

The Marulu* Strategy 2008–2012: overcoming Fetal Alcohol Spectrum Disorder (FASD) in the Fitzroy Valley

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Despite years of public policy targeting health promotion and improved primary care services, health and education outcomes for Aboriginal children are poor relative to the general population.¹ In some remote Aboriginal communities 85% of children were found to be developmentally vulnerable in one or more developmental domains, compared with 22% in the general Australian population.² An important, yet poorly understood, determinant of these outcomes is the impact of prenatal alcohol exposure (PAE) on childhood learning and development.³ Alcohol is a teratogen and PAE may cause damage to the developing brain, leading to a spectrum of lifelong learning and behavioural problems termed Fetal Alcohol Spectrum Disorder (FASD). The adverse effect of FASD on child development, education and behaviour has been identified as posing a risk to the continuation of Aboriginal culture that is passed down through oral stories and songs.⁴ Across the life course, affected individuals have a reduced opportunity for participation and productivity within the community because of disrupted education, trouble with the law, mental health problems, and alcohol and other drug dependency common in FASD.⁵

*Marulu means 'precious, worth nurturing' in the Bunuba language of the Fitzroy Valley

Abstract

Objective: Aboriginal leaders concerned about high rates of Fetal Alcohol Spectrum Disorder (FASD) in the Fitzroy Valley, remote north-western Australia, introduced restrictions on access to take-away full-strength alcohol. Following this, Aboriginal leaders engaged strategic partners in a broader strategy to address FASD in the region. The aim of this study was to develop and implement a community-led, researcher-supported, FASD strategy.

Methods: A review of literature focusing on community-led FASD strategies identified key components that informed the Marulu FASD strategy. These included strategy ownership, leadership, and governance by participating communities, and a research framework.

Results: Community meetings and workshops led to the development of The Marulu FASD Strategy (2008). Feasibility and community consent to conduct a FASD prevalence study (the Lililwan Project) was confirmed, and implementation was progressed (2010–2013). Concurrent FASD prevention activities were conducted. In 2012, the Marulu FASD Unit was established within a local Aboriginal organisation to sustain and coordinate ongoing strategy activities.

Conclusions: Community control of public health initiatives can be achieved when Aboriginal communities prioritise issues of significant concern, and engage strategic partners to overcome them.

Implications for public health: The Marulu Strategy forms a template for action to address FASD and other public health issues in Aboriginal communities in Australia and internationally.

Key words: Australian Aboriginal; Fetal Alcohol Spectrum Disorder (FASD); prevention; prenatal alcohol exposure; social change

In responding to the social and health impacts of FASD, broad strategies that address prevention, diagnosis and targeted therapy are considered best practice.^{6–8} The majority of interventions relating to FASD have been documented in North America.⁹ These include national and regional policy

frameworks, community education and prevention initiatives, health and education-based programs and family-based programs.⁹ An international inventory of Indigenous community-based initiatives cites the following key components of a successful FASD strategy: strengthening and supporting

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families, being community-led and culturally appropriate, building capacity in community members and organisations, and engaging collaborative partnerships in a coordinated approach.¹⁰

In Australia there has been a sustained research and advocacy effort to increase awareness and action around FASD for almost two decades.^{3,11} In recent years the Australian Government has increased its focus on FASD through research into diagnosis and prevention initiatives. A national plan to reduce the impact of FASD was announced in 2014 with a focus on nationally coordinated programs in primary prevention, secondary prevention targeting pregnant women with alcohol dependency, improved access to diagnosis and management services, and targeted measures to support Indigenous and socially disadvantaged communities.⁸ This plan has been considered by emerging community-based strategies, most initiated by Aboriginal community organisations. These strategies include an innovative community-designed antenatal education program, delivered since 2008 by the Ord Valley Aboriginal Health Service in the Kimberley region of Western Australia. An evaluation of this program reported cessation of drinking during the pregnancy period in all women receiving FASD education over a 12-month period.¹² Complementing community-led strategies, the Western Australian (WA) Government has developed a FASD Model of Care and funded the WA Drug and Alcohol Office's (now the Mental Health Commission) evidence-based FASD prevention program, Strong Spirit Strong Future (SSSF).^{6,13} SSSF has included statewide media campaigns (television, radio), health workforce training and resource development, and a small grants program to fund community-based FASD prevention initiatives.¹³

