Lililwan Project - FASD
Prevalence study in the Fitzroy Valley
Our Journey

- In 2007 leadership shown by local Aboriginal women in our community lobbied for restrictions on the sale of full strength take away alcohol.

- The alcohol restrictions were implemented in 2007, it was then our community became aware of a condition that threatens the quality of life for people in our community.

- In 2008 The Marulu Strategy was developed to address Prevention, Diagnosis and Support for those affected by FASD.

- In October 2009 The Lililwan Project FASD prevalence study was initiated in our community, being the first to have ever been conducted in Australia and a world first population based study.
Marulu Strategy Partners

- Nindilingarri Cultural Health Services
- Telethon Institute for Kids
- Patches Pediatric Child Health and Education services
- Department of Education
- University of Sydney
- George Institute for Global Health
What is FASD?

- Fetal Alcohol Syndrome
- Partial Fetal Alcohol Syndrome
- Alcohol-Related Neurodevelopmental Disorders
Features of FASD

Main signs and symptoms of FASD

- Cranial and facial distortion.
- Learning disability.
- Hyperactivity.
- Impaired emotional, social and cognitive development.
- Attention deficits.

FETAL ALCOHOL SYNDROME

- Low nasal bridge
- Sparse eyebrows
- Small palmar creases
- Exposed molars and teeth
- Short palate and tongue
- Flared nostrils and mouth
- Low upper lip

MARNINWARNTIKURA
Features of FASD

Smooth Philtrum

Thin upper lip.

Small eye openings
Features of FASD
Features of FASD
How to diagnose FASD?

Multi Disciplinary Team:

- Paediatrician
- Occupational Therapist
- Speech Therapist
- Psychologist
Fetal Alcohol Syndrome (FAS)

Three facial features.

Growth Restriction

Brain Abnormality
Partial Fetal Alcohol Syndrome (P-FAS)

Two facial features + Brain Abnormality
Neurodevelopmental Disorder - Alcohol Exposed (ND-AE)

Brain Abnormality
What did we do?

- Located all children born in 2002 or 2003 and currently living in the Fitzroy Valley
- Interviewed all parents or carers
- Asked about pregnancy and birth, health, development and early life trauma
- Reviewed health records
- Information from most (95%) families
- Each child had full medical check in addition to FASD assessments.
Stage 1 – Results from Parent /Carer interviews

Alcohol use in pregnancy by risk category:

- Did not drink: 47%
- Drank low risk: 3%
- Drank risky: 5%
- Drank high risk: 45%
Results of Lililwan Project - FASD Prevalence Study

1 in 5 children with FASD
Results of Lililwan Project – FASD Prevalence study

1 in 8 children with FAS
Benefits for children and families..

• A Full Medical check
• A FASD Diagnosis and Management plan
• Referral's to appropriate health services
Benefits for our community...

- Clinical guidelines – Diagnosis and care for those affected by FASD.

- Marulu Unit – Advocacy and Support for children and families.

- Collaborative Circle of Care – to strengthen the capacity of services to respond to the needs of children and families.
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