

## 1 **Appendix B: A Community Response to Fetal Alcohol Spectrum Disorders**

The following case study is from Section 3.3, Chapter 3 of the Social Justice Report 2010 which is also available online:

[http://www.humanrights.gov.au/social\\_justice/sj\\_report/sjreport10/chap3.html](http://www.humanrights.gov.au/social_justice/sj_report/sjreport10/chap3.html)

When Aboriginal people are given or take responsibility to address the issues in their community and can come up with their own solutions you will end up with a better way of addressing these issues. This is what we did with issues of Fetal Alcohol Spectrum Disorders and early life trauma in the Fitzroy Valley.<sup>[19]</sup>

You all know the destructive impact of alcohol. For many families and communities in the Kimberley it has been an unmanaged epidemic... The most insidious element of this evil is that it diminishes the lives of so many of the unborn. The horrors of Fetal Alcohol Spectrum Disorders are now just beginning to be understood by Australian governments.<sup>[20]</sup>

Excessive alcohol consumption is an increasing health concern across Australia. A report released in 2010, titled The Range and Magnitude of Alcohol's Harm to Others, stated that alcohol abuse is costing Australia in excess of \$20 billion each year.<sup>[21]</sup>

The numbers of Australians reported to drink at risky and high risk levels has risen from 8% in 1995, to 13% in 2004-05.<sup>[22]</sup> This increase has been more pronounced in women, where the numbers have doubled from 6% to 12% in that timeframe.<sup>[23]</sup> The highest rates of alcohol consumption are in adolescents and young adults.<sup>[24]</sup> Experts argue that these high rates of alcohol consumption by women of a childbearing age are a cause for concern, particularly given the evidence that approximately half of all pregnancies are unplanned.<sup>[25]</sup> Furthermore, surveys suggest that between 50-59% of women consume alcohol at some stage whilst pregnant. In one study, 20% of women indicated that they had participated in binge drinking at least once when pregnant.<sup>[26]</sup>

Considering these statistics, it is possible that the issues associated with alcohol exposure during pregnancy, resulting in FASD, will become an increasingly prominent health and wellbeing concern for the Australian community to respond to.

The people of the Fitzroy Valley have identified FASD as an issue of particular concern that they want to exert control over addressing. Paediatricians working in the Kimberley estimate that up to 30% of children in the Fitzroy Valley are affected by FASD.<sup>[27]</sup>

FASD are a set of disorders that may occur when a mother consumes harmful quantities of alcohol at crucial points during pregnancy and are potentially 100% preventable. The disorders create barriers to normal child development; including learning and behaviour.

FASD represent a group of permanent disorders caused by exposure of the unborn child to alcohol consumed by the mother during pregnancy. These disorders include fetal alcohol syndrome (FAS) and partial FAS, alcohol-related neurodevelopmental disorder (ARND) and alcohol-related birth defects (ARBD). Babies exposed to alcohol in utero may be born with deformities of the brain, nervous system, kidneys, heart, lungs, eyes, ears; may have growth problems; and may display a series of specific facial characteristics. Developmental, behavioural and learning problems are common. What is most devastating about this condition is that it is 100% preventable.

Long term outcomes for children with FASD are poor. Overseas research suggests that 90% will have mental health problems, 80% will remain unemployed, 60% will come into aggravated contact with the law and less than 10% will be able to work independently by the age of 21.<sup>[28]</sup>

Every child, including a child with FASD, has the right to health, happiness and educational attainment.<sup>[29]</sup> Children with FASD have complex health, social and educational needs that require targeted service and policy responses. Exposure to alcohol in the womb can cause many problems including birth defects, learning difficulties, abnormal hearing or vision, and behavioural and psychological disorders. The key to ensuring that affected children are able to reach their full potential, and to lead happy and healthy lives, is to enable early diagnosis and intervention using multi-disciplinary assessment. The provision of ongoing family support is also necessary.<sup>[30]</sup> It is therefore imperative that children with FASD – wherever they live in Australia – have equitable access to the services they need to optimise their health, development and educational outcomes.

