Royal Far West
Children's health, country-wide

Royal Far West submission to the Senate Community Affairs References Committee regarding the Inquiry into Effective Approaches to Prevention, Diagnosis and support for Fetal Alcohol Spectrum Disorder (FASD)

August 2020

INTRODUCTION: FASD AND ROYAL FAR WEST

Fetal Alcohol Spectrum Disorder (FASD) is a form of brain injury from prenatal alcohol exposure. It has lifelong impacts on child development, leading to a range of learning, behavioural and mental health challenges in later life. National diagnostic guidelines have now been established.[i]

For children, adolescents and families in regional, remote and rural communities, it is likely that FASD contributes to already high rates of developmental and mental health problems, with potential lifespan and intergenerational impacts.

Royal Far West (RFW) is a national rural and remote developmental health service with experience in clinical service provision and research in FASD.[ii] Our submission to the Senate Community Affairs References Committee Inquiry into effective approaches to prevention, diagnosis and support of FASD, advocates for enhanced FASD informed care, education and research for rural and remote communities.

ROYAL FAR WEST'S KEY RECOMMENDATIONS AND RELATED OBJECTIVES

Royal Far West has formulated three key recommendations and related objectives for the Senate Community Affairs Reference Committee Inquiry into Effective Approaches to Prevention, Diagnosis and support for Fetal Alcohol Spectrum Disorder (FASD) to consider:

1. DEVELOP AND FUND PUBLIC HEALTH AWARENESS PROGRAMS TO EDUCATE ABOUT THE RISKS OF DRINKING IN PREGNANCY IN RURAL AND REMOTE COMMUNITIES, INCLUDING TRAINING FOR HEALTH, EDUCATION, CHILD PROTECTION AND JUSTICE SYSTEM PROFESSIONALS

Objective: Prevent FASD in rural and remote communities.

2. INCREASE ACCESS TO BEST PRACTICE FASD ASSESSMENT AND THERAPEUTIC SUPPORT IN RURAL AND REMOTE REGIONS

Objective: Provide equity of access to early diagnosis and early intervention to improve the functioning and developmental trajectory of children and adolescents with FASD, as well as improved lifespan, health and vocational outcomes.

3. FUND RESEARCH FOCUSSED ON UNDERSTANDING THE SPECIFIC IMPACTS OF AND BEST PRACTICE SUPPORTS FOR FASD IN THE BUSH

Objective: Determine the most effective methods to implement Key Recommendations 1 and 2, monitor their impact, and use the evidence to guide FASD strategies rurally.

WHY FASD NEEDS A SPECIFIC RESPONSE IN THE BUSH

We know that an increasing number of children from rural and remote communities experience developmental, behavioural and emotional issues that impact their ability to thrive, and that there is an increasing gap in developmental vulnerability between rural children and their urban counterparts.[iii] Up to 32% of children in rural and remote areas may be unable to access the health services they need.[iv] These gaps have specific implications for children and families impacted by FASD.

Drinking during pregnancy occurs in 50-60% of pregnancies in Australia.[v,vi] Drinking rates in rural areas are higher for men and women compared to their metropolitan counterparts.[vii]

FASD prevalence rates in Australian children, in the city or country, are not known apart from in some specific population (e.g. 36 % of youths in juvenile justice detention in Western Australia had FASD[viii]). However, North American studies have demonstrated that FASD occurs in at least 1% of the general paediatric population, at a rate similar to autism.[ix] Rates of drinking in pregnancy Australia are higher than in North America.[x]

In light of this evidence, FASD rates are likely to affect at least 1% of children in the bush, and may well be higher. This assumption is supported by the FASD National Strategic Action Plan 2018 – 2028, which acknowledges children from regions and communities with high levels of alcohol use are considered an 'at-risk' group for FASD.[xi]

FASD is likely to be contributing to the already documented high rates of developmental and mental health problems in rural children e.g. more than 1 in 6 children and adolescents aged 4-17 in rural areas have mental health problems[xii], although access to best practice FASD assessment and diagnosis is limited.

Children with FASD have at least 3 domains of their development severely impaired (e.g. language, cognition, motor skills), which require extensive specialised care and support. Difficulties accessing specialised care in the bush may have further impact on the functioning of individuals and families living with FASD over their lifespan.

