



**Australian
Human Rights
Commission**

Inquiry into Foetal Alcohol Spectrum Disorders

Australian Human Rights Commission Submission
to the Standing Committee on Social Policy and Legal Affairs

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1 Introduction

1. The Australian Human Rights Commission makes this submission to the Standing Committee on Social Policy and Legal Affairs in its Inquiry into Foetal Alcohol Spectrum Disorders (FASD).

2 Summary

2. This submission proposes and outlines a human rights-based response to developing a national approach to the prevention, intervention and management of FASD.
3. This submission includes an example of a community-led response to FASD by Aboriginal communities in the Fitzroy Valley, which was originally published in Section 3.3, Chapter 3 of the Australian Human Rights Commission's *Social Justice Report 2010*. The full chapter is also attached to this submission to provide the context of this case study.

3 Recommendations

4. The Australian Human Rights Commission recommends that:
 1. A human rights-based approach should underpin all measures to address FASD in order to protect and promote the rights of women, children, families and communities affected by FASD. This requires:
 - a. The core human rights principles—of equality and non-discrimination, human dignity, participation and inclusion, empowerment, accountability, equity and access—guide all phases in the development, implementation, monitoring and evaluation of strategies, policies and programs to address FASD.
 - b. The human rights standards contained in the Universal Declaration of Human Rights and other international human rights instruments guide prevention, intervention and management strategies that address FASD.
 2. In accordance with a human rights-based approach and the Convention on the Rights of Persons with Disabilities, prevention, intervention and management strategies should be developed, implemented and monitored in close consultation and active involvement of people impacted by FASD including children and adults, women, families and communities, including through their representative organisations. Strategies to address FASD within communities should be community-led and community focused.
 3. Education about FASD, in particular the risks of alcohol during pregnancy, should be provided without discrimination. Given the escalation of alcohol consumption during pregnancy, a population-based approach is advised.
 4. There should be measures to improve access to family planning services for parents, and maternal health services for pregnant women with alcohol

dependency or at risk of alcohol dependency. This should include adequate prenatal and postnatal health care.

5. In accordance with the Convention on the Rights of Persons with Disabilities, a national approach to the intervention and management of FASD should utilise a social model of disability. A social model of disability addresses the interactions between the impairments and the environment and attitudinal barriers which hinder the full and effective participation of people affected by FASD on an equal basis with others.

6. There should be adequate training for health and other professionals who provide services for people impacted by FASD.

7. Communities, families and individuals affected by FASD should have improved access to appropriate community care and support services across education, health, community services, and employment and criminal justice sectors.

8. People with impairments resulting from FASD should have opportunities for the fullest possible social integration and individual development.

4 Background: Causes, Prevalence and Impact of FASD

(a) Alcohol consumption

5. 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.¹ The numbers of Australians reported to drink at risky and high risk levels has risen from 8% in 1995, to 13% in 2004-05.² This increase has been more pronounced in women, where the numbers have doubled from 6% to 12% in that timeframe.³ The highest rates of alcohol consumption are in adolescents and young adults.⁴
6. 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

¹ AM Laslett, P Catalano, T Chikritzhs, C Dale, C Doran, J Ferris, T Jainullabudeen, M Livingston, S Matthews, J Mugavin, R Room, M Schlotterlein and C Wilkinson, *The Range and Magnitude of Alcohol's Harm to Others*, Alcohol Education and Rehabilitation Foundation (2010), p 177. At http://www.aerf.com.au/Harm_to_Others_Full_Report_with-errata.pdf (viewed 10 September 2010).

² L Burns, E Black and E Elliott (eds), *Fetal Alcohol Spectrum Disorders in Australia: An Update*, Intergovernmental Committee on Drugs: Working Party on Fetal Alcohol Spectrum Disorders (2009), p 18.

³ L Burns, E Black and E Elliott (eds), *Fetal Alcohol Spectrum Disorders in Australia: An Update*, Intergovernmental Committee on Drugs: Working Party on Fetal Alcohol Spectrum Disorders (2009), p 18.

⁴ L Burns, E Black and E Elliott (eds), *Fetal Alcohol Spectrum Disorders in Australia: An Update*, Intergovernmental Committee on Drugs: Working Party on Fetal Alcohol Spectrum Disorders (2009), p 19.

approximately half of all pregnancies are unplanned.⁵ 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.⁶

(b) *Prevalence of FASD*

7. 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 well-being concern across all communities in Australia and for the Australian community to respond to.
8. While there has been some important work undertaken to assess the prevalence of FASD in identified Aboriginal and Torres Strait Islander communities (see the Appendix: *A Community Response to Fetal Alcohol Spectrum Disorders*⁷), the prevalence of FASD in Australia has not yet been determined.
9. The Commission urges the Standing Committee to consider strategies that target all people and communities across Australia in the development of a national approach to the prevention, intervention and management of FASD.