In evidence provided to the Coronial inquest in the Kimberley, Professor Fiona Stanley referred to the problem of FASD as being ‘another Stolen Generation’.<sup>[31]</sup>

Paediatricians in the Kimberley are talking about 1 in 4 children affected by alcohol in our current cohort of young children. If you are talking about an Indigenous culture that relies on the maintenance of an oral history and oral tradition and the ability to pass on that tradition and of knowledge then the underpinning foundation of that is your memory. And if you can’t remember things then how our Indigenous people going to pass on their culture?<sup>[32]</sup>

The Commission highlights the actions of Fitzroy Valley leaders in addressing FASD because of their community-ownership over an identified issue of concern. The FASD project is led by the Fitzroy Valley communities, and where needed, the skills and expertise of trusted external partners are utilised. Consent processes are embedded into the fabric of this project to create a community-wide climate of consent. These key features provide an example of processes that address sensitive and seemingly intractable issues in an appropriate and targeted manner. The consequent result borne out of these processes is a high level of community buy-in and engagement.

### **1.1 *Designing the Fetal Alcohol Spectrum Disorders strategy***

FASD has been an issue of concern for Fitzroy Valley residents for some time. It was discussed at a community meeting on alcohol and other drugs in 2004.<sup>[33]</sup> However, it took the advent of the alcohol restrictions to unite the communities into taking action.

FASD had been an issue but with the chronic supply of alcohol you couldn't get traction. People did want to know about it. A lot of people knew something was wrong with our children because of the alcohol. It was after the restrictions that people were ready. And it started to get traction when it was explained to the elders that passing on culture to the next generation would be broken. The elders were concerned about the loss of culture.<sup>[34]</sup>

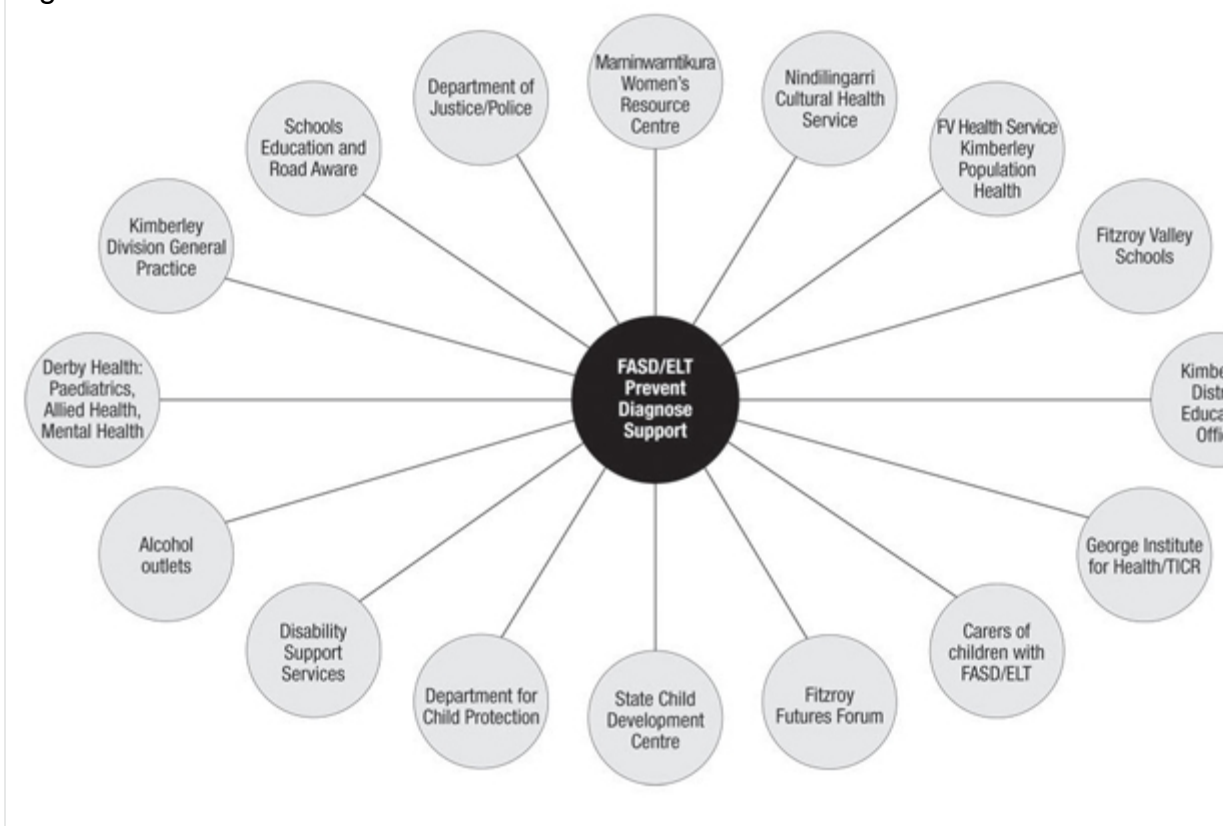
There has been significant recent international focus on the importance of culture and identity in the development processes of Indigenous communities.<sup>[35]</sup> This work builds on the central importance placed on culture and identity in the United Nations Declaration on the Rights of Indigenous Peoples. International human rights standards have developed to the point where states have obligations to work with Indigenous peoples to implement measures for the maintenance, protection, development and transmission of culture and cultural knowledge.<sup>[36]</sup>

