

# From Statewide Coverage to Rural Connection: Transforming FASD Diagnosis with a Unique Model of Care



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## Background – Fetal Alcohol Spectrum Disorder (FASD)

- FASD is a lifelong neurodevelopmental condition caused by **prenatal alcohol exposure (PAE)**
- FASD affects **~3.6% of Australians, approximately one child per classroom**
- FASD is **higher among priority populations**, including children in out-of-home care, Aboriginal and Torres Strait Islander communities (up to 19%), and youth in detention (up to 36%)
- The NSW CICADA Centre supports children and families impacted by substance use from birth to 18 years. The **NSW FASD Service** delivers **statewide multidisciplinary assessment, diagnosis, and management** for children with confirmed PAE and neurodevelopmental difficulties



### Aims & Objectives

- Describe demographic and FASD diagnostic outcomes of children and young people assessed and diagnosed with FASD across NSW
- Evolution of tailored care pathways to improve diagnosis and support for vulnerable groups

### Methods

- Retrospective review of clinical records (2014-2024) of children and young people referred and assessed FASD including:
- Demographics (age, gender, postcode, priority population)
  - FASD diagnostic neurodevelopmental profiles per Australian Guidelines for Assessment and Diagnosis of FASD (9 domains)

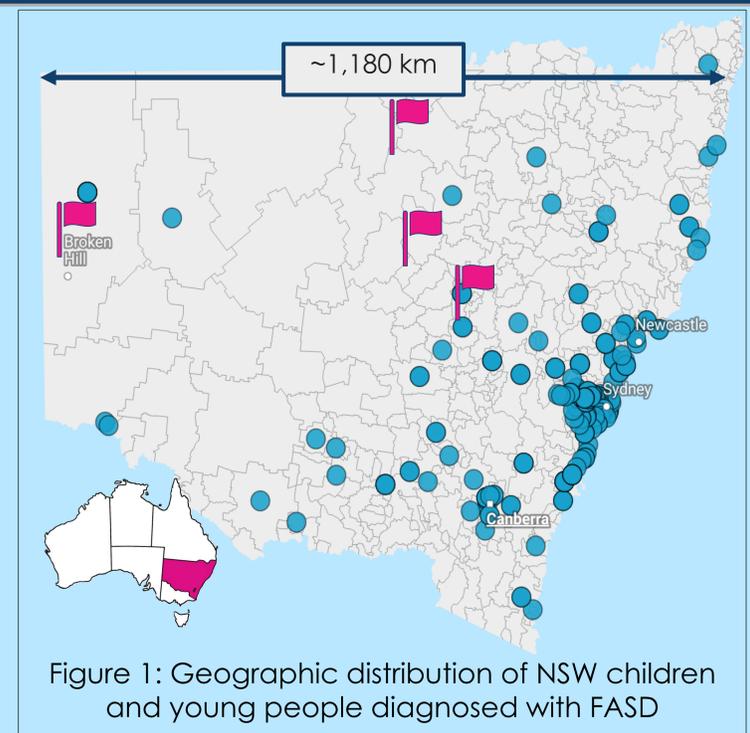
## Results – NSW FASD Service Findings

During 2014-2024, the NSW FASD Service:

- Received **848 referrals**, of these **470 (55%)** children and young people were **assessed for FASD**
- 311 (68%)** children and young people have a **confirmed diagnosis of FASD**

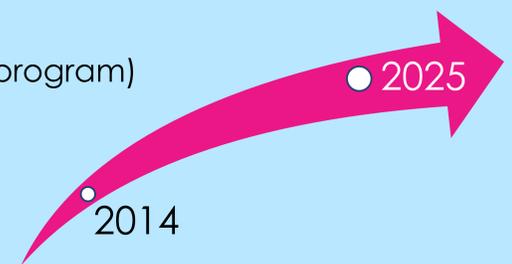
NSW Children and Young People Diagnosed with FASD:

- Aged **7-13 years**, predominantly **male** (61%)
- Overrepresented in **Aboriginal and Torres Strait Islander communities** (49%)
- 86% living in **out-of-home care**, including **foster care** (44%)
- Disproportionately residing in **regional** (43%) and **remote** (6%) areas (Figure 1)
- Exposure to **high levels of PAE**: AUDIT-C $\geq$ 5, 50%; data unavailable, 49%
- 1 in 10** had all **3 sentinel facial features** (Small palpebral fissure length ( $\leq$ 2 Z score), smooth philtrum and thin upper lip (Rank 4 or 5) using University of Washington Lip-Philtrum Guides)
- One-third had  **$\geq$ 5 neurodevelopmental domains** with **severe** impairment
- Key neurodevelopmental domains with severe impairment:



## Evolution of NSW FASD Service

- Employed male and female **Aboriginal Care Navigators**
- Formalised **referral pathways** (SUPPS, Koori Court, Healthy Communities Foundation, and ELVER program)
- Implemented **telehealth** for initial and feedback appointments
- Developed **specialised clinics** (FASD-Track, Baby Clinic, Outreach and Genetic Consultation)
- Conducted **outreach clinics** (Broken Hill, Collarenebri, Dubbo and Orange) (Figure 1 - )



## Conclusions & Looking Forward

- The **NSW FASD Service** provides assessment and diagnosis of FASD in children and young people including those in out of home care, Aboriginal and Torres Strait Islander communities and regional/remote locations
- Our data shows high rates of severe impairment across multiple domains indicates **complex support needs** and emphasises the need for addressing **systemic vulnerabilities, limited access** to services and **culturally safe** care pathways
- Evolution of NSW FASD Service** has led to: **support** for early intervention; **coordinated** links between services; **expanded** access for regional/remote locations; and **enhanced** engagement through culturally safe and responsive care
- Challenges**: Increasing waitlist times, funding constraints, service capacity and sustainability, pre- and post-diagnosis care gaps