(c) *Impact of FASD*

10. Evidence indicates that FASD may result in a range of impairments including brain injury, birth defects, behavioural and mental health issues.
11. Impaired memory and an inability to learn and retain information may limit educational gains and also impact on future employment and opportunities for economic participation.
12. Impaired memory and an inability to learn and retain information may also result in a threat to the preservation of Aboriginal and Torres Strait Islander Peoples' cultures, given their oral traditions of passing down cultural knowledge through stories and ceremony. It is a 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.

⁵ L Burns, E Black and E Elliott (eds), *Fetal Alcohol Spectrum Disorders in Australia: An Update*, Intergovernmental Committee on Drugs: Working Party on Fetal Alcohol Spectrum Disorders (2009), p 19.

⁶ See L Burns, E Black and E Elliott (eds), *Fetal Alcohol Spectrum Disorders in Australia: An Update*, Intergovernmental Committee on Drugs: Working Party on Fetal Alcohol Spectrum Disorders (2009), p 20.

⁷ NB: This submission adopts the English (UK) spelling of 'foetal' whereas the case study used 'fetal' as it was aligned with terminology used by the Lirilwan Project in the Fitzroy Valley prevalence study.

5 A Human Rights-Based Response to FASD

13. The Australian Human Rights Commission recommends that a human rights-based approach underpin all measures to address FASD in order to protect and promote the rights of women, children, families and communities affected by FASD.
14. A human rights-based approach requires integrating the norms, principles, standards and goals of the national and international human rights system into prevention, intervention and management strategies that address FASD.⁸
15. There are a range of international human rights conventions and declarations that need to be considered when responding to FASD including:
 - Universal Declaration of Human Rights
 - Convention on the Rights of Persons with Disabilities (CRPD)
 - Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)
 - International Covenant on Economic, Social and Cultural Rights (ICESCR)
 - Convention on the Rights of the Child (CRC)
 - UN Declaration on the Rights of Indigenous Persons (the Declaration)
16. The human rights standards contained in the Universal Declaration of Human Rights and other international human rights instruments should guide the prevention, intervention and management strategies that address FASD.⁹
17. It is imperative that human rights principles including equality and non-discrimination, participation and empowerment, and accountability are applied in any response to FASD.

5.1 Consultation and partnership

18. Given the sensitive nature of FASD, prevention, intervention and management strategies should be developed in partnership with the people impacted by FASD including children and adults with disability, women, families and communities. Specifically:
 - The development and implementation of legislation and policies should be developed in close consultation with, and actively involve, persons

⁸ Kirkemann Boesen, J and Martin, T, *Applying a Rights-Based Approach: An Inspirational Guide for Civil Society*, The Danish Institute for Human Rights (2007)

⁹ See for example: The Human Rights Based Approach – Statement of Common Understanding. Developed at the Inter-Agency Workshop on a human rights-based approach in the context of UN reform, 3 to 5 May 2003. Available at http://www.google.com.au/url?sa=t&rct=j&q=kofi%20annan%20human%20rights%20based%20approach&source=web&cd=1&ved=0CCUQFjAA&url=http%3A%2F%2Fwww.unicef.org%2Fsowc04%2Ffiles%2FAnnexB.pdf&ei=X5wnT6beBayUiAf1uYDSA&usq=AFQjCNHvQblx_H72TCqHM9tyQGg7Ncy13w; Kirkemann Boesen, J and Martin, T, *Applying a Rights-Based Approach: An Inspirational Guide for Civil Society*, The Danish Institute for Human Rights (2007)

with disabilities, including children with disabilities, through their representative organisation, in accordance with Convention on the Rights of Persons with Disabilities (CRPD) (article 43). Children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right (CRPD, article 7).

- The right to participate in decision-making is particularly important for Indigenous peoples.¹⁰ In Australia today, Aboriginal and Torres Strait Islander Peoples do not have genuine decision-making authority and power over their lives and futures. Governments have a legacy of imposed interventions and the power and decision-making authority continues to rest in the hands of governments.¹¹ Furthermore, 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.¹²

19. The specific application of human rights conventions and principles to prevention, intervention, management strategies for FASD is outlined in the following sections.

6 Prevention Strategies

6.1 Education and awareness

20. Education and community awareness about FASD should be accessible to all people, without discrimination, including people with disability, people from culturally and linguistically diverse backgrounds, people living in rural and remote areas, Indigenous communities, and people with low socio-economic status.

¹⁰ The importance of the right to participation in decision-making for Indigenous peoples is reflected through its consistent reference in the *United Nations Declaration on the Rights of Indigenous Peoples*, GA Resolution 61/295 (Annex), UN Doc A/RES/61/295 (2007), articles 3-5, 10-12, 14, 15, 17-19, 22, 23, 26-28, 30-32, 36, 38, 40 and 41. At <http://www.un.org/esa/socdev/unpfii/en/drip.html> (viewed 10 October 2011). See also Expert Mechanism on the Rights of Indigenous Peoples, *Progress Report on the study on Indigenous peoples and the right to participate in decision-making*, Report to the Human Rights Council, 15th session, UN Doc A/HRC/15/35 (2010), paras 7-41.

