

Consumer and Community Participation in Fetal Alcohol Spectrum Disorder (FASD) Intervention Research

By Bree Wagner
Telethon Kids Institute, The University of Western Australia

Fetal Alcohol Spectrum Disorder (FASD)

Alcohol can cause birth defects and exposure *in utero* can lead to adverse pregnancy outcomes including miscarriage, prematurity, stillbirth and low birth weight.¹ A spectrum of lifelong physical, behavioural and neurocognitive abnormalities is recognised in children with Fetal Alcohol Spectrum Disorder (FASD). The term Fetal Alcohol Spectrum Disorder (FASD) previously referred to a range of disorders that may be caused by alcohol exposure *in utero*: Fetal Alcohol Syndrome (FAS), partial FAS (pFAS), and Neurodevelopmental Disorder-Alcohol Exposed (ND-AE). In May 2016 the new Guide to the diagnosis of FASD in Australia was released. Fetal Alcohol Spectrum Disorder is now used as a diagnostic term with two diagnostic sub-categories: FASD with three sentinel facial features and FASD with less than three facial features.² Functional impairment of the brain in FASD results in problems with memory, cognition, executive function, hearing and vision, gross and fine motor control, sensory processing, language and behaviour and cerebral palsy. The neurodevelopmental disabilities associated with FASD significantly impact on quality of life and social and economic participation.³

Commonly, individuals with FASD experience difficulties with their executive functioning skills.⁴ These are a set of cognitive processes which organise purposeful, goal directed behaviour and are responsible for a person's ability to plan, organise, attend, inhibit responses and self-regulate emotion and behaviour.⁵ Deficits in these skills can make school and learning frustrating for children, which can impact on their behaviour, attendance and ultimately their educational outcomes. Early diagnosis and intervention are key to reducing the likelihood of these secondary disabilities.³

FASD Intervention Research

The Telethon Kids Institute is currently working with the communities of the Fitzroy Valley to develop, implement and evaluate a school based FASD intervention founded on the "Alert Program® for Self-Regulation". The Alert Program® is based on the analogy of the body being like a car engine to teach self-regulation and improve executive functioning. The body can run at different levels of alertness such as high, low or just right. Children are taught five ways to change their level of alertness through listening, moving, touching, looking or putting something in their mouth. The program also supports families, school staff and occupational therapists (OTs) to develop strategies to change or maintain states of alertness to optimise student functioning.⁶ Whilst the Alert Program® can be used in a variety of group and individual therapy settings, this research will focus upon upskilling teachers and school support staff to deliver the program to their primary school classes using a curriculum guide.



The Context

The Fitzroy Valley is located approximately 400km east of Broome in the remote Kimberley region of Western Australia. The Valley is home to approximately 3500 predominantly Aboriginal people belonging to four language groups and living in more than 45 remote communities, some up to 190km from the main town of Fitzroy Crossing.⁷ After implementing alcohol restrictions in 2007, the community turned their attention to the issue of FASD and early life trauma (ELT), which posed a threat to intergenerational transfer of language and culture. This led to the initiation of a comprehensive and community driven strategy to make FASD history in the Fitzroy Valley. This approach known as the Marulu FASD Strategy is led by a committed group of community leaders and is supported by a circle of friends to prevent, diagnose FASD and provide support to individuals, families and communities who are affected by FASD and/or ELT.⁸ An important component of the strategy was for the community to invite researchers to conduct Australia's first population based study into the prevalence of FASD called the Lililwan Project. Results of this study have been reported in the 'Journal of Paediatrics and Child Health'.⁹

