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The Lililwan Collaboration: Inquiry into Fetal Alcohol Spectrum Disorders (FASD)

Submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs, 23rd March, 2012.

ACKNOWLEDGEMENTS

The Lililwan[1] Project is a prevalence study on Fetal Alcohol Spectrum Disorders (FASD) in the Fitzroy Valley. It is part of the Marulu* strategy developed by the Aboriginal community to address the diagnosis and prevention of FASD and provide support for families of affected children. The partners in The Lililwan Collaboration are Marninwarntikura Women's Resource Centre and Nindilingarri Cultural Health Services in the Fitzroy Valley and The George Institute for Global Health and The Sydney Medical School, University of Sydney.

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Cover Image: Bruce Hunt, Revolver.

[1] Lililwan is a Kimberley Kriol word meaning "all the little ones". Marulu is a Bunuba word meaning "precious, worth nurturing".

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EXECUTIVE SUMMARY

As foreshadowed in The Lililwan Project Collaboration's preliminary submission dated 8th December 2011, this document expands on its overall recommendations and highlights a specific opportunity that could be harnessed now to advance the prevention, diagnosis and management of FASD in Australia.

The present submission uses the expertise of The Lililwan Project Collaboration to offer a multifaceted approach to progress the FASD agenda in Australia. We recognise that progressing the agenda nationally is a complex undertaking and will involve significant commitment of time, energy and resources. At the same time, our experience suggests that it is possible to build momentum for the larger scale endeavour from smaller scale local success.

In this submission we outline a potential path to achieving a cohesive, national approach that is evidence-based, effective, and community owned. The path is based on a convergence of iterative local successes with larger scale national action. The purpose of this submission is to harness the full continuum of opportunities for impact as part of the development of a national approach to intervention, prevention and management of FASD in Australian communities.

Alongside development of the national agenda we propose to:

- raise national awareness of FASD
- consolidate a national reference group
- engage with key national stakeholders
- capitalise on the successes of The Lililwan Project

The approach used in The Lililwan Project for diagnosis of FASD and development of an individual management plan for affected children, provides a model that is widely recognised as best practice.

Our plan builds on the lessons learned and achievements of The Lililwan Project. An evaluation of the inter-disciplinary model of care used in thIs project is timely, as is its trial in appropriate settings outside the Fitzroy Valley.

In taking the next steps The Lililwan Project Collaboration would welcome the support of colleagues and other organisations who have an interest in FASD, many of whom have highlighted the Fitzroy Valley model in their submissions to the Inquiry Committee.

The Lililwan Project Collaboration remains committed to supporting the Inquiry and assisting the Commonwealth Government to address the challenges of FASD.

INTRODUCTION

Position

Scope of this submission

As foreshadowed in The Lililwan Project Collaboration's preliminary submission dated 8th December 2011 (see Appendix A), this document expands on the overall recommendations and highlights a specific opportunity that could be harnessed now to advance the prevention and management of FASD in Australia.

The preliminary submission (found at: http://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=/spla/fasd/subs.htm)provided an overview of the key challenges of FASD in Australia and made a suite of overall recommendations against the Inquiry Terms of Reference. The submissions of other key stakeholders and colleagues – The Foundation for Alcohol Research and Education (FARE), The Australian FASD Collaboration, the Australian Human Rights Commission, Blake Dawson, The Telethon Institute for Child Health Research and the Rural Health Alliance to name several - are welcomed and cover essential ground across the Terms of Reference. In particular, FARE'S call for a National FASD Plan to map out responsibilities, priorities and targets is one supported by this submission.

The Lililwan Project Collaboration intends to engage actively in ongoing discussion of such a plan. In the spirit of identifying high priority opportunities, the present submission draws the attention of the Inquiry Committee to the success of a community-initiated model for diagnosis and management of FASD that was put in place in Fitzroy Crossing for the Lililwan Project and, to the fact that the potential of the model is well recognised by others. One recommendation of the FARE submission is the need to:

> *"Develop culturally specific prevention, intervention and management strategies for Aboriginal and Torres Strait Islander peoples that are supported and managed by local communities. These strategies should be based on current good practice examples such as the 'Marulu Strategy' in Western Australia."*[2]

Perhaps most importantly, this submission aims to outline an approach for capitalising on the success drivers of the Fitzroy Valley model, and the opportunity the model presents for 'quick wins' within a broader and longer-term framework of national action on FASD.

Value Proposition

The community-initiated model of diagnosis and management of FASD trialled in the Indigenous communities of the Kimberley's Fitzroy Valley is a unique mix of community drive and engagement with academic and health expertise. The Lililwan Project Collaboration has successfully brought current medical knowledge to assess and begin to address the challenges of FASD in the Fitzroy Valley. The model was built from first principles with the initiative, support, consent and engagement of the community and its leaders.

> *The project is "a genuine partnership - one where research is done **with** the community and not just **about** the community*[3]

[2] Foundation for Alcohol Research & Education. Submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs: Inquiry into Fetal Alcohol Spectrum Disorders, 2011

[3] Mick Gooda, Aboriginal and Torres Strait Islander Social Justice Commissioner. In:
Latimer J, Elliott E, Fitzpatrick J, Ferreira M, Carter M, Oscar J, Kefford M. Marulu, The Lililwan Project. Fetal Alcohol Spectrum Disorders (FASD) Prevalence Study in the Fitzroy Valley. A Community Consultation. The George Institute for Global Health, April 2012. ISBN 978-0-646-53390-2

The ability and reputation of this group to provide academic expertise (EE, JL, JF) is evidenced by the Inquiry Committee's request to them for background materials. Australian publications relating to FASD were provided with the preliminary submission (see Appendix B). In addition, the team includes Aboriginal people (JO, MC) able to provide cultural context for the work. Beyond research, the project team is able to provide real world experience of a model for engaging all voices in the solution – across many stakeholders and disciplines, nationally and internationally – that is, most importantly community-owned and driven. The clinical team consists of a paediatrician, occupational therapist, clinical psychologist, physiotherapist, speech therapist and local Aboriginal People (Community Navigators) with local language skills and trained in research techniques (Appendix C).