¹¹ D Smith and J Hunt, *Do They Get It? Indigenous Governance: The Research Evidence and Possibilities for a Policy Dialogue with Australian Governments* (Speech delivered at the National Indigenous Policy Dialogue Conference, University of New South Wales, Sydney, 18-19 November 2010). At http://nipdc.arts.unsw.edu.au/assets/Powerpoints/Smith_Hunt.pdf (viewed 10 October 2011).

¹² *United Nations Declaration on the Rights of Indigenous Peoples*, GA Resolution 61/295 (Annex), UN Doc A/RES/61/295 (2007), arts 11, 12, 13, 31. At <http://www.un.org/esa/socdev/unpfii/en/drip.html> (viewed 31 August 2009).

21. Health education measures should highlight the risks alcohol poses for pregnant women. Given the escalation of alcohol consumption during pregnancy a population-based approach is advised.
22. It is also important that young people have access to information and education about sexual and reproductive health, and alcohol consumption and its dangers.

6.2 Family planning and maternal health care

23. Access to adequate, appropriate and affordable health care for women, particularly for sexual and reproductive health, is also central to preventing and addressing FASD.
24. Article 12 of the Convention on the Elimination of all forms of Discrimination Against Women (CEDAW) states that:

State parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.

State parties shall ensure to women appropriate services in connection with pregnancy, confinement and the postnatal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.

25. This is also supported by the Conventions on the Rights of the Child (CRC), which states that Australia is obliged to ensure adequate prenatal and postnatal health care for mothers (article 24(d)). Under the CRC, Australia is required to develop preventive health care, guidance for parents and family planning education and services (CRC, article 24).
26. Furthermore, in emphasising women's right to health, the Committee on Economic Social and Cultural Rights underlines the need for state parties to provide a full range of high-quality and affordable health care, including sexual and reproductive services. The Committee's general comment calls for state parties to remove all barriers to women's access to health services, education and information, including in the area of sexual and reproductive health (GC 14).

7 Intervention Needs and Management Issues

7.1 Applying a social model of disability

27. In accordance with the CRPD, the Commission urges the Committee to adopt a social model rather than a medical model of disability in the development of a national approach to the intervention and management of FASD.
28. The social model of disability recognises that "disability is an evolving concept and that disability results from the interaction between persons with

impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others,”¹³

29. The CRPD does not define disability. Article 1, in describing the purpose of this Convention states:

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

30. As noted in the Terms of Reference of this Inquiry, FASD is “an overarching term used to describe a range of cognitive, physical, mental, behavioural, learning and developmental disorders” that result from foetal exposure to alcohol.
31. Unlike the medical model of disability, the social model of disability does not require a focus on diagnosis to access necessary supports and services and programmes to raise awareness. Rather a focus is required on addressing the interactions between *the impairment* and the environment and attitudinal barriers that are hindering full and effective participation on an equal basis with others.

7.2 Access to support and services

32. The CRPD describes in detail the measures required to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. These measures include training for health and other professionals, early intervention and access to appropriate community care and support services across education, health, community services, employment and criminal justice sectors for the communities, families and individuals affected by FASD.
33. The necessary supports and services (including but not limited to health, community, education and employment services) should be accessible to all people with impairments resulting from FASD, including those in rural and remote areas, Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse communities, women and people with low socio-economic status.
34. Importantly, the CRPD notes that to prevent concealment, abandonment, neglect and segregation of children with disabilities (which includes children

¹³ CRPD, Preamble (e)

with FASD), state parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families (article 23(3)).¹⁴

35. The CRC also states that a child with physical and mental disabilities should enjoy a full and decent life, in conditions which promote self-reliance and facilitate the child's active participation in the community. This includes the right of the disabled child to special care and assistance designed to promote the fullest possible social integration and individual development (article 23).

7.3 The National Disability Insurance Scheme

36. On 17 February 2010, the Australian Government requested the Productivity Commission undertake an inquiry into a National Disability Long-Term Care and Support Scheme. On 21 July 2011, the Productivity Commission, in its final report into Disability Care and Support to the Australian Government concluded:¹⁵

Current disability support arrangements are inequitable, underfunded, fragmented, and inefficient and give people with a disability little choice. They provide no certainty that people will be able to access appropriate supports when needed. While some governments have performed much better than others, and there are pockets of success, overall, no disability support arrangements in any jurisdiction are working well in all of the areas where change is required. The current arrangements cannot be called a genuine 'system' in which different elements work together to achieve desired outcomes.

The central message of this report is that a coherent and certain system for people with a disability is required — with much more and better-directed resourcing, a national approach, and a shift in decision-making to people with a disability and their careers. This overview explains what is wrong with the current arrangements and how to improve them. It shows how a new system would work for people with a disability and their families, and how it would provide benefits for the community as a whole.

37. The Productivity Commission recommended the establishment of two schemes: a National Disability Insurance Scheme (for people with significant and ongoing disability) and a National Injury Insurance Scheme (for people requiring lifetime care and support as a result of catastrophic injuries).

¹⁴ CRPD. Article 23(3). States parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, states parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.