While there are examples of promising practice in FASD prevention in Australia, there have been no comprehensive FASD prevention, diagnosis and management programs in place in Aboriginal communities, or indeed in any Australian communities. Sustainable solutions to public health problems require approaches across multiple levels, incorporating organizational, psychological, cultural, community, and regulatory methods.¹⁴⁻¹⁷ These perspectives form the basis of a sound social-ecological approach.¹⁷ This multi-layered perspective needs considerable attention in Aboriginal

health, where research has traditionally been done on, not with, Aboriginal people.^{18,19} Discussion focused on improving the conduct of Aboriginal health research has stressed the importance of engaging with the community to address community priorities and goals before the design process. In addition, facilitating local ownership, control, and the development of research capacity is essential to respecting cultural protocols. Specific recommendations to improve research conduct include working with community and local organisations to embed research in local services, employment of local people in research, having a flexible research approach, and patience to allow sufficient time for consultation and data collection.¹⁹

Unfortunately much of the dialogue about Aboriginal people controlling their own research agenda has been theoretical with research activities 'on the ground' very rarely reported.¹⁹⁻²¹ The following paper describes the development and implementation of a multifaceted strategy to prevent, diagnose, and manage FASD driven by community leaders in the Fitzroy Valley, and their research partners.

Setting

The Fitzroy Valley is located along the Fitzroy River floodplains in remote north-western Australia, about 2,500 km north-east of Perth, and 400 km from the Kimberley's regional hub of Broome. Fitzroy Crossing provides a service centre for some 45 remote satellite communities of the Fitzroy Valley within a 200 km radius.²² Of the 4,500 people in the Fitzroy Valley, about 80% are Aboriginal and identify with four main language groups: Bunuba, Gooniyandi, Walmajarri/Wangkatjungka and Nyikina.²² Traditional cultural practice and languages are maintained, and systems of cultural governance provide a framework for community priority setting and decision making.⁴ Leadership and cultural authority are maintained by community elders. Certain aspects of community leadership are determined on the basis of gender. For example, women decide on key community priorities relating to pregnancy and parenting.²³

Historical context

Over time the Fitzroy Valley communities have survived many challenges to the preservation of their culture and control of country (land). These have included European

pastoralists removing them from country by force in the 1890s,²⁴ the killing of Aboriginal people in the early 1900s in disputes with settlers, the removal of Aboriginal children from their families as a result of assimilation policies between the early 1900s and the 1960s, religious transformation by the missions beginning in the 1950s, and oil drilling and mineral exploration in the 1960s.^{25,26} Between 1960 and 1975 a series of laws was passed in the Australian Parliament to recognise Aboriginal people as citizens of Australia, granting them the right to vote, to be paid equal wages in the pastoral industry and to consume alcohol.²³ In the Fitzroy Valley, the Pastoral Industry Award, while ensuring equal wages for Aboriginal workers, had the unfortunate consequence of forcing people off their traditional lands, since pastoralists could no longer pay workers with simple rations.²⁷ The resultant town-based concentrations of Aboriginal people, dislocated from country and without the ability to carry out a traditional life or participate in meaningful employment, laid the foundations for an epidemic of social and emotional ill health and chronic alcohol overuse that has persisted for almost four decades.²⁵

A focus on FASD in the Fitzroy Valley

In 2006 a 'tipping point' was reached when the impact of alcohol oversupply and overuse in the Fitzroy Valley became critical, with almost 50 deaths in as many weeks, including 13 suicides (personal communication, June Oscar 2011). This triggered a coronial enquiry which determined that alcohol was a contributing factor in each of 22 cases investigated in the Kimberley region.²⁸ In 2007, leaders in the Fitzroy Valley became aware that many children in their communities displayed learning and behavioural difficulties, as well as unusual facial features and poor growth. They believed that the common practice of women drinking alcohol during pregnancy, which they themselves had observed, might be adversely affecting their children's ability to grow, learn and develop. They had heard about FASD and were concerned that this could threaten the continuation of their language and culture. At a Women's Bush Camp in 2007, discussions were held between senior women of the Valley's four main language groups. Due to the growing awareness of the threat FASD posed to culture, FASD was prioritised as an issue

for the community to act upon (personal communication June Oscar, Maureen Carter, Olive Knight, 2008).