> *A partnering of the Fitzroy Valley community with researchers at The George Institute and The University of Sydney is "setting an example to the rest of Australia of how to best approach Indigenous Affairs. A process guided by a relationship underpinned by meaningful, respectful engagement and collaboration."*[4]

There is a unique opportunity to capitalise on this existing model, utilising the academic and Aboriginal expertise of The Lililwan Project Collaboration. The transferable lessons and key success drivers of The Lililwan Project need to be captured in a robust and comprehensive evaluation. The evaluation would provide the starting point for mobilising implementation and evaluation of the model of care in other communities in Australia. The design of an evaluation should build in opportunities for feedback that would provide essential evidence and insight to policy makers and the communities themselves while a broader and longer term National FASD Plan is designed and implemented. Suggested next steps are outlined later in this document.

> *"The Marulu Project for overcoming FASD and early life trauma in the Fitzroy Valley will have far-reaching implications which need to be taken up by all agencies and services."*[5]

OVERALL PICTURE

Background

The condition

Fetal Alcohol Spectrum Disorders (FASD) are tragic but preventable outcomes of exposure to alcohol during pregnancy. Alcohol exposure *in-utero* may result in a range of disorders that include brain injury, birth defects and lifelong learning, and behavioural and mental health issues. FASD are the most common causes of preventable intellectual impairment. Affected individuals also face a range of secondary disabilities as adults including unemployment, mental illness, alcohol and substance abuse and contact with the justice system. Individuals with Fetal Alcohol Syndrome (FAS) have characteristic facial features and may also have birth defects enabling relatively easy diagnosis[6]. However, a larger group of children in the FASD spectrum have neuro-developmental problems in the absence of facial or physical features and the diagnosis in these children is more difficult.

[4] Mick Gooda, Aboriginal and Torres Strait Islander Social Justice Commissioner. In: 2010 Social Justice Report Australian Human Rights Commission 2011. ISSN 1837-6428 (Print) and ISSN 1837-6436 (On-line)

[5] White, M Pathways to a good life well lived. Community owned Recovery Plan for overcoming suicidal despair in the Fitzroy Valley. Herculeia Consulting, September 2011 prepared for Marninwarntikura Fitzroy Women's Resource and Legal Centre, Marra Worra Worra Aboriginal Corporation, Nindilingarri Cultural Health and Kimberley Aboriginal Law and Cultural Centre.

[6] Elliott EJ, Payne J, Morris A, Haan E, Bower C. Fetal alcohol syndrome: a prospective national surveillance study. Arch Dis Child. 2008 Sep;93(9):732-7. Epub 2007 Aug 17.

Size of the problem

Service development and prevention depends on understanding the size of the problem of FASD. FASD prevalence in Australia has not been accurately determined. Past studies have been hampered by under-recognition and under-reporting. A high quality prevalence study is underway in the Fitzroy Valley - a high risk community (The Lililwan Project). The results of this study will be applicable to other communities in Australia with similar patterns of alcohol use.

The Lililwan Project

At a Women's Bush Meeting in 2008 the Fitzroy Valley communities identified the need to address Fetal Alcohol Spectrum Disorders (FASD) – the legacy of alcohol use in pregnancy - as an issue of particular concern[7]. In October 2008 a FASD leadership team was formed and in November 2008 they embraced a 'circle of friends' - partners in government, business and community organisations - and developed a strategy to address FASD. The strategy, called *Marulu* includes diagnosis and prevention of FASD, community education, and support for parents and carers of affected children[8]. Marulu is a word in the Bunuba language meaning "precious, worth nurturing".

In 2009 Indigenous leaders in Fitzroy Valley (Kimberley, WA) initiated a research partnership between Nindilingarri Cultural Health Services and Marninwarntikura Women's Resource Centre (both at Fitzroy Crossing), The George Institute for Global Health and The University of Sydney Medical School to conduct the first Australian study of FASD prevalence, which they called *The Lililwan Project*[9]. Lililwan is a Kriol (Aboriginal English) word meaning "all the little ones".

Stage 1 of the project (2009-11), funded by a philanthropist, included development and use of a medical history checklist to obtain information about antenatal exposures, early life trauma, health and development from parents and carers of all children born in 2002 or 2003. Stage 2 involves multi-disciplinary assessment of the health and development of these children and is funded by the Commonwealth (DOHA, FaHCSIA and Save the Children). *Pro bono* support has been provided by Ashurst (formerly Blake Dawson Solicitors), M&CSaatchi and The Australian Human Rights Commission.

The project will enable us to estimate the prevalence of FASD and other health problems and to develop individual treatment plans for children. The project includes community education, support for parents and carers and advice for teachers. It provides opportunities for capacity building in the community, including training and employment of local Aboriginal people. The unique data from the project will enable the community to advocate for improved health, community and education services.

The project demonstrates the importance of community led research. Australia's Aboriginal Torres Strait Islander Social Justice Commissioner, Mick Gooda, described the project as "a genuine partnership - one where research is done with the community and not just about the community," saying it is "setting an example to the rest of Australia" being a process "guided by a relationship underpinned by meaningful, respectful engagement and collaboration."

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[7] Elliott E, Latimer J, Fitzpatrick J, Oscar J, Carter M. There's hope in the valley. Journal of Paediatrics and Child Health 48 (2012) 190–192

[8] Kirby T. Blunting the legacy of alcohol abuse in Western Australia. *Lancet*. 2012 Jan 21;379(9812):207-8.