¹⁵ Productivity Commission, *Disability Care and Support, Productivity Commission Inquiry Report, Overview and recommendations, No.54, 31 July 2011. Available at http://www.pc.gov.au/_data/assets/file/0014/111317/disability-support-overview-booklet-word.zip*

38. In a summary of the key points of the NDIS, the Productivity Commission noted:¹⁶

The scheme should involve a common set of eligibility criteria, entitlements to individually tailored supports based on the same assessment process, certainty of funding based on need, genuine choice over how their needs were met (including choice of provider) and portability of entitlements across borders. There would be local area coordinators and disability support organisations to provide grassroots support. The insurance scheme would take a long-term view and have a strong incentive to fund cost effective early interventions, and collect data to monitor outcomes and ensure efficiency.

39. Chapter 7 and Recommendations 7.1-7.10 of the Productivity Commission's Final Report focus on assessing care and support needs. Recommendation 7.1 states:

Working within the framework of the International Classification of Functioning, Disability and Health (ICF), the assessment process undertaken by the NDIA should identify the supports required to address an individual's reasonable and necessary care and support needs across a broad range of life activities, and should take account of an individual's aspirations and the outcomes they want to achieve.

40. In relation to assessment tools, Recommendation 7.8 states:

The NDIS should establish a coherent package of tools (a 'toolbox'), which assessors would employ across a range of disabilities and support needs (including planning and active support, attendant care, aids and equipment, and home modifications).

41. The Australian Government has commenced work with State and Territory Governments to build the foundations for a National Disability Insurance Scheme (NDIS)¹⁷. The NDIS has the potential to transform the way services are funded and delivered, ensuring people with significant and ongoing disability, which would include many people with FASD, are better supported and have greater choice and control. The NDIS will also mean better support for the families and carers of people with disability.

8 Fitzroy Valley Case Study—A Community-Led Response to FASD

42. Aboriginal and Torres Strait Islander communities are leading the way in developing a human right-based response to FASD.

43. The threat of losing culture was one of the key drivers that led the Aboriginal communities in the Fitzroy Valley to identify FASD as an issue of concern. The steps taken by these communities to address FASD are outlined in detail

¹⁶ *Disability Care and Support* p. 2. Available at:

http://www.pc.gov.au/_data/assets/pdf_file/0014/111272/disability-support-overview-booklet.pdf

¹⁷ <http://www.ndis.gov.au/>

in the Commission's *Social Justice Report 2010* (see the Appendix: *A Community Response to Fetal Alcohol Spectrum Disorders*¹⁸).

44. The Fitzroy Valley 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 comprehensive community consultations were embedded into the fabric of the strategy, and there was widespread community support for a FASD prevalence study.
45. 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.
46. The lesson from Fitzroy Valley is clear: when communities are enabled to own their own challenges, appropriately supported by governments, they can address their most confronting and intractable issues. Strategies to address FASD within communities should be community-led and community focused.

¹⁸ NB: This submission adopts the English (UK) spelling of 'foetal' whereas the case study used 'fetal' as it was aligned with terminology used by the Liliwan Project in the Fitzroy Valley prevalence study.

9 Appendix: 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

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.¹⁹

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.²⁰

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.²¹

The numbers of Australians reported to drink at risky and high risk levels has risen from 8% in 1995, to 13% in 2004-05.²² This increase has been more pronounced in women, where the numbers have doubled from 6% to 12% in that timeframe.²³ The highest rates of alcohol consumption are in adolescents and young adults.²⁴ 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.²⁵ Furthermore, surveys suggest that between 50-59% of

¹⁹ M Carter, community member and CEO of Nindilingarri, meeting with the Aboriginal and Torres Strait Islander Social Justice Commissioner, 2 August 2010.

²⁰ J Oscar, community member and CEO of Marninwarntikura, *East Kimberley achievements award speech* (Speech delivered 19 September 2009), p 2.

²¹ AM Laslett, P Catalano, T Chikritzhs, C Dale, C Doran, J Ferris, T Jainullabudeen, M Livingston, S Matthews, J Mugavin, R Room, M Schlotterlein and C Wilkinson, *The Range and Magnitude of Alcohol's Harm to Others*, Alcohol Education and Rehabilitation Foundation (2010), p 177. At http://www.aerf.com.au/Harm_to_Others_Full_Report_with-errata.pdf (viewed 10 September 2010).

²² L Burns, E Black and E Elliott (eds), *Fetal Alcohol Spectrum Disorders in Australia: An Update*, Intergovernmental Committee on Drugs: Working Party on Fetal Alcohol Spectrum Disorders (2009), p 18.

²³ L Burns, E Black and E Elliott (eds), *Fetal Alcohol Spectrum Disorders in Australia: An Update*, Intergovernmental Committee on Drugs: Working Party on Fetal Alcohol Spectrum Disorders (2009), p 18.

²⁴ L Burns, E Black and E Elliott (eds), *Fetal Alcohol Spectrum Disorders in Australia: An Update*, Intergovernmental Committee on Drugs: Working Party on Fetal Alcohol Spectrum Disorders (2009), p 19.

²⁵ L Burns, E Black and E Elliott (eds), *Fetal Alcohol Spectrum Disorders in Australia: An Update*, Intergovernmental Committee on Drugs: Working Party on Fetal Alcohol Spectrum Disorders (2009), p 19.

