

## Caregiver experience of fetal alcohol spectrum disorder (FASD) diagnosis and the impact of FASD on families

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**Introduction:** Research into caregivers' perceptions of the diagnosis of FASD is limited. Our aim was to investigate the diagnostic process and the impact of FASD on families.

**Method:** Caregivers of 58 children diagnosed using the Australian Guide to FASD Diagnosis at a state-wide, multi-disciplinary FASD assessment service were invited to complete an online survey containing validated tools to evaluate the impact of FASD on health-related function (RACP-MOF) and family function (IOF).

**Results:** 35(60%) caregivers, mostly(74%) foster-carers participated. Median age at FASD diagnosis was 7.0y and delay in diagnosis 3.8y. Most(84%) children saw  $\geq 3$  doctors before diagnosis; 63% received prior diagnoses (ADHD(50%), Global Developmental Delay/Intellectual Disability(41%), Autism Spectrum Disorder(23%), Complex PTSD(14%), or Reactive Attachment Disorder(14%)). Only 14% had 3 sentinel facial features; 54% were male; 40% Aboriginal. Most caregivers (69%) believed diagnostic delay was due to lack of health professionals' knowledge (54%), family awareness (33%), or a diagnostic test for FASD (21%). Delay was associated with older age at assessment ( $p < 0.01$ ); prior alternative diagnosis ( $p = 0.011$ ); and Aboriginality. Perceived consequences included delayed treatment/funding(33%); uncertainty regarding behavioural support(17%); and lack of understanding from clinicians/teachers(17%). Reported barriers to diagnosis included difficulty accessing specialists(80%), long waitlists(49%), travel distance(46%), and sibling care(37%). Caregivers informed of peer-supports e.g. NOFASD were more satisfied. Most (60%) believed psychological support should be offered at diagnosis but few received this.

**Discussions and Conclusions:** Despite a small sample these unique data confirm caregivers' experience of diagnostic delay for their child's FASD.

**Implications for Practice or Policy:** We demonstrate the benefit of consumer-informed research to guide future practice and policy and identified the need for patient-centred services for FASD beyond tertiary settings, improved screening, clinician education, and better referral pathways to diagnosis.

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