FASD is a genuine threat to the preservation of the Aboriginal cultures of the Valley. Impaired memory and an inability to learn and retain information are major components of FASD. Behavioural and learning problems also limit educational gains. Given our oral traditions of passing down cultural knowledge through stories and ceremony, there is a very real possibility that cultural knowledge will be lost as a result of FASD. The majority of cultural knowledge is not part of a written history. Therefore, its continuation is reliant upon the ability of elders to pass this knowledge on to future generations.

In October 2008, just over a year after the alcohol restrictions were brought into the Fitzroy Valley, members of the communities gathered to discuss FASD and other alcohol-related problems. The meeting was led by Aboriginal organisations Marninwarntikura and Nindilingarri Cultural Health Services (Nindilingarri). Community members voiced their concerns that many children and families were suffering from the affects of FASD and Early Life Trauma (ELT). ELT is a term used to describe the environmental factors that can negatively impact on a child's development. Poor nutrition, neglect, and exposure to violence and stress can all lead to ELT. Meeting participants agreed to a multi-pronged strategy of action to address these challenging issues.<sup>[37]</sup>

In November 2008, a coalition of government agencies, business and community organisations formed a 'Circle of Friends'. All parties pledged in-principle support to a FASD/ELT Strategy and action plan. Below is a diagrammatical representation of the 'Circle of Friends':

Figure 3.2: 'A Circle of Friends'



The 'Circle of Friends' is a similar model to the Fitzroy Futures Forum in that it engages all relevant stakeholders from a local, regional and national level including the Aboriginal organisations of the Valley and government agencies. All participants

are actively involved in the development and implementation of the FASD/ELT Strategy that was endorsed by the FASD leadership team.

## **1.2 The Marulu Project**

In November 2008, a draft strategy was developed by the CEO of Marninwarntikura, June Oscar and Dr James Fitzpatrick, a paediatric trainee serving the communities. The strategy was called Overcoming Fetal Alcohol Spectrum Disorders (FASD) and Early Life Trauma (ELT) in the Fitzroy Valley: a community initiative. This strategy is now described locally as the Marulu Project. Marulu is a Bunuba word meaning 'precious, worth nurturing'.<sup>[38]</sup>

Nindilingarri is the head of a leadership team guiding the project. The Marulu Project has a number of areas of focus:

- Prevention – including consulting with the communities to raise awareness of the Marulu Project, education across the communities and working with women who are pregnant to prevent alcohol use.
- Diagnosis – including the development of screening and diagnostic processes.
- Support – including mapping the support services in the Valley and developing a network of carers.
- High level dialogue – including strategic use of media, contributing to scientific discussions on FASD, and raising the profile of FASD through strategic partnerships.
- Build local capacity – including participation in relevant workshops and conferences and capturing the process of the project.
- Focus resources – identify and leverage existing resources, approach government and other funders to secure targeted funding for the strategy, and engage local community resources in FASD prevention, support and diagnosis.<sup>[39]</sup>

Below is a schematic overview outlining the journey in developing the Marulu Project.

Figure 3.3: Schematic of the Marulu Project<sup>[40]</sup>





Nindilingarri uses the Fitzroy Futures Forum meetings to report to the communities, government and businesses on the progress of the Marulu Project.

FASD was earmarked for a full day discussion at the 2009 Marninwarntikura Annual Women's Bush Meeting. The Bush Meeting, attended by the Commission, included a presentation by Carolyn Hartness, an Eastern Band Cherokee and FASD consultant from Canada, who has extensive experience working on FASD with Indigenous communities in the United States and Canada. Carolyn Hartness' attendance was made possible through a grant from the Fitzroy Futures Fund.

#### Text Box 3.5: Support for action on FASD from the Women's Bush Camp

The women at the Bush Meeting gave their support to community led approaches to addressing FASD:

We the women at the annual Marninwarntikura Women's Bush Meeting (6-10 July at Wamali Springs on Leopold Downs Station) acknowledged that rebuilding our families and our communities will move forward on the basis of unity and collaboration.

We have agreed that our priorities over the next 2-3 years are:

- To raise awareness of FASD and recognize its impact on all aspects of our community including loss of cultural knowledge, lack of employment opportunities, unaddressed educational needs, impact on the justice system and child protection etc. This will require us to create culturally appropriate strategies to address these issues. These strategies will be community driven and maintained.<sup>[41]</sup>

The Bush Meeting and the Fitzroy Futures Forum were pivotal platforms for keeping the people in the Valley, outside of the leadership team, informed and involved in the development and implementation of the project.

In 2009, the Marulu Project leadership group began discussions with researchers from the George Institute for Global Health (The George Institute) about the possibility of conducting a prevalence study of FASD in the Fitzroy Valley. The rationale for conducting a prevalence study was to understand how many children were affected by FASD and to attract funding and resources to manage these children, and prevent FASD. Funding would only be forthcoming once there was a strong evidence base.<sup>[42]</sup>

### **1.3 Working with trusted partners**

In Fitzroy we bring people in when we identify a problem and a need, rather than people coming in and telling us our problems and our needs. It is about forming strategic partnerships with government and the corporate sector. It is about asking for help but that is strategic and targeted help.<sup>[43]</sup>

The Marulu Project leadership team, headed by Nindilingarri, identified The George Institute as the most appropriate organisation to provide technical and other expertise to the project. The George Institute had previously developed relationships with the communities in producing a documentary, Yajilarra. The documentary told the story of alcohol restrictions in Fitzroy Valley.

#### **Text Box 3.6: Yajilarra: using media as a lever for social change**

The alcohol restrictions campaign in the Fitzroy Valley is a powerful story that has been told through a documentary film entitled Yajilarra. The women of Marninwarntikura wanted to use the documentary film as a lever for social change. They knew that telling this story would raise the profile of the Fitzroy Valley and alert key players to their continuing needs. The documentary could also act to inspire other Indigenous communities to take control of the issues confronting them. It was felt that film was the ideal medium to communicate the story to the widest audience.

In 2007, June Oscar and Emily Carter from Marninwarntikura invited Elizabeth Broderick, Sex Discrimination Commissioner (Australian Human Rights Commission), to visit Fitzroy Crossing. Commissioner Broderick wanted to assist in making the documentary. Commissioner Broderick introduced the Fitzroy leaders to The George Institute who assisted in sourcing funding to produce the film.