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.²⁶

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.²⁷

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 21.²⁸

Every child, including a child with FASD, has the right to health, happiness and educational attainment.²⁹ 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

²⁶ See L Burns, E Black and E Elliott (eds), *Fetal Alcohol Spectrum Disorders in Australia: An Update*, Intergovernmental Committee on Drugs: Working Party on Fetal Alcohol Spectrum Disorders (2009), p 20.

²⁷ J Latimer, E Elliott, J Fitzpatrick, M Ferreira, M Carter, J Oscar and M Kefford (eds), *Marulu The Lililwan Project Fetal Alcohol Spectrum Disorders (FASD) Prevalence Study in the Fitzroy Valley: A Community Consultation*, The George Institute for Global Health (2010), p 6.

²⁸ J Latimer, E Elliott, J Fitzpatrick, M Ferreira, M Carter, J Oscar and M Kefford (eds), *Marulu The Lililwan Project Fetal Alcohol Spectrum Disorders (FASD) Prevalence Study in the Fitzroy Valley: A Community Consultation*, The George Institute for Global Health (2010), p 5.

²⁹ *Convention on the Rights of the Child*, 1989, preambular para 6, arts 23, 24, 25, 28, 29. At <http://www2.ohchr.org/english/law/crc.htm> (viewed 15 September 2010).

necessary.³⁰ 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’.³¹

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?³²

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.

(a) *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 2004.³³ 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.³⁴

There has been significant recent international focus on the importance of culture and identity in the development processes of Indigenous communities.³⁵ This work

³⁰ E Elliott, J Payne, A Morris, E Haan and C Bower, ‘Fetal alcohol syndrome: a prospective national surveillance study’ (2008) 93 *Archives of Disease in Childhood* 732.

³¹ A Hope, State Coroner of Western Australian, *Coronial inquest into 22 deaths in the Kimberley*, Ref No: 37/07, Coroner’s Court of Western Australia (2008), p 14.

³² J Ross, community member, in *Yajilara* (Directed by M Hogan, Reverb, 2009), 16:34.

³³ E Carter, community member and Chair of Marninwarntikura, meeting with the Aboriginal and Torres Strait Islander Social Justice Commissioner, Fitzroy Crossing, 2 August 2010.

³⁴ E Carter, community member and Chair of Marninwarntikura, meeting with the Aboriginal and Torres Strait Islander Social Justice Commissioner, Fitzroy Crossing, 2 August 2010.

³⁵ See Permanent Forum on Indigenous Issues, *Report of the ninth session*, UN Doc E/C.19/2010/15 (2010), paras 4-35. At http://www.un.org/esa/socdev/unpfii/documents/E_2010_43_EN.pdf (viewed 31 August 2010).

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.³⁶

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.

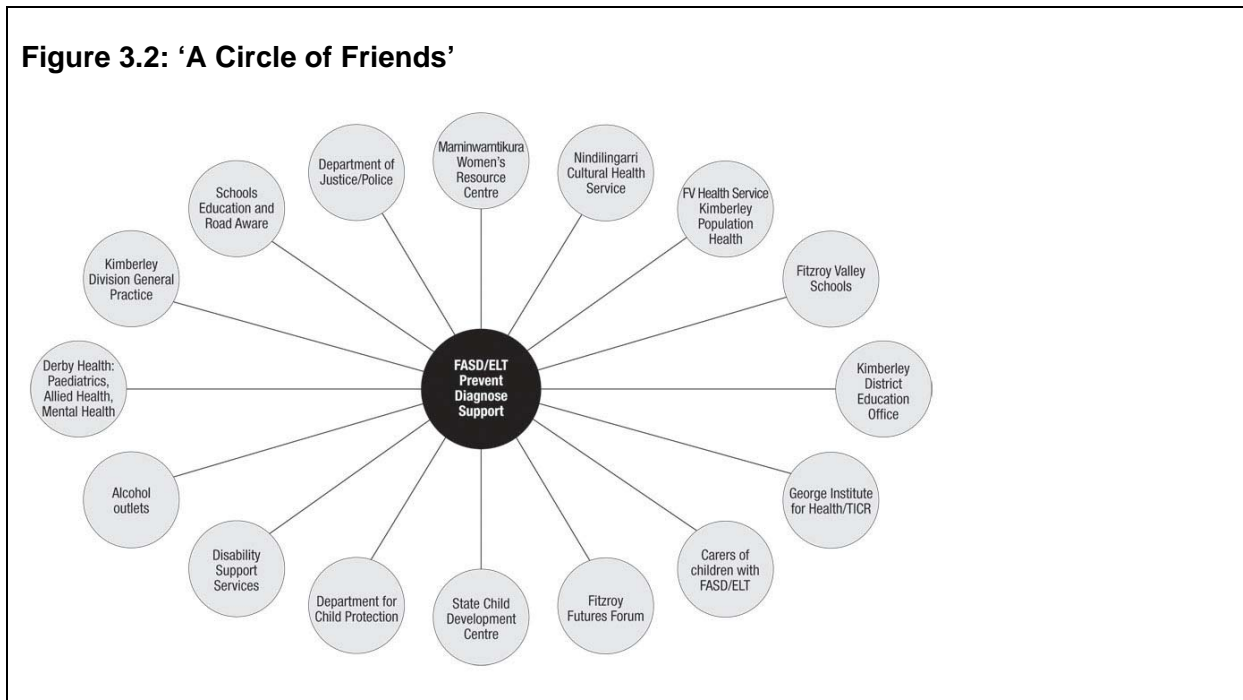
In October 2008, just over a year after the alcohol restrictions were brought into the Fitzroy Valley, members of the communities gathered to discuss FASD and other alcohol-related problems. The meeting was led by Aboriginal organisations Marninwarantikura and Nindilingarri Cultural Health Services (Nindilingarri). 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.³⁷

