Fetal Alcohol Spectrum Disorder Australian Registry: informing practice and policy

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Introduction: There are no national Australian data on Fetal Alcohol Spectrum Disorder (FASD) to guide diagnostic and prevention strategies. Using the FASD Registry (FASDAR) we aimed to describe the epidemiology of FASD.

Methods: Paediatricians reported standardised, de-identified data to the Australian Paediatric Surveillance Unit (APSU) on children aged <15 years and newly diagnosed with FASD in response to a monthly email reminder. Cases were classified using criteria from the 2016 *Australian Guide to the Diagnosis of FASD* and included in the FASD Australian Registry (FASDAR).

Results: Between January 2015-June 2022, 926 FASD cases were confirmed (incidence estimate $2.7/10^5$ children aged <15 years/annum), the rate increasing over time $p<0.001$. Mean age at diagnosis was 8.5 years (range 1-14.9), 68% were boys, 56% Aboriginal and/or Torres Strait Islander. Most came from WA (28%), Queensland (24%) and NSW (23%) and 20% from remote regions. Only 21% lived with a biological parent; 74% had contact with child protection.

Prenatal alcohol exposure (PAE) was confirmed in 99% (89% high risk) from official records (45%), direct witnesses (41%) and biological mothers (27%). Only 17% had all 3 sentinel facial features, 18% had microcephaly, 17% major congenital anomalies. Common neurodevelopmental (ND) impairments were: attention (80%), executive functioning (76%), adaptive behaviour (72%), language (66%) and academic achievement (65%). Common comorbidities were trauma, sleep disorder, Autism and anxiety.

Discussion and conclusions: FASDAR provides unique, current, national data to inform policy and practice. Increasing numbers of FASD diagnoses suggest better clinician awareness and use of the Australian Guide to Diagnosis.

Implications for Practice or Policy: Children who are Indigenous, remote-dwelling, in out-of-home care and with high-risk PAE are over-represented, indicating urgent need for targeted prevention strategies. NDI is severe and pervasive, and comorbidities are common, confirming the importance of multidisciplinary services to identify needs and strengths, advocate for NDIS support.