RECOMMENDATIONS

1. DEVELOP AND FUND TAILORED PUBLIC HEALTH AWARENESS PROGRAMS TO EDUCATE ABOUT THE RISKS OF DRINKING IN PREGNANCY IN RURAL AND REMOTE COMMUNITIES, INCLUDING TRAINING FOR HEALTH, EDUCATION, CHILD PROTECTION AND JUSTICE SYSTEM PROFESSIONALS

Objective: Prevent FASD in rural and remote communities.

This can be achieved through:

- *Public awareness campaigns* tailored to rural and remote communities, especially to reduce and prevent drinking before pregnancy awareness, which understand and address drinking cultures and patterns in those regions and communities.
- *Improving prenatal care pathways* in rural and remote areas, to better include identification of, and early intervention and support for, drinking in pregnancy.
- *Rural and remote practice initiatives* to implement whole-of-service prevention and awareness models of drinking in pregnancy risks and FASD. This includes intensive training for:
    - *Clinicians*: e.g. child health nurses, midwifes, obstetricians, general practitioners, health workers and alcohol and drug counsellors
    - *Educators*: e.g. early childhood educators, school teachers and education support staff
    - *Child protection and justice system professionals*: including police.

These initiatives need:

- Adequate funding to ensure design and delivery of interventions that meet the specific needs of rural and remote communities and practice in those areas, compared to urban centres.
- Funding and design should take into account the reduced access to prenatal/obstetric, paediatric specialist and allied health services, with the ultimate goal of improving access to better prevent, assess and support people living with FASD in the bush (see Recommendation 2 for further discussion).

2. INCREASE ACCESS TO BEST PRACTICE FASD ASSESSMENT AND THERAPEUTIC SUPPORT IN RURAL AND REMOTE REGIONS

Objective: **Provide equity of access to early diagnosis and early intervention to improve the functioning and developmental trajectory of children and adolescents in rural and remote areas with FASD, as well as improved lifespan, health and vocational outcomes.**

This can be achieved through:

- *Funding for capacity building and training* of existing developmental and paediatric services to establish best practice FASD assessment and care pathways that reach rural and remote communities, in line with the National Guidelines.
- *Amending relevant MBS item numbers* to enable comprehensive FASD assessment and therapy through Medicare rebates (e.g. updated MBS Item 135), and better access to and flexibility of Telehealth item numbers (e.g. for case conferences between urban specialist units and rural care teams to support best practice wrap-around support).
- *Additional funding and support for government and non-government services working with children and adolescents in out-of-home or kinship care, and/or those with parents living with alcohol and drug use disorders,* to enhance FASD prevention, diagnosis and support, given increased risk of prenatal alcohol exposure/FASD and developmental trauma in this cohort.

- *Ensuring the NDIA recognises and understands the FASD spectrum* under current diagnostic criteria, and the inherent functional impairments of the condition in order to support optimally individuals and families living with FASD.
- *Improving documentation of prenatal alcohol and drug use by health and child protection services,* including reducing barriers to securely sharing information between child protections agencies and clinical services.

3. FUND RESEARCH FOCUSSED ON UNDERSTANDING THE SPECIFIC IMPACTS OF AND BEST PRACTICE SUPPORTS FOR FASD IN THE BUSH

Objective: Determine the most effective methods to implement Key Recommendations 1 and 2, monitor their impact, and use the evidence to guide FASD strategies rurally.

This can be achieved *through research focussing on unique aspects relevant to rural and remote communities regarding*:

- *Effective community and population alcohol harm reduction strategies* specifically tailored for the rural and remote context.
- *Effective clinical approaches to FASD prevention in the bush,* including effective and safe methods for discussing drinking in pregnancy in primary care and other "safe" community settings.
- *Culturally safe and respectful models to support Aboriginal and Torres Strait Islander children, families and communities, and other unique populations.*
- *Further investigate use of Telehealth and other technology* (e.g. 2D/3D facial photography) to facilitate best practice FASD assessment and care at a distance to improve access.
- *Mapping local care pathways for child developmental surveillance, assessment and early intervention* to better ensure these are FASD informed and work effectively and efficiently, including assessing and addressing skills gap in rural practitioners.