The documentary has been instrumental in raising the profile of the Fitzroy Valley and issues of FASD and securing funding for the Marulu Project. The documentary has been screened in many places in Australia and internationally, including Parliament House and at the United Nations.

Yajilarra was a solid foundation for further partnership with The George Institute:

[O]ut of the liquor restrictions the women formed a relationship with The George. They assisted the women to produce Yajilarra. There was already that relationship that existed. As a result of the relationship it was easy for us to contact them to help with the strategy. Because of the relationship The George knew about the people they were working with. That is the big difference, it is always the academics that had seen a problem and tell the people 'we are doing it my way'. This is totally different, here the Aboriginal people said FASD was a problem and we worked with The George Institute on the project.<sup>[44]</sup>

The George Institute was a natural partner in the FASD work with Nindilingarri. The George Institute has expertise in conducting research and in advocacy and has strong relationships with Fitzroy Valley community members. The George Institute engaged an expert paediatrician, Professor Elizabeth Elliott from The University of Sydney, to provide clinical expertise on FASD and sought approval from the leadership team for her involvement in the project.<sup>[45]</sup>

The current research team includes Nindilingarri, The George Institute, and the Sydney University Medical School at The University of Sydney. Maureen Carter (community member and CEO of Nindilingarri) leads the team that includes June Oscar (community member and CEO of Marninwarntikura), Professors Jane Latimer (The George Institute) and Elizabeth Elliott (Sydney Medical School, The University of Sydney), Dr Manuela Ferreira (Faculty of Health Sciences, The University of Sydney) and paediatric senior registrar Dr James Fitzpatrick, who has been working in the Kimberley for the last two years, and is currently a PhD student at the Sydney Medical school.

The FASD project is community led research working through partnerships with trusted external organisations. Indigenous knowledge is acknowledged and respected in the research process consistent with international human rights standards.<sup>[46]</sup> External players are brought in to provide strategic support.



#### **1.4 Community consent for a prevalence study of Fetal Alcohol Spectrum Disorders**

The whole issue with wanting to address FASD had come from the community. We, as a community, have driven this whole project from the start and will drive it to the finish. Each step we had engagement with the people.<sup>[47]</sup>

The prevalence study is known as the Lililwan Project. Lililwan is a Kriol word meaning 'all the little ones'.<sup>[48]</sup> The prevalence study focuses on children in the Valley aged seven and eight years. The entire study, from the decision to proceed with it through to actual participation, employs an informed consent process.

The leadership team were committed to the study but they were even more committed to ensuring a prevalence study was what the community wanted. And that the community wanted to go ahead with it. We all knew this was really sensitive stuff and if the time was not right then we were going to stop it.<sup>[49]</sup>

The research team was invited to consult with the communities and service providers in the Fitzroy Valley between 19-23 October 2009. Members of the consultation team who were not from the Valley undertook cultural awareness training. The consultations were conducted in a range of formats including community forums, planned meetings with key stakeholders and informal meetings. All relevant information about the prevalence study, its aims, methods and possible outcomes was transmitted to the communities. Importantly, a full explanation of the possible risks associated with undertaking this research project was clearly explained. Follow up consultations were had with the Fitzroy Futures Forum and regional government agencies. This consultation process has been documented in Marulu: The Lililwan Project Fetal Alcohol Spectrum Disorder (FASD) Prevalence Study in the Fitzroy Valley: A Community Consultation, which includes summaries and recommendations from each of the consultation sessions.<sup>[50]</sup>

The consultations showed overwhelming support to proceed with a prevalence study from all stakeholders, including the Aboriginal communities and service providers. The widespread feeling was that this study would be an integral component to addressing FASD in the Valley. The community-led nature of this project and the continuing engagement through public forums like the Fitzroy Futures Forum ensured that the residents were kept up to date and were fully informed about the proposed prevalence study. This was fundamental to obtaining consent to proceed with the FASD prevalence study.<sup>[51]</sup>