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':

³⁶ *United Nations Declaration on the Rights of Indigenous Peoples*, GA Resolution 61/295 (Annex), UN Doc A/RES/61/295 (2007), arts 11, 12, 13, 31. At <http://www.un.org/esa/socdev/unpfii/en/drip.html> (viewed 31 August 2009).

³⁷ J Latimer, E Elliott, J Fitzpatrick, M Ferreira, M Carter, J Oscar and M Kefford (eds), *Marulu The Lililwan Project Fetal Alcohol Spectrum Disorders (FASD) Prevalence Study in the Fitzroy Valley: A Community Consultation*, The George Institute for Global Health (2010).

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.

(i) The Marulu Project

In November 2008, a draft strategy was developed by the CEO of Marninwarrtikura, 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'.³⁸

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

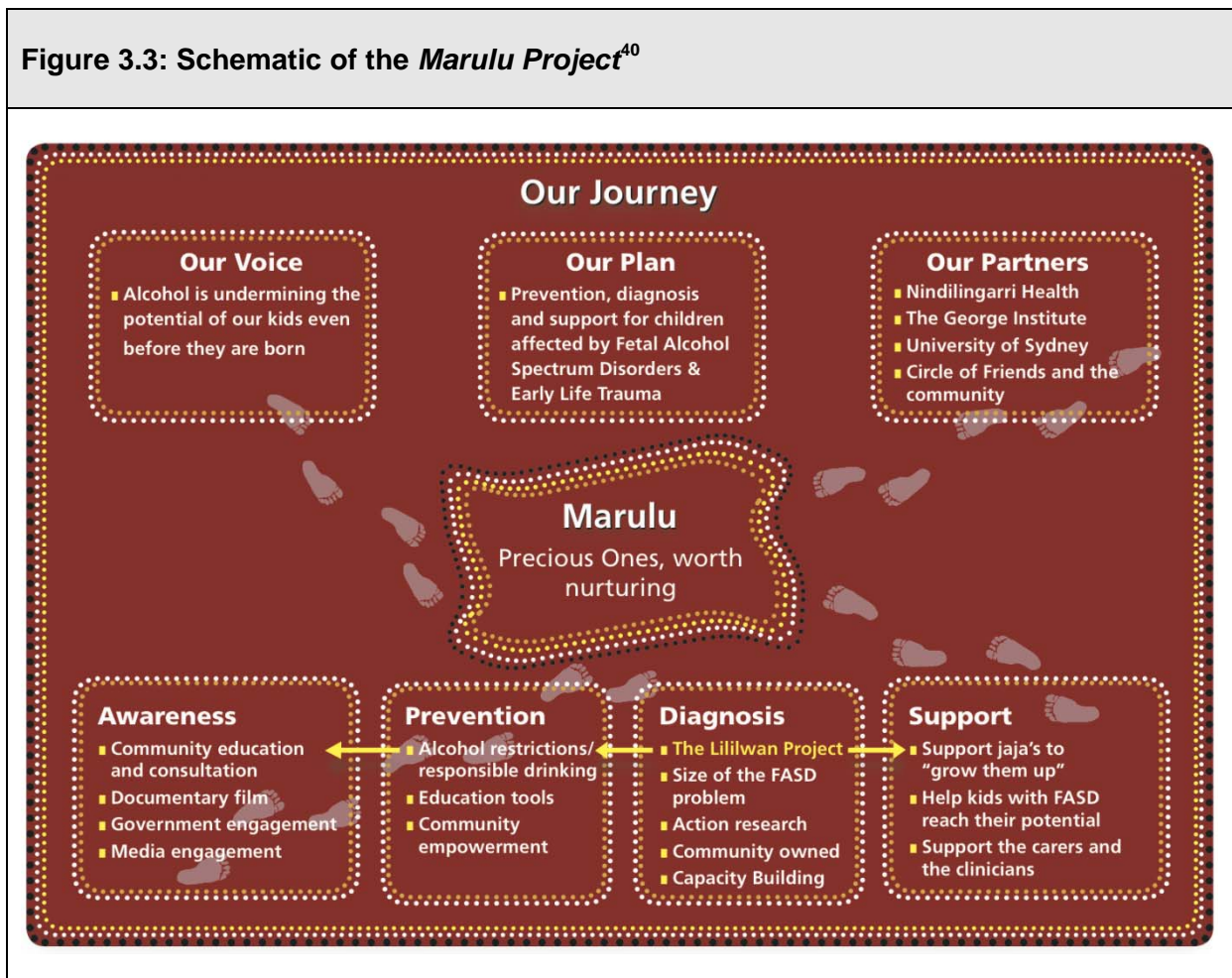
- Prevention – including consulting with the communities to raise awareness of the *Marulu Project*, education across the communities and working with women who are pregnant to prevent alcohol use.
- Diagnosis – including the development of screening and diagnostic processes.