[9] Fitzpatrick J, Elliott E, Latimer J, Carter M, Oscar J, Ferriera M, Carmichael-Olson H, Lucas B, Doney R, Salter C, Peadon E, Hawkes G, Hand M. The Lililwan Project: study protocol for a population based, active case ascertainment study of the prevalence of Fetal Alcohol Spectrum Disorders (FASD) in remote Australian Aboriginal communities. In Press. *BMJ Open*. March 2012.

Overall Recommendations to the inquiry

The following recommendations – highlighted in our preliminary submission (see Appendix A) - target the broader challenges of FASD and the types of issues that would be incorporated in the National FASD Plan. We note that these concur with the suggestions in submissions from colleagues. We have highlighted the priority issues.

Prevention strategies

- **Develop and implement a national public health campaign to raise awareness of the harms of alcohol use in pregnancy, commencing at school age. In addition, targeted information for high-risk groups should be provided. Promote the use of film in advocacy**
- Fund high quality research evaluating prevention strategies to reduce alcohol use in pregnancy
- Improve access to services for women with alcohol dependency, and women using alcohol during pregnancy (and their partners)
- Educate health professionals to recognise women at risk and to use strategies to prevent alcohol use in pregnancy
- Encourage the uptake of National Health and Medical Research Council of Australia (NHMRC) guidelines on alcohol use in pregnancy and in women planning pregnancy
- Restrict access to alcohol e.g. through volumetric taxes, community-initiated restrictions (e.g. legislated 'dry' communities, restrictions on strength of take-away alcohol), responsible marketing and sale of alcohol products
- Legislate for warning labels on alcohol products and in licensed premises in relation to alcohol use in pregnancy. Labels should be easily legible, contain a clear meaning and should indicate the number of standard drinks per beverage
- Provide contraception advice for women of childbearing age who are drinking at risky levels

Intervention needs

- Adopt the Australian FASD Collaboration's recommendations regarding an Australian FASD diagnostic and screening tool and explore the rationale and content of a screening tool
- Embed FASD education and prevention messages in all undergraduate and postgraduate health related curricula
- Educate health professionals in diagnosis of FASD and assessment of health and developmental needs of affected children
- Improve the capacity of existing child development units and paediatric services to diagnose and manage FASD
- **Evaluate the feasibility of the interdisciplinary model of FASD diagnosis and management used in The Lililwan Project (in the Fitzroy Valley) and assess its potential for application in other Indigenous and non-Indigenous communities**
- Invest in high quality research evaluating treatments for FASD
- Implement evidence-based therapies for FASD as they become available
- Encourage State and Territory Education and Justice Departments to acknowledge and develop policy on FASD management
- Review State and Territory eligibility criteria for carer's allowance, disability allowance, and in school support to enable access for children with FASD

- Train teachers to understand the impact of FASD on learning, behaviour and educational attainment, and develop strategies for classroom management

Management

- **Fund and evaluate the Collaborative *Community Circle of Care model* developed in the Fitzroy Valley for support of families and children with FASD and provision of community education and support**
- Engage agencies including health, education, justice and policing, disability services, child protection, employment and training and housing to recognise the issue of FASD, and consider alternative education, training and employment pathways across the lifespan, such as therapeutic economies being developed in the Fitzroy Valley for people with FASD
- Review international best practice management strategies to inform management strategies for Australia

As well as considering the broad landscape, our preliminary submission briefly canvassed the potential of The Lililwan Project to provide opportunities for immediate progress across the Terms of Reference for the Inquiry.

Box 1 highlights recommendations from the preliminary submission that relate more directly to the model developed in The Lililwan Project. The remainder of our follow-up submission considers these in more detail.

Box 1 – Priority recommendations from preliminary submission

Inquiry Terms of Reference (TOR)	Priority Recommendations – Opportunity for Progress now
Prevention Strategies	➢ **Develop** and implement a national public health campaign to raise awareness of the harms of alcohol use in pregnancy, commencing at school age. Maintain alcohol restrictions in forcing remote communities, these being important to limit access to alcohol. In addition, targeted information for high-risk groups should be provided. Promote the use of film in advocacy. (Also see below under engagement opportunities)
Intervention Needs	➢ **Evaluate** the feasibility of the interdisciplinary model of FASD diagnosis and management used in The Lililwan Project (in the Fitzroy Valley) and assess its potential application in other remote Indigenous and non-Indigenous communities
Management	➢ **Fund** and evaluate the Collaborative Community Circle of Care model developed in the Fitzroy Valley for support of families and children with FASD and community education and support ➢ **Engage** agencies including health, education, justice and policing, disability services, child protection, employment and training and housing to recognise the issue of FASD, and consider alternative education, training and employment pathways (such as therapeutic economics being developed in the Fitzroy Valley) for people with FASD across the lifespan.

A UNIQUE OPPORTUNITY: CONVERGENCE OF LOCAL IMPACT AND NATIONAL ACTION

"Local people are saying that the valley has already lost one generation to alcohol abuse. Without decisive action now, it stands to lose a second generation."[10]

The major focus of this submission uses the expertise of The Lililwan Project team to offer a multifaceted approach to progress the FASD agenda. With others who have made submissions, we recognise that progressing the agenda nationally is a complex undertaking, involving significant commitment of time, energy and resources. At the same time, our experience suggests that it is possible to build momentum for the larger scale endeavour from aggregation of smaller scale local success, building in 'quick wins' along the way.