The Special Rapporteur on the situation of human rights and fundamental freedoms of indigenous people (Special Rapporteur), Professor James Anaya, has noted that

the absence of this type of intensive engagement process can derail programs and projects intended to benefit Indigenous peoples:

The Special Rapporteur has observed that, without the buy-in of indigenous peoples, through consultation, at the earliest stages of the development of Government initiatives, the effectiveness of Government programmes, even those that are intended to specifically benefit indigenous peoples, can be crippled at the outset. Invariably, it appears that a lack of adequate consultation leads to conflictive situations, with indigenous expressions of anger and mistrust, which, in some cases, have spiralled into violence.<sup>[52]</sup>

The consultation process for the FASD prevalence study is consistent with a number of the key standards for consulting with Indigenous peoples under international law as outlined by the Expert Mechanism on the Rights of Indigenous Peoples<sup>[53]</sup> and the Special Rapporteur.<sup>[54]</sup>

1. Consultations are carried out through Indigenous peoples representatives, that are chosen by Indigenous peoples themselves – The consultations were led by the Indigenous members of the research team. The Fitzroy Futures Forum which has representatives from each of the four language groups in the Fitzroy Valley was also used as a vehicle for consultation.
2. Consultations should be carried out through ‘appropriate procedures’. General public hearings are generally not considered to be ‘appropriate procedures’ – The consultations involved community forums, as well as planned and informal meetings. Follow up consultations were also held.
3. Consultations should be undertaken in good faith and in the appropriate form. This means that consultations are to be conducted with mutual trust and transparency – Prior to the consultations, cultural awareness training was provided to the non-Indigenous participants. The consultation process was undertaken over an extended period of time to allow participants the time to absorb information about the project. All relevant information was provided including potential risks of the research project. The report of the consultations process was provided to participants.
4. Consultations should be in good faith and with the objective to achieve agreement or consent – At the beginning of the process it was agreed that the study would only proceed on the basis of the informed consent of the people of the Fitzroy Valley. All parties acted in good faith.
5. There should be periodic evaluation of effectiveness – The project ensures that evaluations will occur at each stage of the research.

This research project is setting an example to the rest of Australia of how best to approach Indigenous affairs. A process guided by a relationship underpinned by meaningful, respectful engagement and collaboration will always be more effective and successful than one that is not. Harnessing this way of thinking and operating opens a myriad of opportunities to address difficult and sensitive issues in Aboriginal and Torres Strait Islander communities.

Having received informed consent to proceed with the project, the research team set out designing the study. Associate Professor Jane Latimer of The George Institute, described this process:

So then we started to design the study with the community. We would teleconference each week and we would design it a bit more. From our end we had ethics committees to go through.<sup>[55]</sup>

Maureen Carter, CEO of Nindilingarri and community member, outlined her perspective of the project's development:

We would look at information given to us by The George Institute but we could sit with them to change the words to make it culturally appropriate. We put the research into our context but it still had to fit within the ethical guidelines of The George.<sup>[56]</sup>

The project is designed to incorporate necessary elements of Indigenous culture and knowledge as well as meeting the requirements of Western research ethics standards. For example, the parent/carer questionnaire developed by Professor Elliott and Dr Fitzpatrick was modified extensively following consultations with Fitzroy Valley residents and the Kimberley Interpreting Service to ensure its content and language were culturally appropriate.<sup>[57]</sup>

The Liliwan Project is guided by a set of principles and preconditions that are relevant to each phase of the project. These are:

#### Principles

1. First, do no harm.
2. Commit to a process of two-way learning.
3. All activity must deliver short and longer term benefits for the communities.
4. Informed participation and consent must be ensured through the sharing of information and knowledge.