Project Strengths and Challenges



The high level of consumer and community participation from within the Fitzroy Valley is a strength of the Alert Program® study and other Marulu FASD projects. Service providers, such as researchers, must invest significant time in the formative stage of projects in order to establish and develop strong and meaningful relationships between project personnel and the communities in which they are working with.¹⁰ Whilst the Study Coordinator lived and worked in Fitzroy Crossing for over five years prior to joining this project, it was absolutely vital that she reconnect with local community members in Valley and

develop trust in the context of her new role. The formative process involved seven visits to the Fitzroy Valley and included working with the Kimberley Education Regional Office (KERO), the Marulu FASD Leadership Team, schools and the Kimberley Population Health Unit occupational therapists. Relationships were also formed between researchers, families and community representatives through a series of school visits, by running community barbecue and breakfast events, presenting information about the study at school conferences, community and service provider meeting, joining community networks and being visibly present on a regular basis within the community. This has also meant getting to know people outside of more formal situations by embracing the chance to be involved in activities like camping, fishing and cultural events with local community members. Regular communication and input into project design has also been facilitated by convening consumer reference group meetings, publishing a regular study newsletters and keeping in touch with key stakeholders by email and telephone.



Conducting a pilot study at a small remote community school enabled the team to trial all aspects of the Alert Program® project and to gain valuable feedback from teachers, school support staff and families before finalising plans for the full study phase in 2016 and 2017. This included piloting research procedures, information and consent forms, the Alert Program® curriculum guide, resources and equipment, assessment tools and staffing processes. Investing time in community and consumer participation, as well as running a pilot study during the formative stage, has ensured the research design is not only rigorous but appropriate to the Fitzroy Valley context.

This process can be challenged by the timelines set for funding expenditure by grant bodies that sometimes don't align with the time it takes to establish relationships. Another challenge is remaining considerate of the ability of key stakeholders to balance existing needs and priorities of their core business whilst being invited to engage with new projects as partners. Sometimes there are varying expectations between the service provider/researcher and the consumer as to what constitutes effective community engagement, consultation and participation. Indigenous ways of knowing and doing must also be taken into account when working with Indigenous communities. An open mind, an ability to be flexible and a willingness to take on board the input of consumers of services and research is an important factor in empowering communities and effecting positive and sustainable change.¹⁰

The employment of Aboriginal community members as community researchers on this project has been fundamental to researchers and community members developing a shared understanding and expectations for culturally and contextually sensitive research practices and processes. Locally employed community researchers have provided language and cultural support to both families participating in the research and to non-Aboriginal research staff. This two way research partnership has been central to the project being accepted by the community and to maximising participation from schools and families. Additional funding has been received to enable locally based Aboriginal research staff to complete a Certificate II in Community Services between 2016 and 2017. By doing so,



community researchers working on this project will develop the research skills to complement their existing expertise and knowledge which will enable them to seek employment across other research projects taking place in the Fitzroy Valley. This has already occurred in 2015 whereby Alert Program® Community Researchers were able to be employed on the Fitzroy Valley FASD Prevention research project that is also taking place through the Telethon Kids Institute.

Where to Next?

Analysis of findings in 2018 will contribute to the basis for recommendations and preparation of guidelines for the use of the Alert Program® with children who have impairments in self-regulation and executive functioning in similar settings. The team also hopes to report on the importance of the formative process undertaken to inform and enhance the project and by doing so, hopefully influence similar projects to recognise the benefits of including community and consumer participation in program design, service delivery and research.

Further Reading

Alcohol and Pregnancy and FASD – <http://alcoholpregnancy.telethonkids.org.au/>

Community and Consumer Involvement - <http://telethonkids.org.au/join-us/community-consumers/>

Marulu Strategy - <http://www.mwrc.com.au/pages/the-marulu-strategy>

Dr James Fitzpatrick's Marulu Strategy TEDX talk - <https://www.youtube.com/watch?v=EEJbB-Ke2tc>

Alert Program® - www.alertprogram.com

Kimberley FASD Resource – www.kimberleyfasdresource.com.au

Contact

For additional information about this project, please contact Study Coordinator, Bree Wagner at bree.wagner@telethonkids.org.au or (08) 9489 7752.

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