Contemporaneous with the growing community focus on FASD, local paediatricians had linked heavy alcohol use in the Fitzroy Valley with adverse child outcomes,²⁹ and were developing service capacity to respond to this issue. Lack of awareness of FASD among the community members and service providers of the Fitzroy Valley had been recognised. Further, there was little capacity to prevent, diagnose or manage this condition. In 2008, a series of meetings and workshops were held between community leaders and local paediatricians to develop a strategy to better understand, and overcome, FASD in the Fitzroy Valley. This strategy led to an attitudinal shift in the community from a state of crisis relating to alcohol use in pregnancy, to one of control. The community chose the term Marulu to describe the strategy. Marulu is a Bunuba word meaning 'precious, worth nurturing' and is how the Aboriginal communities of the Fitzroy Valley regard their Lillilwan, meaning 'little ones' in Kimberley Kriol. The aims of the strategy were to raise awareness of and prevent FASD, to determine its prevalence, to build local diagnosis and management capacity in health and education services, and to enhance support for families.

Alcohol restrictions: disrupting the chronic oversupply of alcohol

In response to the adverse health and social outcomes from high levels of alcohol use in the Fitzroy Valley, community leaders determined that the detrimental effects of alcohol use must be addressed. Following extensive community consultation and with the endorsement of senior cultural leaders, an appeal was made by local women June Oscar and Emily Carter to the WA Director of Liquor Licensing to introduce restrictions on the sale of full-strength take-away alcohol in 2007. This was despite significant opposition from businesses and some community members. A determination was made in their favour such that: *"The sale of packaged liquor, exceeding a concentration of ethanol in liquor of 2.7 per cent, is prohibited to any person, other than a lodger."*³⁰ This restriction provided a circuit-breaker to the oversupply and overuse of alcohol and was extended indefinitely when an independent evaluation documented improvements in health, education and policing outcomes in the

two-year period following the restrictions.^{31,32} During that time, rates of alcohol-related crime and injury decreased, while school attendance and food purchases at the local stores increased.^{31,32}

Methods

Process for strategy development

FASD is a complex issue and requires a multi-faceted approach across the community and service landscape. The Marulu Strategy was framed within a social ecological framework integrating policy, environmental, organisational, community and individual strategies to address a specific public health issue.¹⁷ This multi-level approach is key to addressing the systemic drivers of alcohol use in pregnancy, as well as factors at the community, family, and individual levels. A number of key principles, including community engagement and collaborative efforts across sectors to address a common issue, were incorporated into strategy planning. Importantly, the interventions were developed at the community level, rather than externally imposed or enforced. There is evidence suggesting that public health interventions (such as alcohol restrictions) that are community led, are more effective and sustainable than those imposed upon a community.³³ Furthermore, evidence from initiatives addressing similar public health issues indicate that approaches combining research, sophisticated communication strategies and high-level advocacy have been most effective in influencing policy and health behaviour.^{34,35}

Challenges in implementing a broad strategy to address FASD included engaging health, education, justice and policing, disability, child protection and other organisations in a meaningful way during the process. Agency

staff and management often had limited time to allocate to new or emerging work, such as a FASD strategy. Furthermore, the high turnover of agency staff and management in the remote Kimberley region posed a challenge to continuity of commitment and leadership. The fact that community leaders had prioritised FASD, and the significant impact FASD has across multiple agencies, provided a strong incentive for agencies to collaborate in a Marulu FASD Strategy Leadership Team.

Funding limitations were a significant challenge to establishing a multi-agency approach to FASD. However, the engagement of a volunteer coordinator, and in-kind contributions from participating agencies, enabled the strategy to be progressed until dedicated funding was made available for strategy coordination and management.