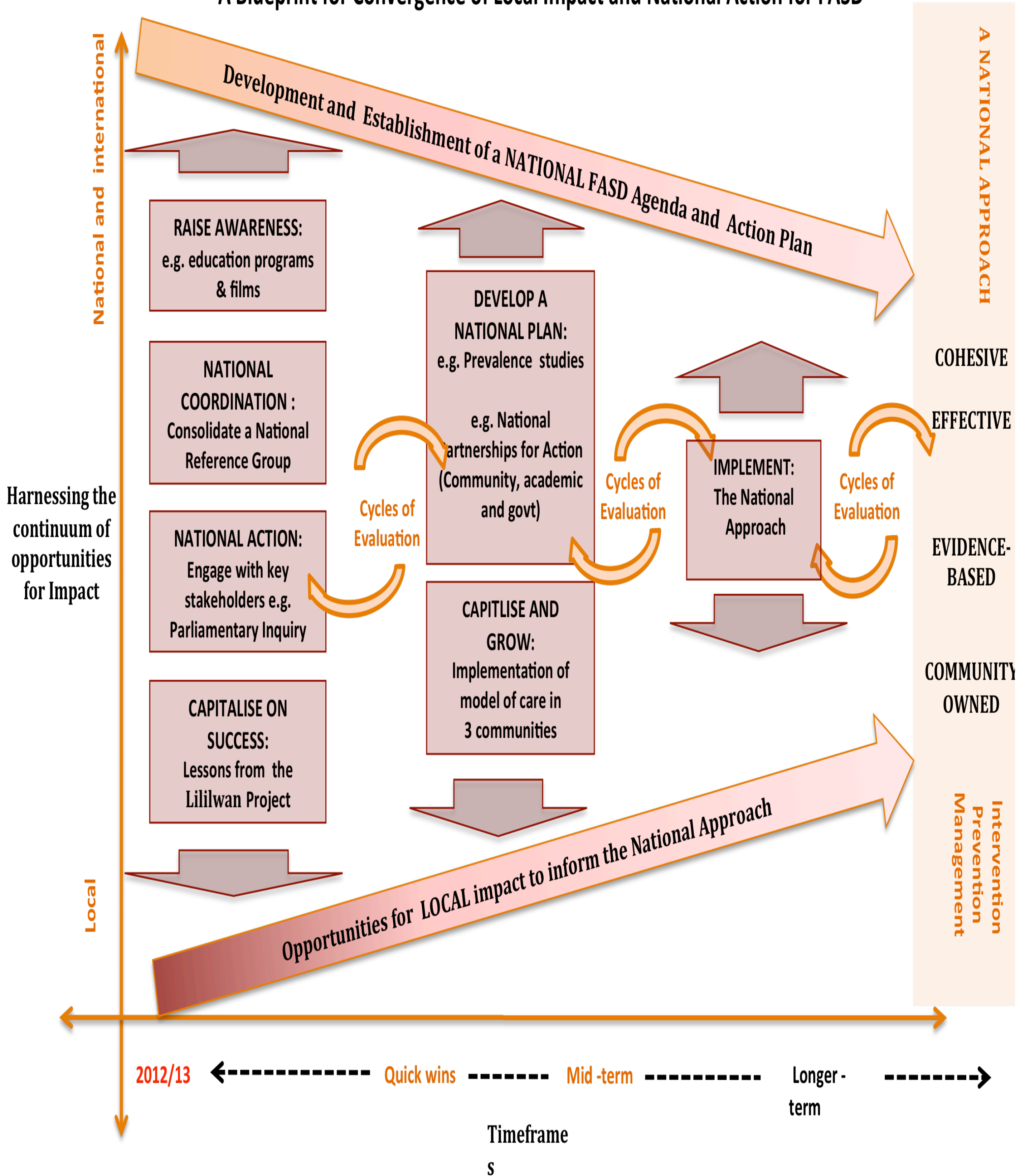
Simultaneously, governments must progress legislation to ensure that measures that have been proven to decrease alcohol use (eg: taxation, minimum pricing, restricted advertising and limiting access) are introduced.

The purpose of this submission is to offer a potential plan to harness the full continuum of opportunities for impact as part of the development of a national approach to intervention, prevention and management of FASD in Australian communities. The fundamental premise of our proposition is that achieving a cohesive, evidence-based, effective and community owned approach for FASD is based on a convergence of iterative local successes with larger scale national action.

Figure 1 provides a schematic representation of developing a national approach for FASD, based on convergence of local, national and international action. Briefly, the high level blueprint we envisage can be seen as having three chronological phases. These are not meant to represent discrete timelines, but rather to signal that the national plan is underpinned by a necessary timeframe, ranging from the immediate to the longer term. Below we describe the potential intersecting lines of activity that across time, will contribute to immediate ('quick wins'), medium-term and longer term success in developing a national approach to FASD. Activity is described at a high level to illustrate the sorts of component parts of building the national approach, based on our experience, and acknowledging the recommendations made by our colleagues.

7 White, M Pathways to a good life well lived. Community owned Recovery Plan for overcoming suicidal despair in the Fitzroy Valley. Herculeia Consulting, September 2011 prepared for Marninwarntikura Fitzroy Women's Resource and Legal Centre, Marra Worra Worra Aboriginal Corporatio Nindilingarri Cultural Health and Kimberley Aboriginal Law and Cultural Centre

Figure 1



Phase 1 – Developing the National FASD AGENDA

The first phase of building the national approach for FASD is likely to be concerned with developing a cohesive national agenda. The four key streams of work in this first phase will be around raising awareness, establishing national coordination mechanisms, establishing national action mechanisms and feeding in the lessons from The Lililwan Project (see Figure 1).

Raising awareness

This stream of work will include a range of educational and communication campaigns. These are likely to use a range of media, and tailor messages for a range of important target groups. For example, during the course of The Lililwan Project documentaries entitled 'Marulu' [11]and 'Tristan' were developed to raise awareness of FASD. 'Tristan' will be launched by the Governor General of Australia in Sydney in April 2012 and shown at the Eleventh Session of the United Nations Permanent Forum on Indigenous Issues at the United Nations Headquarter in New York, 7-18 May 2012.

