Marninwarntikura Women's Resource Centre - Inquiry into Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Emily Carter is the CEO of Marninwarntikura Women's Resource Centre (MWRC) and a Gooniyandi-Kija woman with strong family connections to the Fitzroy Valley and a lifetime of work for her community.

Historical context

- Many Aboriginal people's connection to country, family, language and culture has been disrupted by government policies, such as removal of children from their families, including my own family story. These Government policies impact us all, including the way welfare payments are distributed, punitive approaches and the lack of housing and fundamental human rights, like safe water and adequate health services for the most vulnerable communities.
- The impact of intergenerational trauma continues to be felt today. We are living in a time when more children than ever before are in out of home care, and this has a devastating effect on our communities, all of us.
- The impact of underinvestment into communities is being seen as domestic violence, ongoing disadvantage, drug and alcohol use, alcohol-related deaths and suicide. Communities are our safe haven, yet they have been starved of infrastructure, and their very survival is threatened.
- We know that intergenerational trauma and post-traumatic stress disorder are almost universal in our community, and we see the devastating impact it has on our families every day. We live it.
- Each week we experience another loss and tragedy. My children and grandchildren have been to more funerals than they can count.
- In 2007 there were 50 deaths, including 13 suicides in 13 months. We have just had another suicide which brings back the pain and adds to our collective grief.

Alcohol restrictions

- In 2007, June Oscar and I successfully lobbied the WA liquor licensing board for restrictions on the sale of full-strength alcohol. We continue to fight for this today.

Lililwan Project

- In 2009, community leaders were worried about the impact of alcohol on the community, and particularly on children.
- So, we partnered with experts from the University of Sydney and the George Institute to lead the Lililwan Project.
- In this study, all families with a child born in 2002 and 2003 living in the Valley in 2010 were invited to participate, and 127 or 95% gave consent. An incredible participation rate, particularly given the nature of the study, and this was because the project was a community-initiated and led. So, families trusted the team and felt safe to participate.

We found that:

- almost all children in the study had experienced significant early life trauma
- 55% had prenatal alcohol exposure
- and 20% met criteria for FASD, which is the second-highest rate in the world.

Professor Elizabeth Elliott is a Paediatrician and Leading FASD expert. She has continued to work with The Marulu Leadership team and with Marninwarntikura Women's Resource Centre as the Chief Investigator on a range of research projects that build the evidence and grow community capacity and knowledge.

Lililwan Project continued

- High prevalence of PAE and FASD
- Complex chronic' disorders – inadequate child health services
- Behaviour problems – home and school
- Outcomes, e.g. Marulu Unit, education, referrals, services

Jandu Yani U Project

- Modified Triple-P (positive parenting) program
- Benefit – training parent coaches: skills, knowledge, empowerment
- A decrease in challenging child behaviours
- decreased parental stress, increased good parenting, increased empowerment
- Part of a suite of programs in Marnin – that offers families supports and builds on strengths, led by Aboriginal people

needs funding to develop a hub and spoke model that builds capacity in our community, need to maintain the integrity of the program

Sue Thomas - Strategic Priority Lead Marninwarntikura Women's Resource Centre and author of the internationally recognised FASD Resource for Educators

- Marulu Strategy is a community-led initiative that draws on Aboriginal-Controlled Organisations, Government Services and all those working with children with FASD and complex trauma.
- The tagline Making FASD History was coined in Fitzroy Crossing, and the strategy has been designed to Make FASD History and strengthen community capacity, resilience and wellbeing.
    - 1) Prevent Children in The Fitzroy Valley from being born with FASD and experiencing ELT (Championed by Nindilingarri Cultural Health Service, NCHS)
    - 2) Support children and families living with FASD and ELT throughout different stages of their lives (Championed by MWRC)
    - 3) Build capacity and enhance services for children, adults and families affected by FASD and ELT (Championed by MWRC)
    - 4) Develop a sustainable community-driven response to FASD and ELT (MWRC and NCHS).
- FASD in the education system, FASD is not recognised as a disability and doesn't attract much-needed supports. Even though the prevalence of FASD was recognised in the Fitzroy Valley, the Government and Aboriginal Independent Community Schools were not provided with additional resources. Many of the children in our Lililwan Project have disengaged from school and are the children coming into contact with the juvenile justice system. The problems don't go away because we haven't officially recognised them.
- Along with a colleague Jane Weston I co-authored the resource for educators (provided) to build knowledge and understanding of FASD and Complex Trauma. It has been used widely nationally and internationally.