Establishing strategy leadership and governance

FASD affects all aspects of a person's function and participation, is a lifelong condition and requires a broad service response including health, mental health, education, child protection, disability services, police and the justice system.^{36,37} To reflect the complexity of the response required in the Fitzroy Valley, an interagency collaboration was formed to guide strategy development and implementation. A key element to the success of the Marulu Strategy was strong local leadership and meaningful community engagement in planning and implementation processes. In October 2008, a leadership team was established with senior representation from local agencies (Figure 1). Leadership team functions included oversight of the Marulu Strategy to ensure that priorities remained relevant to community members and service providers. Nindilingarri Cultural

Figure 1: Marulu Strategy leadership team local representative organisations.

Nindilingarri Cultural Health Services (Chair)

Marninwarntikura Fitzroy Women's Resource Centre (Chair)

WA Country Health Services (Kimberley paediatric and child health service, Fitzroy Valley Community Health service, Fitzroy Valley Hospital, Kimberley Population Health Unit, Kimberley Mental Health and Drug and Alcohol Service)

Kimberley Education Regional Office and Independent Schools Association

Department for Child Protection and Family Services

Disability Services Commission

Fitzroy Crossing Police

Health Services and Marninwarntikura Fitzroy Women's Resource Centre established lead roles in governance and coordination of the Marulu Strategy.

Strategy coordination

The role of coordinating the leadership team meetings, strategy development and implementation process was significant and the need for a strategy coordinator was identified at an early stage. Without this crucial role, the strategy risked losing the momentum of initial planning and stakeholder engagement. Initial staffing support was received through the non-government organisation Indigenous Community Volunteers, which recommended retiree Ms Meredith Kefford. Ms Kefford performed the Marulu Strategy coordinator role voluntarily from 2009–2011, often living in a camper van or tent, and working out of local Aboriginal organisations Nindilingarri and Marninwarntikura.

Developing strategy objectives and priorities

The Marulu Strategy priorities were developed in a series of leadership team workshops and community meetings. At the local level, three priorities and activities were established. Firstly, FASD prevention was commenced through a process of community consultation, education and prevention messaging. Nindilingarri Cultural Health Services led the delivery of health promotion and prevention activities in local communities, schools and at local liquor outlets. This included the organisation of drug and alcohol awareness with local schools during the school term. For example, primary school children wrote stories about how alcohol may affect people's lives, and these stories were used in promotion activities. Nindilingarri also distributed resources such as DVDs, bookmarks, and FASD dolls to the communities. Plastic cups and posters displaying the message that FASD is preventable were used and displayed at the local Inn.

Secondly, the need to diagnose FASD using accepted guidelines was identified, along with the importance of quantifying the prevalence of FASD in the community. Local health professionals had documented the crisis of high-risk alcohol use in the region, and through medical case note review estimated that as many as one in four children may be affected.²⁹ However,

accurate prevalence data were not available and a formal prevalence study was required. The proposal for a FASD prevalence study was highlighted at community meetings. The risks and challenges of doing so were presented and discussed. Concerns about children and families at risk of stigmatisation and potential findings from a prevalence study reinforcing prejudice that FASD is an Aboriginal issue were raised. Other risks included duplication or contradictory advice given to children/families already in contact with government services, and concerns around long term resource support. Additionally, the opportunities and benefits for the Fitzroy Valley were raised. These were particularly focused on building local longer term capacity to prevent, diagnose and manage FASD. Benefits included the local health workforce receiving training in both diagnosis of developmental disorders and intervention planning. Further, children and families diagnosed with FASD would receive management plans and referrals to services. While there would be new diagnoses and referrals, it was suggested that the work burden of local health services should decrease as the focus of the second stage of the project was service provision and support. There was general consensus at community meetings that the only way to provide support for children and families is to first assess the extent of the issue.

Thirdly, the importance of supporting those living with and managing FASD in the family, school and justice systems was identified as a priority area by school representatives, carers of people with FASD, service providers and local police. Suggestions for family support included monthly coordinated meetings for carers, the involvement of fathers and men in discussions about FASD, the need for respite care and activities such as family camps, and carers sharing their expertise and knowledge through story telling.

