

Diagnosis and support for children with FASD: lessons from a remote Indigenous Australian community.

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Abstract

In 2008 Aboriginal women from Fitzroy Valley, Western Australia fought for to prevent take-away sale of all but low strength beer. Restrictions decreased alcohol consumption, alcohol-related admissions and injuries. This journey was captured in the film *Yajilarra*.

Women concerned about the harms of alcohol in pregnancy then initiated a partnership between Marninwarntikura Women's Resource Center and Nindilingarri Cultural Health Services in Fitzroy Crossing and the University of Sydney. The *Marulu* strategy was developed to address FASD diagnosis and prevention and support affected families. *Marulu* is a Bunuba word meaning 'precious, worth nurturing.'

In 2009 we were invited to investigate the prevalence of FASD and initiated the *Lililwan* ('all the little ones') project. In a population-based sample of primary school children from 45 very remote communities 55% were exposed to alcohol prenatally and 19% had FASD with significant neurodevelopmental impairment, behavioural challenges and poor academic performance.

Community benefits were increased awareness of alcohol harms and FASD (including through the film *Tristan* about a boy with FASD); employment and training of health professionals and researchers; post-graduate opportunities; and multi-disciplinary assessments and management plans for all children. Study data informed a national Inquiry into FASD and allowed advocacy for improved services and family supports. It led to research funding for trials of the positive parenting program (Jandu Yani-U) and Alert program for impulse control; the Bigiswun longitudinal study; and the Marrura-U project to develop/evaluate trauma-informed telecare. Community leadership, consent, trust and equity are essential for successful research with Indigenous communities.