- Marurra U Partnership (Bunuba word meaning to embrace with love and care). Emily Carter and June Oscar visited Royal Far West. They saw quality, innovative service delivery using telecare into remote NSW communities. Emily said we need this in the Fitzroy Valley, so we have spent the last five years building a strong partnership where we access their expertise, trial different supports into very remote communities such as professional learning capacity sessions for teachers, community members and parent/carers, coaching and individual therapy sessions and intensive therapeutic camps. Our motto is we will show people *'what good looks like'*. We are building a model of wrap-around supports and integrated care that gives families with complex needs some resources they have not been provided by conventional health services.

Lauren Rice is a Research Fellow from the University of Sydney working with the Marulu Team to co-lead the research and provide expertise to the community about the NDIS.

Bigiswun Kid Project

- The overarching aim of the Bigiswun Kid Project is to identify the needs and build the knowledge to improve services and the health and wellbeing of adolescents in remote Aboriginal communities.
- We are conducting interviews with the Lililwan cohort, their parent and teachers to provide a voice to adolescents and their families and understand the health and wellbeing status of the Lililwan cohort at 17-18 years.
- We will use the data collected in the Lililwan and Bigiswun Kid Projects to identify modifiable prenatal and early childhood predictors of positive and adverse adolescent outcomes, so we know how and when to intervene early to support the next generation.
- There were over 400 referrals made to health services in the Lililwan project as well as a range of other recommendations. We are going to review the health, education, police and child protection records to determine whether these referrals and recommendations were followed and identify past and present service gaps and support needs as well as barriers to service use.
- We are going to conduct cognitive assessments with young people to examine the relationship between adaptive and executive function and positive and adverse adolescent outcomes. We know there are some young people with high rates of contact with the justice system. We want to find out whether these young people share similar impairments that increase their risk of offending. If so then, these are the traits we need to look for in young children so we can provide wrap-around support in their formative years.
- Some longitudinal studies suggest that the FASD facial features become more subtle after puberty but at the moment doctors are using the same clinical cut-offs for children and adults. We are going to take photos of the Lililwan cohort to determine how the facial features change from childhood (age 7-9) to adolescence (age 17-19) and use this to inform new clinical cut-offs for adults.
- During our consultation process for this project the community made it clear that any research must provide direct and immediate benefits to the participants. So, we are offering a range of services to young people during the data collection process.

    - We are going to help young people with a disability apply for the NDIS. There were 21 children who met criteria for FASD in the Lililwan Project and none of them have received disability services in the past ten years.
    - We are running workshops and camps with young people to provide positive on country experiences and talk about issues identified by parents.
    - We have conducted 40 interviews with parents so far, and their most common concerns are around the young person not having enough sexual health knowledge and not having one to speak to about mental health. We started the youth interviews last week. We have conducted six interviews so far, and all six of them told us that they have thought about killing themselves in the last month, meaning all six of them are currently suicidal.
    - There are around 4,000 people in the region, and we know trauma is almost universal. Yet there is only one clinical psychologist for the whole region. She is employed by an external NGO and drives in from Broome for six days a month, and we have just been told that she is leaving and being replaced by an art therapist.
    - WA Country Health Service do not currently have any clinical psychologists working in the Fitzroy Valley who can either support people with mental health problems or diagnosis people with FASD.
    - Marninwarntikura Women's' Resource Centre have been paying for a clinical psychologist to fly up from Sydney to help support the paediatrician to diagnose children. In the past month, we have had eight families with a child over 16 years who have told us they would like to be assessed for FASD and we can't find a single person in the region who is willing and able to diagnose adults.

Emily's final statement

- Clontarf has been given $39 million when the entire budget for the Aboriginal-controlled health sector is $46.5 million over the same four years. Organisations like ours can't compare. We are at the cold face, and we are struggling to exist, let alone keep up with the demand of services required to help our community heal.
- We need:
    - Secure funding so we can establish sustainable programs and supports for our community, including funding so we can provide our Jandu Yani U parenting program to the 80 families on our waitlist.
    - Our Marulu team consists of four local Aboriginal women who do an amazing job at supporting children with FASD and their families, but these are often the families with the most complex needs. We need a social worker on the team who can help families break down the many barriers preventing them from being able to support their children.
    - Finally, we need FASD to be recognised as a disability in schools so our children can get the support they need to thrive in the classroom.

Our organisation has become service delivery because we are the only ones willing to tackling the complex issues like early life trauma, domestic violence and the effects of drug and alcohol abuse. These issues exist because of the under investments in our communities.

My staff spend every day responding to people in crisis because the lack of housing means women and children have no way of escaping violence, sexual abuse and inhumane living conditions. How do we help people heal from trauma when they are still living it every day?

Trauma affects Aboriginal and non-Aboriginal staff, and I'm forced to spend my time worrying about whether we will have jobs next year instead of being available to supervise and support them to do their important work.

We welcome the opportunity of the Senate Committee visiting us at MWRC when the border restrictions are lifted to see our work in action.