³⁸ J Latimer, E Elliott, J Fitzpatrick, M Ferreira, M Carter, J Oscar and M Kefford (eds), *Marulu The Lililwan Project Fetal Alcohol Spectrum Disorders (FASD) Prevalence Study in the Fitzroy Valley: A Community Consultation*, The George Institute for Global Health (2010), p vi.

- 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.³⁹

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

Figure 3.3: Schematic of the *Marulu Project*⁴⁰



³⁹ J Latimer, E Elliott, J Fitzpatrick, M Ferreira, M Carter, J Oscar and M Kefford (eds), *Marulu The Lillilwan Project Fetal Alcohol Spectrum Disorders (FASD) Prevalence Study in the Fitzroy Valley: A Community Consultation*, The George Institute for Global Health (2010), pp 23-24.

⁴⁰ The Marulu project team: M Carter, J Oscar, E Elliott, J Latimer, J Fitzpatrick, M Ferreira, M Kefford.

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.⁴¹

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.⁴²

⁴¹ J Latimer, E Elliott, J Fitzpatrick, M Ferreira, M Carter, J Oscar and M Kefford (eds), *Marulu The Lililwan Project Fetal Alcohol Spectrum Disorders (FASD) Prevalence Study in the Fitzroy Valley: A Community Consultation*, The George Institute for Global Health (2010) pp 28-29.

⁴² J Latimer, The George Institute, meeting with the Office of the Aboriginal and Torres Strait Islander Social Justice Commissioner, Sydney, 22 July 2010.

(b) *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.⁴³

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.⁴⁴

⁴³ J Oscar, community member and CEO of Marninwarntikura, meeting with the Aboriginal and Torres Strait Islander Social Justice Commissioner, Broome, 3 August 2010.

⁴⁴ M Carter, community member and CEO of Nindilingarri, meeting with the Aboriginal and Torres Strait Islander Social Justice Commissioner, Fitzroy Crossing, 2 August 2010.

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.⁴⁵

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.⁴⁶ External players are brought in to provide strategic support.

(c) *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.⁴⁷

The prevalence study is known as the *Lililwan Project*. Lililwan is a Kriol word meaning 'all the little ones'.⁴⁸ 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

⁴⁵ J Latimer, The George Institute, meeting with the Office of the Aboriginal and Torres Strait Islander Social Justice Commissioner, Sydney, 22 July 2010.

⁴⁶ See T Calma, Aboriginal and Torres Strait Islander Social Justice Commissioner, *Native Title Report 2008*, Australian Human Rights Commission (2009), ch 7. At http://www.humanrights.gov.au/social_justice/nt_report/ntreport08/chapter7.html (viewed 12 August 2010).

⁴⁷ M Carter, community member and CEO of Nindilingarri, meeting with the Aboriginal and Torres Strait Islander Social Justice Commissioner, Fitzroy Crossing, 2 August 2010.

⁴⁸ J Latimer, E Elliott, J Fitzpatrick, M Ferreira, M Carter, J Oscar and M Kefford (eds), *Marulu The Lililwan Project Fetal Alcohol Spectrum Disorders (FASD) Prevalence Study in the Fitzroy Valley: A Community Consultation*, The George Institute for Global Health (2010), p vi.

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.⁴⁹

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.⁵⁰

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.⁵¹

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.⁵²

⁴⁹ J Latimer, The George Institute, meeting with the Office of the Aboriginal and Torres Strait Islander Social Justice Commissioner, Sydney, 22 July 2010.

⁵⁰ J Latimer, E Elliott, J Fitzpatrick, M Ferreira, M Carter, J Oscar and M Kefford (eds), *Marulu The Lililwan Project Fetal Alcohol Spectrum Disorders (FASD) Prevalence Study in the Fitzroy Valley: A Community Consultation*, The George Institute for Global Health (2010).

⁵¹ J Latimer, The George Institute, meeting with the Office of the Aboriginal and Torres Strait Islander Social Justice Commissioner, Sydney, 22 July 2010.

⁵² J Anaya, *Report of the Special Rapporteur on the situation of human rights and fundamental freedoms of indigenous people, James Anaya*, Report to the Human Rights Council, 12th session, UN Doc A/HRC/12/34 (2009), para 36. At <http://unsr.jamesanaya.org/PDFs/Annual2009.pdf> (viewed 9 August 2010).

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 Peoples⁵³ and the Special Rapporteur:⁵⁴

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.