> *"Tristan will show the challenges faced by a child and his family who are living with FASD."*[12]

National coordination

A core theme agreed among colleagues in this field, and reflected in most submissions is the absolute need for a national group to drive the development of the approach to FASD. Necessarily this group will need to represent a range of key interests, but also a range of expertise. An existing national group, the Australian FASD Collaboration (Appendix D) might be appropriate to form the basis of the to-be-convened national coordination body, named the FASD *National Advisory Council* for descriptive purposes in this submission. This group will need to include government members, academics, clinicians, researchers, community representatives, parents, advocates and a range of health professionals. The role of this group would be to drive the development of the national approach. They should be charged with responsibility for detailed action planning, refinements in approach, setting of and reporting against key performance indicators and bringing to bear the best evidence available to inform the national approach to FASD including service delivery research, prevention, advocacy and support for families living with FASD.

National action

In the Australian context, 'national action' certainly requires formal buy-in of Commonwealth, State and Territory Governments. As well as formal arrangements across governments, engagement across portfolios, across health and community service professionals and across communities is critical to successfully mobilising a national approach. Comprehensive stakeholder engagement is a foundation of the development of a national approach. Development and execution of the stakeholder engagement strategy will need time and resources to be successful. The *National Advisory Council* would oversee development and execution of the stakeholder engagement plan.

Capitalising on local success: capturing the lessons of The Lililwan Project

Over decades Aboriginal leaders in the Fitzroy Valley noticed an increasing number of children with special needs and recognised that they had been exposed to alcohol *in utero*. In collaboration with their partners (The George Institute for Global Health and The University of Sydney) the communities of the Fitzroy Valley have developed and enacted a community-led strategy to prevent, diagnose and manage FASD and to support families caring for affected children. The strategy is called Marulu, a Bunaba language word meaning *precious,*

[11] Hogan M, Latimer J, for The Lililwan Project: Marulu. A documentary. 2012. Copyright Nindilingarri Cultural Health Services.
[12] Hogan M, Latimer J, for The Lililwan Project: Tristan. A documentary. 2012. Copyright Marninwarntikura Women's Resource Centre

worth nurturing. The Lililwan Project which forms part of this strategy was initiated to determine FASD prevalence in the Fitzroy Valley.

The approach used in The Lililwan Project for diagnosis of FASD and development of an individual management plan for affected children, provides a model that is widely recognised as best practice. The lessons provided by the Project need to be captured, and the general principles distilled to underpin community-led approaches elsewhere. In partnership with the Lililwan Collaboration, an evaluation focused on transferrable lessons should be funded, and overseen by the *National Advisory Council*.

> *Recommendation #4: That government and other investments take community direction, backed up by research provided by the Marulu Project team, on what family support and other services need urgent funding in order to prevent early life trauma and FASD."[13]*

Phase 2 – Development of a National FASD Plan

The second phase of the development of a national approach would have two broad areas of focus: the development of the National Plan, and growth of further examples of local success

Development of the National Plan

The *National Advisory Council* would oversee the development of a National Plan. There would be a range of sub-activities, defined during the first phase of activities. A specific high priority, referenced in most submissions, is the imperative to improve data collection on FASD in line with standard best practice in public and community health. The ultimate ambition should be to develop and maintain a national data repository. Without these data, it will be difficult for the impact of strategies to be understood and measured.

> *"Barriers to diagnosis are accentuated in rural, remote and Indigenous communities where access to health services is limited. Lack of identification of FASD means we are unable to quantify the problem and thus lack evidence to advocate for much needed health professional training and diagnostic services."[14]*

Mobilising a data repository of appropriate quality is a longer-term undertaking. In the short to medium term, it is widely agreed that population based prevalence studies should be funded in a range of populations, Indigenous and non-Indigenous, and a range of settings, urban, rural and remote. The *National Advisory Council* would oversee the development and execution of major prevalence studies. The results would be used to inform the delivery of the national approach to prevention, intervention and management of FASD.

> *"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."[15]*

The development of the National Plan, and its inputs, are likely to rely heavily on a range of National Partnerships for action across communities, academics and Governments. This stream of activity will need to be strategically developed and overseen by the *National Advisory Council*.

[13] White, M Pathways to a good life well lived. Community owned Recovery Plan for overcoming suicidal despair in the Fitzroy Valley. Herculeia Consulting, September 2011 prepared for Marninwarntikura Fitzroy Women's Resource and Legal Centre, Marra Worra Worra Aboriginal Corporation, Nindilingarri Cultural Health and Kimberley Aboriginal Law and Cultural Centre.

[14] Telethon Institute for Child Health Research
Submission to House Standing Committee on Social Policy and Legal Affairs Inquiry into Foetal Alcohol Spectrum Disorder

[15] Mick Gooda, Aboriginal and Torres Strait Islander Social Justice Commissioner. In: 2010 Social Justice Report Australian Human Rights Commission 2011. ISSN 1837-6428 (Print) and ISSN 1837-6436 (On-line)

Capitalising and growing local success

The potential value of the Fitzroy Model of diagnosis and management of FASD is well-recognised. Distillation of the transferrable lessons from the model (Phase 1) provide a starting point for the broader roll out of the principles of the model – as articulated in a range of commentary[16]. A stream of work converging on the development of a national approach to investigate the transferability of the model is essential. Accordingly a medium term activity should focus on the implementation and evaluation of the Fitzroy Model of diagnosis and management of FASD in other Australian communities, to ascertain feasibility and requirements. As part of this activity, the *National Advisory Council* would oversee the development and conduct of the feasibility study. It is likely that advice would be required on such matters as:

- Identifying appropriate demonstration sites and interested communities
- Identifying funding needs and personnel
- Developing appropriate consultation and engagement models
- Implementing the Model in the communities
- Evaluating design and execution

We note the work of the Marulu Project in the Fitzroy Valley (with which the Committee is familiar) and commend the Project to the Inquiry as a model for community devised and driven solutions to community challenges. We suggest projects such as this should be supported as part of any strategy to address FASD rather than government taking a wholly generalised approach to prevention and intervention, given FASD exists in many disparate communities. [17]

Phase 3 – Implementation of a National Approach

Phase 3, the most distal of the phases in the development of the national approach, is less specified. Its features depend entirely on the developments of the earlier phases, and on the converging lines of evidence accumulated. Key principles that will drive effective implementation can be identified; the national approach must be cohesive, evidence based and community owned.