5. All activities must preserve the dignity of participating individuals and communities.

#### Preconditions

1. Clear and broad informed consent from:
  - o the communities broadly
  - o local service providers.
2. Local Control – The Project Leadership Team must be, and perceived to be by the communities as being, in control of the study.
3. An appropriate and adequate workforce.<sup>[58]</sup>

The project was divided into two discrete stages to ensure that the communities are comfortable with the sensitive process:

Stage 1. Collection of demographic, prenatal, and early childhood data from parents/carers using a diagnostic checklist and review of medical records. This involves interviews with parents/carers including questions on the drinking patterns of mothers during pregnancy and the development patterns of children.

Stage 2. Health and developmental screening, opportunistic treatment and referral. This includes medical and allied health examinations of all children born in 2002 and 2003 to estimate the prevalence of FASD.<sup>[59]</sup>

This study will provide an individual assessment of children and estimate the prevalence of FASD in the Valley. The data from the project will stay with the Kimberley Population Health Unit. The study was designed so that it did not simply diagnose children and leave them in limbo. A care plan will be developed for every child with identifiable problems and ensure they are referred for appropriate and ongoing care. The study will also use the principal findings to advocate for better health and education services. The evidence-base generated can be used by governments to develop a targeted service response to FASD in the Fitzroy Valley.<sup>[60]</sup>

### **1.5 Continuing consent in action**

Ongoing consent is a precondition of the Lililwan Project. Therefore, all participants in the study are to give their informed consent throughout the life of the project and before any new developments are undertaken.

In April 2010, the research team began Stage 1 of the Lililwan Project. This involved interviews with mothers and carers of seven and eight year old children in the Valley. The cohort for the study was located using the data from the Fitzroy Population Project. The research team was led by two 'community navigators':

We had Aboriginal navigators to help locate the people. These navigators were chosen because of their standing in the community. We had a male and a female navigator, so it was culturally appropriate. Going in with people who know the community meant we gave the researchers information about the families that might be relevant. You know if there had been a loss. The project was done at the pace of the community and that is key. We met with the right significant people in each community first. The researchers were led by the community navigators.<sup>[61]</sup>

The use of the navigators was an essential component of the continuing consent process. Most of the interviews were conducted by the navigators in conjunction with Dr James Fitzpatrick and Ms Meredith Kefford, a volunteer with Indigenous Community Volunteers, who were both well known in the Fitzroy Valley.

Even though Nindilingarri had been given a strong mandate to proceed with the Lililwan Project from the community consultations, obtaining the informed consent from individual families was a fundamental component of Stage 1.

Women are giving you the most sensitive data in the information they provide as part of this research. This information is so incredibly sensitive in relation to terminations of pregnancies, in relation to drug and alcohol use. It is the most sensitive data in their lives. We wanted to make sure no one was coerced in any way.<sup>[62]</sup>

The consent processes were embedded into the fabric of the project. Consent was sought at every step of the project to ensure participants were not being coerced or did not understand what their involvement entailed.

We wanted to make absolutely sure we were not coercing people in any way, shape or form. So we organised for a senior partner from Blake Dawson to travel with us to be an independent expert in consent and made sure he thought the way we were storing the data and gaining consent from people was the best practice we could have and there was nothing more we could do. It meant there was no risk of coercing people.<sup>[63]</sup>

When the researchers went out into the communities they would go in and have a barbeque and get introduced to the community by the navigators. With this issue [FASD and drinking alcohol during pregnancy] our people will not talk straight away, they have to get to know you. They have to have time to think about these things



before they said yes or no to be involved in the research. We gave them time to think.<sup>[64]</sup>

As with any research project, the Research Team had to apply for permission from an identified human research ethics committee to conduct the study and to have the study design, parent information sheet, consent form, questionnaire and clinical assessment process approved.