In addition to local level activities, a series of high-level advocacy and capacity building targets were prioritised. This involved (1) engaging in high-level dialogue on FASD through strategic use of film and media, (2) contributing to the FASD evidence base, and (3) forming strategic partnerships. Further, there were efforts to build capacity in individuals, local organisations and services through attendance at conferences, training in FASD, and creating local employment opportunities. Of critical importance, the strategy prioritised funding a sustainable

response to FASD, including targeting of existing resources and programs, and leveraging additional and sustainable funding sources.

Engaging strategic partners: a 'Circle of Friends'

In order to broaden the input into strategy development and to create an advocacy network, a number of strategic collaborations, termed a 'Circle of Friends', were developed. These partnerships included regional health and education service managers, government representatives, corporate and philanthropic groups, and human rights organisations. While a comprehensive local strategy was being progressed, the scale and impact was limited, lacked resources and required high quality FASD prevalence data. Through existing relationships between community leaders and the George Institute for Global Health and the University of Sydney, planning for a study of FASD prevalence and other high-level objectives was commenced. Two key activities were progressed, the first being to produce a film, *Yajilarra* (meaning 'to dream' in the Bunuba language)³⁸ that documented the implementation of the Fitzroy Crossing alcohol restrictions. *Yajilarra* was launched at Parliament House, Canberra, in 2009, and later screened at the United Nations Permanent Forum on Indigenous Peoples. The film was used to raise the profile of the community's work and to leverage funding to support ongoing activity. Secondly, the feasibility, risks and benefits of conducting the FASD prevalence study were assessed. In the process of community consultation preceding the prevalence study, the community chose to call it the Lililwan Project. The use of the term Lililwan reflected a commitment to improving the lives of all children in the Fitzroy Valley communities. To develop and implement the Lililwan Project a research collaboration (the Lililwan Collaboration) was formed between Nindilingarri, Marninwarntikura, the George Institute and the University of Sydney.

Results

The Marulu Strategy

A broad community strategy was developed, with discrete and focused targets for preventing FASD, diagnosing FASD, managing affected individuals, and supporting families. A schematic overview of the Marulu strategy journey has been previously published

and is demonstrated below (Figure 2).⁴ The Marulu Strategy leadership team maintained oversight of strategy activities across a range of service agencies in the Fitzroy Valley. The Marulu FASD Unit at Marninwarntikura coordinates the broad strategy objectives and employs a pool of local staff working in FASD-related roles. Local cultural health service Nindilingarri delivers prevention programs in communities and schools. A regular multidisciplinary paediatric and allied health process was established by WA Country Health Services, the Kimberley Population Health Unit, Nindilingarri Cultural Health Services and Paediatric Child Health and Education Services (PATCHES Paediatrics). Sustainability has been enhanced through development of capacity in local Aboriginal organisations, the establishment of the Marulu FASD Unit, and providing local employment and training in relation to FASD. Ongoing process and outcome evaluation is being progressed through formal research partnerships between community organisations and research institutes including Telethon Kids Institute, The George Institute and Sydney University.

The Lililwan Project

Incorporating a prevalence study³⁹ into the community-led Marulu Strategy provided a focal point for initial resources to be sourced from philanthropic groups. With seed funding secured from a private donor in October 2009, the Lililwan Collaboration conducted a community consultation around the risks, benefits and feasibility of conducting the Lililwan Project.⁴⁰ The community provided overwhelming support for the study to proceed and the consultation was documented in a report that was used, along with the high-impact film *Yajilarra*, to lobby for further funding support.⁴⁰ Direct representation to Government Ministers and departmental officials resulted in the Lililwan Project being funded by the then Australian Government departments of Health and Ageing, and Families, Community Services and Indigenous Affairs. The Lililwan Project, through collecting high quality data and using a community engagement and development approach to research, has had a significant influence in creating a sustained impact and progressing all elements of the Marulu Strategy. The Lililwan project documented the prevalence of Fetal Alcohol Syndrome and partial Fetal Alcohol Syndrome in the Fitzroy Valley at 120 per 1000 children.³⁹

Figure 2: An overview of the Marulu Strategy.