Conclusions

The Inquiry presents an opportunity to consider a comprehensive national approach to a significant health issue that, to date, has not received appropriate attention or service support in Australia. In part the lack of public profile for FASD is the umbrella nature of the diagnosis, and the absence of high quality prevalence data. This submission acknowledges the significant and longer-term nature of the effort that will be required to address the gaps in developing a national approach to the prevention, intervention and management of FASD. However, this submission also highlights that local success with immediate smaller scale outcomes can be marshalled at the same time, and could very effectively feed into, the longer- term developments.

The Lililwan Project Collaboration remains committed to supporting the Inquiry and assisting the Commonwealth Government to address the challenges of FASD.

[16] Kirby T. Blunting the legacy of alcohol use in Western Australia. World Report. Lancet 2012. Vol 379: 207-208.
[17] Blake Dawson
Submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs: people with Foetal Alcohol Spectrum Disorder in the disability regime and criminal justice system
http://www.hreoc.gov.au/social_justice/sj_report/sjreport10/chap3.html.

APPENDICES

Appendix A – Preliminary Submission 8th December 2011[18]

Preliminary Submission to The House Standing Committee on Social Policy and Legal Affairs *Inquiry into Fetal Alcohol Spectrum Disorders (FASD)* on behalf of The Lililwan Collaboration

Prepared by: Prof Elizabeth Elliott, Ms June Oscar, Dr James Fitzpatrick, A/Prof Jane Latimer on behalf of Ms Maureen Carter and The Lililwan Project Team

Introduction

Purpose

The purpose of this submission is to:

- Outline the scope of a detailed document we will submit to the Committee by February 17th, 2012,
- Support the presentation we made to the Inquiry Committee on Thursday, 24 November 2011, as recorded in Hansard,
- Supply relevant Australian literature about FASD, as requested by the Committee (attached).

The condition

Fetal Alcohol Spectrum Disorders (FASD) are tragic but preventable outcomes of exposure to alcohol during pregnancy. Alcohol exposure in-utero may result in a range of disorders that include brain injury, birth defects, lifelong learning, and behavioural and mental health issues. Fetal Alcohol Spectrum Disorders are the most common cause of preventable intellectual impairment. Those affected face a range of secondary disabilities as adults including unemployment, mental illness, alcohol and substance abuse and contact with the justice system. Individuals with Fetal Alcohol Syndrome (FAS) have characteristic facial features enabling relatively easy diagnosis. However a larger group of children in the FASD spectrum have neuro-developmental problems in the absence of physical features and the diagnosis of these children is more difficult.

Size of the problem

FASD prevalence in Australia has not been accurately determined. Past studies have been hampered by under-recognition and under-reporting. A high quality prevalence study is underway in the Fitzroy Valley (The Lililwan Project). The results of this study will be applicable to other communities in Australia with similar patterns of alcohol use.

Community-led response to FASD

Over decades Aboriginal leaders in the Fitzroy Valley noticed an increasing number of children with different needs and recognised that they had been exposed to alcohol in-utero. In collaboration with their partners (The George Institute for Global Health, and The University of Sydney) the communities of the Fitzroy Valley have led the way in developing community-based strategies to prevent and diagnose FASD and to support families caring for affected children. These strategies demonstrate the critical role of community in developing and owning the approach to addressing the challenges of FASD.

[18] http://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=/spla/fasd/subs.htm

RECOMMENDATIONS

Prevention Strategies

- Develop and implement a national public health campaign to raise awareness of the harms of alcohol use in pregnancy, commencing at school age. In addition targeted information for high-risk groups should be provided. Promote the use of film in advocacy
- Fund high quality research evaluating prevention strategies to reduce alcohol use in pregnancy
- Improve access to services for women with alcohol dependency, and women using alcohol during pregnancy (and their partners)
- Educate health professionals to recognise women at risk and to use strategies to prevent alcohol use in pregnancy
- Encourage the uptake of NHMRC guidelines on alcohol use in pregnancy
- Restrict access to alcohol e.g. through volumetric taxes, community-initiated restrictions, responsible marketing and sale of alcohol products
- Legislate for warning labels on alcohol products and in licensed premises. Labels should also indicate the number of standard drinks per beverage
- Provide contraception advice for women of childbearing age who are drinking at risky levels

Intervention Needs

- Adopt the Australian FASD Collaboration's recommendations regarding an Australian FASD diagnostic and screening tool
- Embed FASD education and prevention messages in all undergraduate and postgraduate health related curricula
- Educate health professionals in diagnosis of FASD and assessment of health and developmental needs of affected children
- Improve the capacity of existing child development units and paediatric services to diagnose and manage FASD
- Evaluate the feasibility of the interdisciplinary model of FASD diagnosis and management used in The Lililwan Project (in the Fitzroy Valley) for application in other communities
- Invest in high quality research evaluating treatments for FASD
- Implement evidence-based therapies for FASD as they become available
- Encourage State and Territory Education and Justice Departments to acknowledge and develop policy on FASD management
- Review State and Territory eligibility criteria for carer's allowance, disability allowance, and in school support to enable access for children with FASD
- Train teachers to understand the impact of FASD on learning, behaviour and educational attainment, and strategies for classroom management

Management

- Fund and evaluate the Collaborative Community Circle of Care model developed in the Fitzroy Valley for support of families and children with FASD and community education and support
- Engage agencies including health, education, justice and policing, disability services, child protection, employment and training and housing to recognise the issue of FASD, and consider alternative education, training and employment pathways (such as those being developed in the Fitzroy Valley) for people with FASD across the lifespan
- Review international best practice management strategies to inform management strategies for Australia