In the case of the Liliwan Project this involved not only the University ethics committee (University of Sydney Human Research Ethics Committee) but also the relevant committee in Western Australia (Western Australia Country Health Service Board Research Ethics Committee) and the Western Australian Aboriginal Health Information & Ethics Committee. In addition, all research conducted in the Kimberley must be approved by the Kimberley Research Subcommittee of the Kimberley Aboriginal Health Planning Forum.<sup>[65]</sup> This committee was established in 2006 to ensure that research conducted in the region that might include Indigenous peoples was coordinated, that the people of the Kimberley would derive the maximum possible benefit from any research conducted there, and that any adverse impact of the research on either the community or its health services would be kept to a minimum.<sup>[66]</sup> Each part of the Liliwan Project will go through this arduous – but absolutely essential and extremely helpful – process.<sup>[67]</sup>

Data collection for Stage 1 was completed by the end of August 2010.

The success of the Liliwan Project so far is testimony to the careful investment in partnership, consultation, negotiation and consent.

So now we have completed Stage 1 and we know that the entire population of children born in 2002 or 2003 across the Valley is approximately 138 children. Of these, we were able to access and contact 132 and 95% of them gave their permission to be interviewed. So we know that the data we will have is representative of the entire population.<sup>[68]</sup>

In addition to high participation rates, the Research Team reports that Stage 1 of the project has produced high quality data.<sup>[69]</sup>

Although we haven't measured it specifically we know that when we travel around people have a level of knowledge about FASD. You don't need to start explaining from the start. The community has a level of knowledge that if we had been there three years ago they would not have had.<sup>[70]</sup>

The community driven nature of the Lililwan Project, with consent processes embedded into its fabric, provides strong evidence that, when empowered to do so, Indigenous communities can address their most sensitive and difficult issues.

### ***1.6 Assessing the prevalence of FASD and developing appropriate response***

Data collection for Stage 2 of the project will commence in May 2011 led by clinicians from the Discipline of Paediatrics and Child Health Care at Sydney Medical School, Sydney University. It will see a comprehensive multidisciplinary health and developmental assessment of all children. This will include physical and cognitive assessments of the children. It will identify the functionality of each child and to indicate what health and educational support structures will be needed for each FASD affected child. In other words it will create individually targeted management plans. This Stage will be complete by the end of 2011.

The George Institute obtained philanthropic funding for the initial consultations and Stage 1. Nindilingarri, The George Institute and The University of Sydney actively sought government funding for Stage 2. In July 2010, the Minister for Families, Housing, Community Services and Indigenous Affairs (Minister for Indigenous Affairs) and the Minister for Indigenous Health jointly announced that the Australian Government would support Stage 2 of the Lililwan Project with a \$1million grant to the research collaboration.<sup>[71]</sup> This will support approximately half the cost of the project.

This project is considered to be one of the many positive developments emerging out of the Fitzroy Valley since the alcohol restrictions.

### ***1.7 Concluding observations on the Fitzroy experience***

A community approach to Fetal Alcohol Spectrum Disorders

- The Fitzroy Valley communities considered that Fetal Alcohol Spectrum Disorders (FASD) was an area of concern because of its genuine threat to the health and well-being of local children, its threat to the preservation of culture and the damage it would cause to future generations.
- The FASD project is an example of a community-led collaborative process to address a highly sensitive community identified issue of concern.
- A strategy to address FASD was developed by local community leaders. The lead partner is the Nindilingarri Cultural Health Service at Fitzroy Crossing. Other key

partners are The George Institute for Global Health, The Sydney Medical School of the University of Sydney and paediatricians working in the region.

- Nindilingarri Cultural Health Service is the lead agency with responsibility to work with partners to develop the FASD strategy design.
- The Fitzroy Futures Forum keeps the communities informed about all work on FASD and provides an opportunity for local people to have input into the project and provide consent and feedback at key points of its progress.
- Comprehensive community consultations demonstrated widespread community support for a FASD prevalence study.
- The FASD prevalence study will form a key component of the evidence base to advocate for funding and resources to implement remedial projects to address and prevent FASD.
- The FASD prevalence study is a community led model for project development, engagement and consent processes.
- Careful investment in communication and consent processes ensured that 95% of families in the Fitzroy Valley with children aged seven and eight years consented to participate in the study.