



LILILWAN PROJECT

14/08/2012

**Submission to the House of Representatives
Standing Committee on Social Policy and Legal Affairs
Inquiry into Fetal Alcohol Spectrum Disorders (FASD)**

Graham Perrett MP, Chair (Australian Labor Party, Moreton, QLD)
Judi Moylan MP, Deputy Chair (Liberal Party of Australia, Pearce, WA)
Dr Sharman Stone MP (Liberal Party of Australia, Murray, VIC)
Laura Smyth MP (Australian Labor Party, La Trobe, VIC)
Mike Symon MP (Australian Labour Party, Deakin, VIC)
Ross Vasta MP (Liberal Party of Australia, Bonner, QLD)

Dear Mr Perrett, Dr Stone and Ms Smyth,

It was a great pleasure to meet you recently at the 2012 Marninwarntikura Women's Bush Meeting at Mimbi Caves. Your session related to the House of Representatives Inquiry followed our presentation by Prof Elizabeth Elliott on *The Lililwan Project*. I was the Physiotherapist on the *Lililwan Project*, Australia's first study of the prevalence of FASD in remote communities, and conducted the gross motor assessments on the children within the study cohort as part of the diagnostic processes. I worked in the Fitzroy Valley for 6 months throughout Stage 2 of the *Lililwan Project* in 2011.

During your Session (***Meeting for the House Of Representatives Standing Committee into FASD***) it was impressive to hear so many Indigenous women articulate their concerns regarding the prevention and management of Fetal Alcohol Spectrum Disorders (FASD) and their views about future steps their communities might take to address these issues. As there was an overwhelming response by local community members to your session, I had little opportunity to raise issues related to Allied Health service provision. The purpose of this submission therefore, is to highlight the Allied Health needs in the Fitzroy Valley given the experience of the *Lililwan Project* team who have assessed two entire age cohorts of children residing in the Fitzroy Valley (children born in 2002 and 2003) and identified their service needs.

The Deputy Principal of the Fitzroy Valley High School (Ms Bree Wagner) touched on this issue at the meeting when she commented on the lack of Allied Health support for students with FASD in the Fitzroy Valley. She described the ongoing difficulties in getting Allied Health services into Fitzroy Valley schools and that current funding structures prevent employment of Allied Health staff through the Department of Education.

In support of the community and local service provider concerns about limited Allied Health services in the Fitzroy Valley, we present the following submission.

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Yours sincerely,

[Redacted signature]

Ms Barbara Lucas
Specialist Paediatric Physiotherapist
BAppSc(Phty), MPH, FACP

E: [Redacted email address]

M: [Redacted mobile number]

The George Institute for Global Health | AUSTRALIA
Level 13, 321 Kent St | Sydney NSW 2000 Australia

[Redacted address line]

On behalf of the *Lililwan Project* Team

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**Submission to the House of Representatives Standing Committee on Social Policy and Legal Affairs,
Inquiry into Fetal Alcohol Spectrum Disorders (FASD):**

Background:

We highlight the limited paediatric Allied Health services within the Fitzroy Valley – specifically those services provided by Physiotherapists, Occupational Therapists, Speech Pathologists, Psychologists, Social Workers, and Indigenous Allied Health Assistants. Allied Health services to the Kimberley Region are provided through Derby Hospital, which is located 260km west from Fitzroy Crossing. The relatively small Derby Allied Health team service an area of over 104,00 square kilometres including centres of Derby and Fitzroy Crossing in addition to over 45 Aboriginal communities including those of Fitzroy Valley.

The key issues of concern are as follows:

- There is a critical housing shortage in Fitzroy Crossing, which prevents Allied Health staff being accommodated locally.
- The Allied Health team addresses a diverse range of acute and chronic referrals for all age groups in the Fitzroy Valley (from neonates to the elderly).
- These services would potentially be overwhelmed by an increase in referrals of children requiring assessment and treatment for both acute issues and complex long-term health and developmental problems, as a result of the FASD project.