GENERAL RECOMMENDATIONS

That the Committee:

- Visit the Fitzroy Valley to consult with the FASD Leadership Team including Marninwarntikura Women's Resource Centre and Nindilingarri Cultural Health Services
- Consult with member of The Lililwan Project Collaboration
- Consult with the Australian Human Rights Commission (Disability, Social Justice, Sex Discrimination Units) and Blake Dawson Lawyers (Anne Cregan, Robert Todd) regarding legal issues relating to disability status for FASD
- Consult with relevant stakeholders including the Telethon Institute for Child Health Research (Prof Carol Bower), consumer groups (NOFASARD, Russell Family Foundation), the National Indigenous Australian FAS Education Network (NIAFASEN), Foundation for Alcohol Research and Education (FARE)
- Adopt the recommendations from the Intergovernmental Committee on Drugs Working Party on FASD Monograph

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Appendix B – Australian Publications relating to FASD

A list of Australian publications relating to FASD.

Ascertainment of birth defects: the effect on completeness of adding a new source of data.
Bower C, Silva D, Henderson TR, Ryan A, Rudy E.
J Paediatr Child Health. 2000 Dec;36(6):574-6.
PMID: 11115034

Differing influences on Aboriginal and non-Aboriginal neonatal phenotypes: a prospective study.
Humphrey MD, Holzheimer DJ.
Med J Aust. 2001 May 21;174(10):503-6.
PMID: 11419769

Prevalence of **fetal alcohol** syndrome in the Top End of the Northern Territory.
Harris KR, Bucens IK.
J Paediatr Child Health. 2003 Sep-Oct;39(7):528-33.
PMID: 12969208

Fetal alcohol syndrome: diagnosis, epidemiology, and developmental outcomes.
O'Leary CM.
J Paediatr Child Health. 2004 Jan-Feb;40(1-2):2-7. Review.
PMID: 14717994

FAS in **Australia**: fact or fiction?
Elliott EJ, Bower C.
J Paediatr Child Health. 2004 Jan-Feb;40(1-2):8-10.
PMID: 14717995

Health professionals' knowledge, practice and opinions about **fetal alcohol** syndrome and **alcohol** consumption in pregnancy.
Payne J, Elliott E, D'Antoine H, O'Leary C, Mahony A, Haan E, Bower C.
Aust N Z J Public Health. 2005 Dec;29(6):558-64.
PMID: 16366068

Use of record linkage to examine **alcohol** use in pregnancy.
Burns L, Mattick RP, Cooke M.
Alcohol Clin Exp Res. 2006 Apr;30(4):642-8.
PMID: 16573582

Fetal alcohol syndrome.
O'Leary C, Bower C, Payne J, Elliott E.
Aust Fam Physician. 2006 Apr;35(4):184.
PMID: 16649302

A retrospective review of self-reported **alcohol** intake among women attending for antenatal care in Far North Queensland.
Rimmer C, de Costa C.
Aust N Z J Obstet Gynaecol. 2006 Jun;46(3):229-33.
PMID: 16704478

Diagnosis of foetal **alcohol** syndrome and **alcohol** use in pregnancy: a survey of paediatricians' knowledge, attitudes and practice.
Elliott EJ, Payne J, Haan E, Bower C.
J Paediatr Child Health. 2006 Nov;42(11):698-703.
PMID: 17044897

Alcohol consumption during pregnancy in nonindigenous west Australian women.
Colvin L, Payne J, Parsons D, Kurinczuk JJ, Bower C.
Alcohol Clin Exp Res. 2007 Feb;31(2):276-84.
PMID: 17250620

Estimating the prevalence of **fetal alcohol** syndrome in Victoria using routinely collected administrative data.
Allen K, Riley M, Goldfeld S, Halliday J.
Aust N Z J Public Health. 2007 Feb;31(1):62-6.
PMID: 17333611

A review of policies on **alcohol** use during pregnancy in **Australia** and other English-speaking countries, 2006.
O'Leary CM, Heuzenroeder L, Elliott EJ, Bower C.
Med J Aust. 2007 May 7;186(9):466-71. Review.
PMID: 17484709

Health of Aboriginal and Torres Strait Islander children in remote Far North Queensland: findings of the Paediatric Outreach Service.
Rothstein J, Heazlewood R, Fraser M; Paediatric Outreach Service.
Med J Aust. 2007 May 21;186(10):519-21.
PMID: 17516899

Fetal alcohol syndrome: a prospective national surveillance study.
Elliott EJ, Payne J, Morris A, Haan E, Bower C.
Arch Dis Child. 2008 Sep;93(9):732-7. Epub 2007 Aug 17.
PMID: 17704098

A review of policies on **alcohol** use during pregnancy in **Australia** and other English-speaking countries, 2006. Comment.
Morley R, Halliday JL, Donath SM.
Med J Aust. 2007 Sep 3;187(5):315; author reply 316.
PMID: 17767442

A review of policies on **alcohol** use during pregnancy in **Australia** and other English-speaking countries, 2006. Comment.
Miers S.
Med J Aust. 2007 Sep 3;187(5):315-6; author reply 316.
PMID: 17879459

Impacts of **alcohol** use in pregnancy--the role of the GP.
Peadon E, O'Leary C, Bower C, Elliott E.
Aust Fam Physician. 2007 Nov;36(11):935-9.
PMID: 18043782

International survey of diagnostic services for children with **Fetal Alcohol** Spectrum Disorders.
Peadon E, Fremantle E, Bower C, Elliott EJ.
BMC Pediatr. 2008 Apr 15;8:12.
PMID: 18412975