⁵³ Human Rights Council, *Progress report on the study on indigenous peoples and the right to participate in decision-making: Report of the Expert Mechanism on the Rights of Indigenous Peoples*, Report to the Human Rights Council, 15th session, UN Doc A/HRC/15/35 (2010), paras 21-25. At http://www2.ohchr.org/english/bodies/hrcouncil/docs/15session/A.HRC.15.35_en.pdf (viewed 23 September 2010).

⁵⁴ J Anaya, *Report of the Special Rapporteur on the situation of human rights and fundamental freedoms of indigenous people*, James Anaya, Report to the Human Rights Council, 12th session UN Doc A/HRC/12/34 (2009), paras 36-57. At <http://unsr.jamesanaya.org/PDFs/Annual2009.pdf> (viewed 9 August 2010).

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.⁵⁵

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.⁵⁶

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.⁵⁷

The *Lililwan 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:
 - the communities broadly
 - 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.

⁵⁵ J Latimer, The George Institute, meeting with the Office of the Aboriginal and Torres Strait Islander Social Justice Commissioner, Sydney, 22 July 2010.

⁵⁶ M Carter, community member and CEO of Nindilingarri, meeting with the Aboriginal and Torres Strait Islander Social Justice Commissioner, Fitzroy Crossing, 2 August 2010.

⁵⁷ E Elliott, Sydney Medical School, The University of Sydney, meeting with the Office of the Aboriginal and Torres Strait Islander Social Justice Commissioner, Sydney, 25 October 2010.

3. An appropriate and adequate workforce.⁵⁸

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.⁵⁹

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.⁶⁰

(ii) 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.⁶¹

⁵⁸ J Latimer, E Elliott, J Fitzpatrick, M Ferreira, M Carter, J Oscar and M Kefford (eds), *Marulu The Lililwan Project Fetal Alcohol Spectrum Disorders (FASD) Prevalence Study in the Fitzroy Valley: A Community Consultation*, The George Institute for Global Health (2010), pp 17-18.

⁵⁹ Nindilingarri Cultural Health Services, *Marulu Update Report 1/2010* (2010).

⁶⁰ E Elliott, Sydney Medical School, The University of Sydney, meeting with the Office of the Aboriginal and Torres Strait Islander Social Justice Commissioner, Sydney, 25 October 2010.

⁶¹ M Carter, community member and CEO of Nindilingarri, meeting with the Aboriginal and Torres Strait Islander Social Justice Commissioner, Fitzroy Crossing, 2 August 2010.

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.⁶²

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.⁶³

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.⁶⁴

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 *Lililwan 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

⁶² J Latimer, The George Institute, meeting with the Office of the Aboriginal and Torres Strait Islander Social Justice Commissioner, Sydney, 22 July 2010.

⁶³ J Latimer, The George Institute, meeting with the Office of the Aboriginal and Torres Strait Islander Social Justice Commissioner, Sydney, 22 July 2010.

⁶⁴ M Carter, community member and CEO of Nindilingarri, meeting with the Aboriginal and Torres Strait Islander Social Justice Commissioner, Fitzroy Crossing, 2 August 2010.

Aboriginal Health Planning Forum.⁶⁵ 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.⁶⁶ Each part of the *Liliwan Project* will go through this arduous – but absolutely essential and extremely helpful – process.⁶⁷

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.⁶⁸

In addition to high participation rates, the Research Team reports that Stage 1 of the project has produced high quality data.⁶⁹

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.⁷⁰

The community driven nature of the *Liliwan 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.

(iii) 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

⁶⁵ See Kimberley Aboriginal Medical Services Council, Kimberley Aboriginal Health Planning Forum, <http://www.kamsc.org.au/research/kaahpf.html> (viewed 28 October 2010).

⁶⁶ Kimberley Aboriginal Medical Services Council, Kimberley Aboriginal Health Planning Forum, <http://www.kamsc.org.au/research/kaahpf.html> (viewed 28 October 2010).

⁶⁷ E Elliott, Sydney Medical School, The University of Sydney, meeting with the Office of the Aboriginal and Torres Strait Islander Social Justice Commissioner, Sydney, 25 October 2010.

⁶⁸ J Latimer, The George Institute, interview with the Office of the Aboriginal and Torres Strait Islander Social Justice Commissioner, Sydney, 22 July 2010.

⁶⁹ J Latimer, The George Institute, interview with the Office of the Aboriginal and Torres Strait Islander Social Justice Commissioner, Sydney, 22 July 2010.

⁷⁰ J Latimer, The George Institute, interview with the Office of the Aboriginal and Torres Strait Islander Social Justice Commissioner, Sydney, 22 July 2010.

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.⁷¹ 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.

(d) 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.

⁷¹ The Hon J Macklin MP, Minister for Families, Housing, Community Services and Indigenous Affairs and The Hon W Snowden MP, Minister for Indigenous Health, 'Foetal Alcohol Spectrum Disorder study', (Media Release 17 July 2010). At http://www.jennymacklin.fahcsia.gov.au/mediareleases/2010/Pages/foetal_alcohol_study_17july10.aspx (viewed 10 August 2010).

- 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.