The results of the *Lililwan Project*, to be published later this year, provide early indications that the majority of the children in the cohort (127 children were involved in this study) require Allied Health assessment, management and follow-up. The following proportions of children were referred for Allied Health service follow-up based on well-defined definitions of impairment.

- Occupational Therapy: 53 %
- Speech Pathology: 53%
- Psychology: 50%
- Physiotherapy: 31%
- Optometry: 10 %
- Dietician: 4%

Children living with a FASD need to be managed by Allied Health service providers with **specific paediatric expertise** to ensure they receive interventions that will assist with their development. This is regarded as best practice, and would be available in metropolitan and rural locations. Such

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services will enable these children to become the best they can be within school, their communities and into the future. Based on the *Lililwan Project* findings, paediatric Allied Health services are needed for the following:

- **Physiotherapy** – to improve movement skills such as balance, coordination and agility which are so important in Indigenous communities where dance and physical abilities are central to traditional values.
- **Occupational Therapy** – to support the independence and development of learning, play and self-care activities in the school and home environment, and enable children to participate as fully as possible in home and school life.
- **Speech Pathology** – to support children’s language and pragmatic skills to ensure optimal understanding and expression at home, in the broader community and at school. Without strong language abilities, children cannot learn the stories and songs that allow them to maintain and pass on their Aboriginal culture.
- **Social Work** – to provide case management and support to children and their families in dealing with a diagnosis of FASD and navigating the system to ensure that all services and resources required are accessed.
- **Child Psychology** - to provide support, assessment and therapy for potential mental health issues and effects of early life trauma in children and families affected by FASD.
- **Indigenous Allied Health Assistant** – to ensure culturally safe and effective implementation of Allied Health services in the local context, to assist in delivery of programs with children, families, schools and communities, and importantly provide consistent support to the Allied Health team in appropriate service delivery and local orientation.

These Allied Health clinicians would not only be working face to face with children but also working closely with schools and parents/carers to integrate therapy goals within school and home environments. Currently services are provided infrequently from Derby, however a Fitzroy Crossing-based Allied Health team would more effectively engage with communities, work collaboratively with relevant agencies and provide education on FASD related topics as appropriate.

The *Lililwan Project* has assessed two entire age cohorts of children in the Fitzroy Valley and will report very high rates of FASD. It is highly likely there are many more children and adults in the region with FASD and other developmental problems who are undiagnosed and in need of paediatric and adult Allied Health services.

Our recommendations are based on the *Lililwan Project* data and thus may not have captured all health care needs in Fitzroy Valley. Thus, plans to increase Allied Health service capacity in this area must be developed in collaboration with local Paediatric services to capture additional Allied Health needs.

Recommendations

It is critical that local Allied Health services be enhanced to include a dedicated paediatric Physiotherapist (1.0 FTE), paediatric Occupational Therapist (1.0 FTE), paediatric Speech Pathologist (1.0 FTE), paediatric Psychologist (1.0 FTE), paediatric Social Worker (1.0 FTE) and Indigenous Allied Health Assistant (1.0 FTE).

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To ensure the successful and sustainable implementation of these Allied Health services, positions need to be:

- Classified at a level reflecting the experience needed and demands placed on health professionals with a complex and demanding caseload in a remote location.
- Supported by centralised accommodation located in Fitzroy Crossing and ready access to transport suited to Kimberley conditions to enable service to the most remote communities (i.e. Four-wheel drive vehicles).
- Provided with robust orientation to role, appropriate cultural orientation and ongoing support.
- Provided with professional support via satellite support networks (e.g. paediatric and FASD specialist Allied Health services) in addition to that provided by local management.
- Strongly linked to collaborate with Fitzroy Valley communities, education providers and relevant local agencies
- Functioning as an interdisciplinary team who deliver care on an outreach basis in collaboration with local general practitioners and Paediatricians. Such a model of care has been trialled previously in the Fitzroy Valley and successfully used in the *Lililwan Project* in 2011. An ongoing funded pilot study will commence in 2013 – *Marulu Paediatric and Child Health – School Outreach Service*.