ABOUT ROYAL FAR WEST'S INVOLVEMENT WITH CHILDREN AND FAMILIES AFFECTED BY PRENATAL ALCOHOL EXPOSURE AND/OR FASD

RFW is a paediatric multidisciplinary service provider dedicated to working with rural and remote Australian children, adolescents and their families. We have strong connections with rural and remote communities in NSW, QLD and parts of the Kimberley region in WA and deliver a significant proportion of services via telehealth. Around 30% of our clients identify as Aboriginal.

RFW is listed on the National 'FASD Hub' website as a service with experience and expertise in FASD, and our Senior Developmental Paediatrician, Dr Marcel Zimmet is a member of the National FASD Advisory Group. RFW also works in partnership with Marninwarntikura Women's Resource Centre in the Fitzroy Valley developing sustainable multidisciplinary, wrap around service models to support children and families with complex needs, including those impacted by trauma and FASD. In 2019, this collaboration, along with the University of Sydney, was awarded a National Health and Medical Research Council Partnerships for

Better Health Scheme grant - FASD Research Special Initiative to evaluate our unique partnership model for wrap-around care.

This submission is based on paediatric FASD specialist clinician knowledge and an audit of 36 children who have been, or are in the process of being, assessed for FASD (2015-2020) through our Paediatric Developmental Program (PDP). These children were typically:

- *Assessed for FASD at average of 8 years of age (range: 3- 13 years)*
- *Boys (72%)*
- *In out-of-home or kinship care (69%)*
- *Identified as having a history of early life/developmental trauma and/or related developmental challenges (55-70%),*
- *Living remotely – with average Modified Monash Model rating of MMM5 (range: MM3 – MM7) *note: areas classified MM 2 to MM 7 are rural or remote (Department of Health Classification)*

The age of diagnosis and male predominance in this group is similar to the overall cohort of children we assess at RFW, however the rates of out-of-home care and childhood trauma are predictably higher.[xiii]

The RFW FASD audit identifies similar demographic trends to national FASD case surveillance data[xiv], including predominance of children in out-of-home or kinship care, predominance of males and an average age of diagnosis during primary school years. The latter may relate to the fact that many FASD-related learning and behavioural problems are not apparent/or identified until school age, and often this is in boys with externalising behaviours relating to co-occurring conditions such as ADHD or autism, which themselves are more common in boys.

In summary, the FASD audit at RFW suggests:

- Rural children with potential FASD need earlier assessment than is currently occurring.
- There is a need for better FASD assessment and care pathways to be established or enhanced at paediatric developmental services caring for rural or remote children (either local or metropolitan based).
- Children in out-of-home care and/or with a history of early life trauma require special consideration for potential FASD, as do girls (as they are most likely underdiagnosed).

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APPENDIX – ROYAL FAR WEST SERVICE DELIVERY AND ADVOCACY

Our services support children and adolescents who live in eligible regional, rural and remote Australia. Our focus so far has been in NSW, as well as WA and QLD, while a recent Federal Department of Health grant facilitates expansion of our Telecare services nationally. We work in close partnership with local communities, schools and providers to deliver our services and supports.

Our works aim to improve:

- The development, wellbeing and mental health of isolated children
- Functioning of children and adolescents and their families living with developmental challenges and disability
- The vulnerability of rural and remote Australian children
- Access to services, and family support for children with complex needs
- The capacity of isolated teachers, health practitioners and families to support children with complex health and development needs, including FASD.
- Complex problems related to the health and wellbeing of rural and remote children by supporting Governments with opportunities and solutions to address these challenges.

RFW services for rural and remote communities which include:

- Paediatric Developmental Program (PDP): Face-to-face (Manly and in-community) and Telehealth based specialist multidisciplinary assessment, diagnosis and care. This service includes care collaboration with local rural and remote services, clinicians, educators, and other child and family support services.
- Telecare for Kids: Telehealth screening, assessment and therapy program partnering with rural and remote communities and schools.
- Windmill: Multidisciplinary disability support, therapy and care, including Face-to face (Manly and in-community) and Telehealth based programs, therapy immersion weeks and camps.

Our service delivery supports the Government's agenda across multiple portfolios including:

- Indigenous Affairs
- Regional Development
- Disability
- Health
- Education

In 2017, RFW outlined and published nationally, an evidence and experience-based approach to addressing the rate of developmental vulnerability in Australia in "The Invisible

Children". That document has reference here: https://www.royalfarwest.org.au/wp-content/uploads/2018/09/invisible-children-2018-web.pdf

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