The Lililwan* Study: Tackling Foetal Alcohol Spectrum Disorders

The Lililwan study - an Australian first examining the prevalence of Foetal Alcohol Spectrum Disorders (FASD) and early life trauma - will be undertaken in the Fitzroy Valley in the remote Kimberley region of WA. Initiated by the Indigenous community in Fitzroy Crossing, and driven by Nindilingarri Cultural Health Services in Fitzroy Crossing, the study will determine the prevalence of FASD and its impact on the health service needs of children and their families.

Babies born to women who have used alcohol during pregnancy can have distinctive facial stigmata, damage to the brain and nervous system, heart, lungs, eyes and ears, as well as other physical, mental, or behavioral problems. Damage to the developing brain can result in learning difficulties, poor memory, attention deficit disorder, impulsive behaviour and poor cause-effect reasoning as well poor executive functioning – the ability to plan and execute complex tasks. As affected children grow up they may experience academic failure, mental health problems and have a higher risk of drug and alcohol abuse.

A few years ago, family violence, child abuse and suicide were common in Fitzroy Crossing. In 2007, a group of women decided enough was enough and lobbied their community to restrict the sale of full strength take-away alcohol. An evaluation by Notre Dame University performed 1 year later showed that these restrictions were associated with a dramatic reduction in family violence and alcohol related hospital admissions and improved school attendance.

Following the success of these restrictions the community determined to face the enormous challenge of FASD. The women wanted to focus on the health and well-being of children and realised that maternal alcohol use was affecting their children’s potential even before birth. With the help of Dr James Fitzpatrick, they developed a broadly representative leadership team and strategy (which included a FASD prevalence study) to tackle FASD and early life trauma in the Fitzroy Valley. In late 2009, the leadership team invited researchers from Sydney to come to Fitzroy Crossing to consult with the community and local service providers through forums, informal discussions and meetings and to undertake cultural awareness training with Nindilingarri Cultural Health Services. The team presented information about FASD, explained the concept of the high quality study, and examined the feasibility of such a study, which received strong community support.

Professor Elizabeth Elliot AM and Dr James Fitzpatrick were members of this team. Elizabeth is Professor of Paediatrics and Child Health with Sydney Medical School and Consultant Paediatrician at The Children’s Hospital at Westmead (CHW) and James is Fellow in Medical Education and PhD student at The Children’s Hospital at Westmead Clinical School. Other team members were Prof Jane Latimer and Dr Manuela Ferreira from the George Institute for Global Health and Ms Meredith Kefford, an Indigenous Community Volunteer. James and Meredith have previously worked in the Fitzroy Valley. Jane has a longstanding relationship with the Fitzroy
Valley and produced a highly acclaimed film, Yajilarra, documenting the introduction of alcohol restrictions. The team has partnered with the local FASD leadership team, which includes representatives from organisations serving the Fitzroy Valley and is led by Ms Maureen Carter from Nindilingarri Cultural Health Services.

FASD can have an enormous impact on a community as many babies born with FASD will not be able to live or work independently as adults. Aboriginal people in the Fitzroy Valley are also concerned about the impact FASD could have on the continuity of their culture. Elders pass on the traditional stories, ceremonies and images by word of mouth and children affected by FASD have poor memories, so the strong cultural connection through oral history is threatened.

Stage 1 of the Lililwan Project, which began in April 2010, involved collecting information about pregnancy, birth and early childhood from parents and carers of all children born in the Fitzroy Valley in 2002 and 2003, and reviewing their health records. The survey was developed at the Children’s Hospital at Westmead. Information sessions on healthy pregnancy and early childhood were also run. “127 out of a cohort of 134 (95%) of parents and carers in all the communities across the Fitzroy Valley agreed to participate,” said Dr Fitzpatrick, “indicating their appreciation of the importance of addressing FASD. The role of local community navigators Harry Yungabun and Rhonda Shandley, who we employed for the project and enabled the team to work with communities so diverse in language and culture, was invaluable.”

Stage 2 will involve screening all children from Stage 1 to assess their health, behaviour and developmental status and to provide immediate treatment and referral when necessary. “The assessment team will include a paediatrician, nurse, psychologist, audiologist, ophthalmologist and allied health workers,” said Professor Elliott. “This multi-disciplinary team will not only research the prevalence of FASD and provide care plans for children and support to affected families, but will also inform diagnosis and community education strategies which could be used by other similar communities and health departments.” We hope to prove that this model of diagnosis and care is effective and sustainable, even in remote communities,” said Dr Fitzpatrick, who has worked in the Kimberley for the past two years.

The feasibility study and Stage 1 were funded by an anonymous donor. The Federal Government has just announced it will contribute $1m to Stage 2 of the study. “We hope the Lililwan study will help build knowledge and capacity in the community, and that the data we collect will allow us to advocate for better child health services and will inform community and health professional education,” said Professor Elliott. “The most important aspect of this collaborative project is that it is led by the Indigenous community, who want a better future for their children,” she said. “It is a privilege for us to have been invited to assist in collaborating in such important work.”

*Lililwan is a Kriol, or Aboriginal English, word meaning little ones or children