly fewer services available when children transition to adulthood. ^v

Best Practice and culture as care

People with FASD acquired their disability through no fault of their own, and our society must support and advocate for them throughout their lives in order to have quality of life. Community-based supports should be strengthened to promote independence for people with FASD and their families to include natural networks. ^{vi}

Advice for the health workforce

There are several practical measures to enhance local capacity and advocacy in FASD, including:

- Providing ongoing training in FASD across the lifespan.
- Establishing local networks of practitioners from health, education, NDIS, and legal sectors who possess significant experience in FASD.
- Supporting parents, kinship carers, and foster carers raising children with FASD.
- Raising awareness of the gaps in services in local areas between childhood, adolescence, and adulthood.
- Developing an understanding of the NDIS system for children and adults with FASD.
- Holding annual workshop discussions and FASD training with local Aboriginal Legal Services and relevant stakeholders is a recommended approach.
- **Resource:** [FASD and Justice Videos](#) produced by Telethon Kids Institute as part of the 'Understanding FASD: A Guide for Justice Professionals' project.
- **Resource:** [Decolonising Justice for Aboriginal Youth with Fetal Alcohol Spectrum Disorders](#) book available for purchase.
- **Resource:** [Caregiver poster](#) by Edmonton Fetal Alcohol Network (Canada)

References

ⁱ Blagg, H., Tulich, T., Williams, R., Mutch, R., May, S. E., Badry, D., & Stewart, M. (2020). *Decolonising Justice for Aboriginal Youth with Fetal Alcohol Spectrum Disorders*. Routledge.

ⁱⁱ Williams, R., & Badry, D. (2020). A decolonising and human rights approach to FASD training, knowledge, and case practice for justice involved youth in correctional contexts. In *Decolonising justice for aboriginal youth with fetal alcohol spectrum disorders* (pp. 111-133). Routledge.

ⁱⁱⁱ Eades, A., Hackett, M. L., Liu, H., Brown, A., Coffin, J., & Cass, A. (2020). Qualitative study of psychosocial factors impacting on Aboriginal women's management of chronic disease. *International journal for equity in health, 19*(1), 1-8.

^{iv} Williams, R., & Badry, D. E. (2023). Aboriginal Kinship Carers and Carers of Children with Fetal Alcohol Spectrum Disorder in Western Australia: Advancing Knowledge from an Indigenous and Disability Lens. *First Peoples Child & Family Review, 18*(1), 60-80. <https://fpcfr.com/index.php/FPCFR/article/view/603>

^v Williams, R., & Badry, D. (2020). A decolonising and human rights approach to FASD training, knowledge, and case practice for justice involved youth in correctional contexts. In *Decolonising justice for aboriginal youth with fetal alcohol spectrum disorders* (pp. 111-133). Routledge.

^{vi} Flannigan, K., Pei, J., McLachlan, K., Harding, K., Mela, M., Cook, J., ... & McFarlane, A. (2022). Responding to the Unique Complexities of Fetal Alcohol Spectrum Disorder. *Frontiers in Psychology, 6712*.