Significantly higher numbers of children were found to have a neurodevelopmental disorder-alcohol exposed (ND-AE). These results were the catalyst for community members and health and education professionals to identify and implement a culturally appropriate intervention to improve the lives of affected children. A therapy and support program was consequently adapted and embedded in local schools and results of this program are due in 2018.⁴¹

Conclusions and implications for public health

The Marulu Strategy demonstrates a community-led approach to overcoming the complex and sensitive issue of FASD in remote Australian Aboriginal communities. Using a social-ecological approach,¹⁷ the strategy aimed to drive change in policy and practice, service provision, and community and individual knowledge, attitudes and behaviour. By providing a focus for resourcing and activity within the broader Marulu Strategy, the Lililwan Project provides a catalyst for progressing tangible, quantifiable outcomes within the cultural frameworks and priorities of the Fitzroy Valley communities.

In the literature, strategies recommended for research with Aboriginal communities include having community support and building good relationships, employing local people in research, being flexible in the research approach, and allowing sufficient time for consultation and data collection.¹⁹

The Lililwan Project has been cited as demonstrating these characteristics and was singled out as an example of researchers applying these best practice principles for research with Aboriginal communities.¹⁹

An important feature of the engagement strategy was that the community themselves identified FASD as a priority issue, and sought collaborations with research and service provider partners. Community leadership and ownership of the strategy has been ensured through embedding resources for the strategy within local Aboriginal owned organisations. A relationship of trust formed the basis of the research partnership between local community organisations and research institutes. A lead investigator, who was a local paediatrician, lived in the community for the duration of the FASD prevalence study, and this commitment forged a strong relationship between the participant communities and the study team. The process undertaken to consult and plan the Lililwan Project was commended as a template for research in collaboration with Aboriginal communities, and indeed with all communities, in the Aboriginal and Torres Strait Islander Social Justice Commissioner's 2010 Social Justice Report.⁴ This strategy could be applied to a number of different conditions, and in a number of different Aboriginal and non-Aboriginal settings.

Progressing a national FASD agenda is a significant undertaking that needs considerable time and resources. However, teachings from the Marulu strategy

demonstrate that momentum for this endeavour could be harnessed from smaller scale local wins.⁴² Policy around FASD and broader alcohol prevention in Aboriginal communities should align with community goals and focus on delivering sustainable and long term benefits. Control by community members and organisations is imperative to this sustainability. Improving access to services designed to support women with alcohol dependency (and partners / families) needs to be implemented at the local service level. At the same time, governments must develop and introduce legislation supporting the implementation of measures proven to decrease alcohol use. These include focusing on taxation, restricting advertising and limiting access to alcohol – e.g. trading hours and the design of the built environment. Further, there needs to be a focus on improving data collection around FASD, so that the extent of the issue can be defined and the impact of strategies measured and understood.⁴² The Lililwan project has been instrumental in quantifying an evidence base from which to advocate for resources to prevent and manage FASD.⁴ Without strong policy and adequate funding, the people of the Fitzroy Valley face significant challenges into the future. Secondary harms of FASD include disrupted education, mental health and substance abuse problems, and engagement in the justice system.⁴³ A lifetime of secondary disabilities pertinent to FASD and their intergenerational impacts will go on unchecked unless resources are directed at supporting affected individuals and preventing FASD.

There are many transferable lessons from the Marulu Strategy that could be considered for the development of a national approach to tackling FASD. Building on the success of the Marulu Strategy, a multipronged FASD prevention strategy has commenced in the Pilbara region of Western Australia where similar concerns have been documented.⁴⁴ Termed 'Making FASD History', the main focus of the strategy is prevention of FASD. Making FASD History will incorporate broad awareness raising and health promotion efforts, discussion of alcohol use with women of childbearing age and their networks, and antenatal and postnatal interventions to support mothers and their developing children.⁴⁵ This strategy will be further amplified by supportive alcohol policy, FASD diagnostic clinics and a program of research and evaluation

driven by community reference groups and local service providers.⁴⁶⁻⁴⁸ By translating the successful FASD strategy from the Fitzroy Valley, communities across Australia and internationally have an opportunity to address this significant public health challenge.

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