Alcohol and pregnancy: the pivotal role of the obstetrician.
Elliott EJ, Bower C.
Aust N Z J Obstet Gynaecol. 2008 Jun;48(3):236-9.
PMID: 18532952

Pregnancy characteristics of women giving birth to children with **fetal alcohol** syndrome in Far North Queensland.
Coyne KL, de Costa CM, Heazlewood RJ, Newman HC.
Aust N Z J Obstet Gynaecol. 2008 Jun;48(3):240-7.
PMID: 18532953

The effect of maternal **alcohol** consumption on **fetal** growth and preterm birth.
O'Leary CM, Nassar N, Kurinczuk JJ, Bower C.
BJOG. 2009 Feb;116(3):390-400.
PMID: 19187371

Need to establish a national diagnostic capacity for foetal **alcohol** spectrum disorders.
Mutch R, Peadon EM, Elliott EJ, Bower C.
J Paediatr Child Health. 2009 Mar;45(3):79-81.
PMID: 19317758

Systematic review of interventions for children with **Fetal Alcohol** Spectrum Disorders.
Peadon E, Rhys-Jones B, Bower C, Elliott EJ.
BMC Pediatr. 2009 May 25;9:35. Review.
PMID: 19463198

Measurement and classification of prenatal **alcohol** exposure and child outcomes: time for improvement.
O'Leary CM, Bower C.
Addiction. 2009 Aug;104(8):1275-6; discussion 1279-80.
PMID: 19624317

A new method of prenatal **alcohol** classification accounting for dose, pattern and timing of exposure: improving our ability to examine **fetal** effects from low to moderate **alcohol**.
O'Leary CM, Bower C, Zubrick SR, Geelhoed E, Kurinczuk JJ, Nassar N.
J Epidemiol Community Health. 2010 Nov;64(11):956-62. Epub 2009 Oct 19.
PMID: 19843498

Age at diagnosis of birth defects.
Bower C, Rudy E, Callaghan A, Quick J, Nassar N.
Birth Defects Res A Clin Mol Teratol. 2010 Apr;88(4):251-5.
PMID: 20213697

Women's knowledge and attitudes regarding **alcohol** consumption in pregnancy: a national survey.
Peadon E, Payne J, Henley N, D'Antoine H, Bartu A, O'Leary C, Bower C, Elliott EJ.
BMC Public Health. 2010 Aug 23;10:510.
PMID: 20727217

Distinguishing between attention-deficit hyperactivity and **fetal alcohol** spectrum disorders in children: clinical guidelines.
Peadon E, Elliott EJ.
Neuropsychiatr Dis Treat. 2010 Sep 7;6:509-15.
PMID: 20856914

RE-AIM evaluation of the **Alcohol** and Pregnancy Project: educational resources to inform health professionals about prenatal **alcohol** exposure and **fetal alcohol** spectrum disorder.
Payne JM, France KE, Henley N, D'Antoine HA, Bartu AE, O'Leary CM, Elliott EJ, Bower C, Geelhoed E.
Eval Health Prof. 2011 Mar;34(1):57-80.
PMID: 21292723

Paediatricians' knowledge, attitudes and practice following provision of educational resources about prevention of prenatal **alcohol** exposure and **Fetal Alcohol** Spectrum Disorder.
Payne JM, France KE, Henley N, D'Antoine HA, Bartu AE, Mutch RC, Elliott EJ, Bower C.
J Paediatr Child Health. 2011 Oct;47(10):704-10. doi: 10.1111/j.1440-1754.2011.02037.x. Epub 2011 Mar 30.
PMID: 21449899

Changes in health professionals' knowledge, attitudes and practice following provision of educational resources about prevention of prenatal **alcohol** exposure and **fetal alcohol** spectrum disorder.
Payne J, France K, Henley N, D'Antoine H, Bartu A, O'Leary C, Elliott E, Bower C.
Paediatr Perinat Epidemiol. 2011 Jul;25(4):316-27. doi: 10.1111/j.1365-3016.2011.01197.x. Epub 2011 Apr 24.
PMID: 21649674

Health initiatives by Indigenous people in **Australia**.
Clark S.
Lancet. 2011 Jun 18;377(9783):2066-7.
PMID: 21684368

Attitudes and behaviour predict women's intention to drink **alcohol** during pregnancy: the challenge for health professionals.
Peadon E, Payne J, Henley N, D'Antoine H, Bartu A, O'Leary C, Bower C, Elliott EJ.
BMC Public Health. 2011 Jul 22;11:584.
PMID: 21781309

Guidelines for pregnancy: What's an acceptable risk, and how is the evidence (finally) shaping up?
O'Leary CM, Bower C.
Drug **Alcohol** Rev. 2011 Sep 29. doi: 10.1111/j.1465-3362.2011.00331.x. [Epub ahead of print]
PMID: 21955332

Blunting the legacy of **alcohol** abuse in Western **Australia**.
Kirby T.
Lancet. 2012 Jan 21;379(9812):207-8.
PMID: 22272393

There's hope in the valley.
Elliott E, Latimer J, Fitzpatrick J, Oscar J, Carter M.
Journal of Paediatrics and Child Health 48 (2012) 190–192

The Lililwan Project: study protocol for a population based, active case ascertainment study of the prevalence of Fetal Alcohol Spectrum Disorders (FASD) in remote Australian Aboriginal communities.
Fitzpatrick J, Elliott E, Latimer J, Carter M, Oscar J, Ferriera M, Carmichael-Olson H, Lucas B, Doney R, Salter C, Peadon E, Hawkes G, Hand M.
BMJ Open. 2012 March. (In Press)

Appendix C – The Lililwan Project Team

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Appendix D – The Australian FASD Collaboration

The Australian FASD Collaboration

Contracted by the Commonwealth Department of Health and Ageing to provide a Screening-Diagnostic Instrument for the Fetal Alcohol Spectrum Disorders

Members

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