

## The Lililwan Project: the power of diversity in achieving a common goal

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Dr Jane Latimer is an Associate Professor at The George Institute for Global Health and at The University of Sydney. She has received over \$7.5 million to fund her research and published in leading medical journals. In 2009 she made a short movie called "Yajilarra" that told the story of a group of strong Aboriginal women. She is part of a team that recently received \$1.1 million from the Australian Government to fund the first study of FASD prevalence in a remote Indigenous community in Australia.

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### Background

In 2007 Aboriginal women from the Fitzroy Valley in Australia's remote northwest decided to address the excessive use of alcohol in their community. In the previous year the community experienced 13 suicides in 13 months with alarming reports of rising alcohol consumption, alcohol-fuelled violence and child abuse. These courageous women lobbied their community and the West Australian Liquor Licensing Board to impose, for the first time in Australia, a restriction on the sale of take away alcohol. Evaluation of these restrictions demonstrated the enormous success of this community-led initiative, noting significant improvements in community safety, health, education, and cultural engagement.

The community determined to build on the success of these restrictions by addressing the biggest challenge facing remote Aboriginal communities today, FASD. In 2008 the community developed a strategy to overcome FASD, and importantly, engaged a 'circle of friends' to assist in the enormous task. The community extended an invitation to medical research organisations (The George Institute for Global Health and the University of Sydney Medical School) to collaborate on the first high quality study of FASD prevalence in Australia. Understanding the enormity and significance of this work, an innovative, collaborative approach was developed that fundamentally challenged the way in which research is traditionally conducted and funded in Indigenous communities.

### The project team

A diverse team was assembled, including experts in research design and statistics, FASD and paediatrics; aboriginal community navigators and mentors; human rights commissioners; advertising executives, journalists, film directors and intellectual property lawyers. Their crucial roles will be discussed. Despite their diversity in expertise, individuals and their organisations worked together towards the community's common goal of overcoming FASD.

### The project tasks

Prior to commencing the study the community initiated an extensive community consultation to determine whether there was strong support for the prevalence study. With the community, we identified project tasks to support conduct of the prevalence study. Additionally, funding was needed before detailed planning for the study could commence.

### The project funding

An innovative and successful approach was taken to obtaining funding, including approaches to Federal and state governments, non-government organisations, philanthropists, foundations, high-net-worth individuals and corporate Australia. In-kind support was sought from a diverse range of organisations including the Australian Human Rights Commission and a large Sydney law firm. Competitive peer-reviewed grants were submitted. A communications strategy developed for us by one of the world's leading advertising agencies, and a short film trailer were used to motivate potential funders.

## **Conclusion**

We present a new way of bringing committed individuals and organisations together to support Aboriginal communities to develop solutions to the most sensitive issues affecting their lives. Our approach confronts the challenges of remoteness, lack of resources, language difficulties and cultural sensitivities, and highlights the importance for success of valuing diversity and promoting relationships built on trust and respect. Australia's Aboriginal Social Justice Commissioner (Mr Mick Gooda) commented that this work "is an example of researchers reciprocating both the spirit and intent of the community by working to address the challenges of foetal alcohol spectrum disorders (FASD) in a genuine partnership - one where research is done with the community and not just about the community."

## **Learning objectives**

1. To demonstrate an innovative approach to collaborative FASD research with Indigenous communities by exploring new, genuine, community-led partnerships and new models of operating, including fundraising, advocacy and research conduct.
2. To encourage Indigenous communities to build diverse partnerships to support them in addressing sensitive issues such as FASD.