Adoption of the above recommendations would resolve many of the issues surrounding previous initiatives that have unsuccessfully endeavoured to increase Allied Health capacity in the Fitzroy Valley.

However, development of the Allied Health arm of Paediatric service delivery in this area is only one step in tackling the health needs of children within this area. Any paediatric Allied Health team needs to strongly integrate with the Kimberley Paediatrics and Child health team. Currently there are no local GP's working within the Fitzroy Valley. Medical services are provided through District Medical Officers situated in local hospital Emergency Departments and work at capacity managing emergency admissions. They are not able to do any community liaison or case management with outpatient paediatric clients. Capacity within the Kimberley Paediatrics and Child health team also needs expansion to effectively manage paediatric outpatient cases and deliver ongoing follow-up to secure improved health outcomes for Fitzroy Valley children.

This report has been written with the support of local Allied Health services and with Dr John Boulton, Senior Regional Paediatrician, Kimberley Health Region. It primarily recommends the need to increase capacity in Allied Health services based on the *Lililwan Project* outcomes. In our **proposed model of care this team should be strongly integrated the with Kimberley Paediatrics and Child health team, with Fitzroy Valley communities, and with relevant local agencies and education providers.**

Conclusion:

The current Allied Health service provided from Derby is inadequate to meet demand for paediatric services in the Fitzroy Valley. There is a need for **increased Allied Health capacity to deal with FASD and other developmental disorders**. Allied Health professionals should be trained in, and dedicated **to paediatrics and have knowledge of the diagnosis and management of FASD**.

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Accommodation must be made available to allow professionals to stay in the community. Allied Health and Paediatric services should not operate in isolation, but be co-ordinated with maternal and child health services to allow diagnosis and management of children using an interdisciplinary model of care. Our experience from the *Lililwan Project* suggests that such a model is efficient, cost-effective and provides professional development opportunities and a supportive working environment for team members. In particular, this approach enhances communication between health professionals and promotes case-conferencing involving the inter-disciplinary team. This allows team members to discuss and jointly allocate diagnoses, develop a management plan and communicate this plan to parents and carers, local health professionals and teachers, resulting in the best outcomes for each child.

Please do not hesitate to get in touch if you wish to discuss this further.

Yours sincerely,

[Redacted signature]

Barbara Lucas

Specialist Paediatric Physiotherapist

BAppSc(Phty), MPH, FACP

E: [Redacted email]

M: [Redacted mobile]

The George Institute for Global Health | AUSTRALIA
Level 13, 321 Kent St | Sydney NSW 2000 Australia

[Redacted address line]

On behalf of the following *Lililwan Project* clinicians

Allied Health team

Robyn Doney: **Occupational Therapist**

Claire Salter: **Speech Pathologist**

Julianne Try: **Psychologist**

Genevieve Hawkes: **Physiotherapist/ Personnel Co-ordinator**

Chief Investigators – *Lililwan Project*

Prof Elizabeth Elliott

Associate Professor Jane Latimer

Dr James Fitzpatrick

June Oscar

Maureen Carter

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Reviewed by

Prof John Boulton MD FRACP, Senior Regional Paediatrician, Kimberley Health Region
Locked Bag 4011. Broome WA 6725.

Kate Baxter: Allied Health Manager , Kimberley Population Health Unit, Northern and Remote
Country Health Service - on behalf of local Allied Health Services

Bree Wagner: Deputy Principal, Fitzroy Valley High School

Marulu - The Lililwan Project

Overcoming Fetal Alcohol Spectrum Disorders in the Fitzroy Valley

The George Institute for Global Health; Sydney University Medical School;

Marninwarntikura Women's Resource Centre;

Nindilingarri Cultural Health Service Fitzroy Crossing.

W: www.georgeinstitute.org.au/marulu

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