Royal Far West Response to further written questions on notice from Senator Stirling Griff

Ref; 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)

November 2020

We thank Senator Griff for the opportunity to respond to the following questions on notice, in relation to the Royal Far West (RFW) Submission to the Senate Community Affairs References Committee for the Inquiry into Effective Approaches to Prevention, Diagnosis and support for Fetal Alcohol Spectrum Disorder (FASD):

QUESTION 1

HOW MANY CHILDREN HAVE YOU ASSESSED FOR FASD THROUGH YOUR PAEDIATRIC DEVELOPMENTAL PROGRAM?

Between 2015 and 2020 (Jan-July), 36 children have been, or were in the process of being assessed for FASD. exposure (PAE). These 36 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 (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).

There have been 2 more children diagnosed with FASD since July 2020, and 4 more who are now in the process of FASD assessment as they have a history of prenatal alcohol exposure (Royal Far West sees 200-250 new clients for assessment each year).

CAN YOU EXPLAIN YOUR ASSESSMENT PROCESS – IS IT MULTIDISCIPLINARY?

The assessment is multidisciplinary, and essentially the same as for all children we see with complex developmental issues – involving a team consisting of a developmental paediatrician, psychologist, occupational therapist, speech pathologist, nursing, and where required, a child and adolescent psychiatrist. It normally takes place over multiple visits to RFW in Manly (or telehealth blocks in COVID-19 times). This assessment is provided through our Paediatric Developmental Program, which is part-funded by NSW Health.

The difference, where FASD is being considered, is we get specific consent from the parents/caregivers to complete specific physical examination (including facial photos), and developmental testing, with a view to considering FASD explicitly. This occurs if a history of prenatal alcohol exposure is identified during the assessment process (which is discussed with all families in the course of the developmental assessment process). The RFW assessment process follows the Australian Guide to FASD diagnosis.[i]

When rural and remote families travel to Royal Far West for developmental assessment, they are typically new to the service. Due to the sensitive nature of a FASD diagnosis and potential stigma experienced by children, parents/carers with a query of or confirmed diagnosis, RFW focuses on progressing the FASD assessment process in a staged, compassionate and sensitive way to reduce child and parent/caregiver stress. The diagnostic process is usually conducted over a period of two or more week-long visits. This ensures a best practice approach is maintained regarding: informed consent, obtaining relevant clinical and historical information from other providers or agencies, and rapport building to ensure families are comprehensively supported through the diagnostic process. and eventual diagnosis if this occurs.

Connecting families with appropriate FASD-informed local services and national support organisations (e.g. National Organisation For FASD - NOFASD) is critical to our FASD care pathway following a diagnosis. Where there are gaps, RFW works extensively to support local providers, including clinicians and schools, to be able to understand and meet the needs of families who have a new FASD diagnosis. In some cases, RFW provides ongoing review and therapy, where the necessary services are not available in the local community,

CONDUCTED FACE-TO-FACE?

FASD assessment and diagnosis is best conducted face-to-face with neurodevelopmental (psychometric testing), and physical examination/ photos.

However, a diagnosis of FASD can be made if prenatal alcohol exposure is confirmed and pre-existing or new RFW assessments confirm severe neurodevelopmental impairment in multiple functional domains according to criteria. For example, online standardised language assessment by our speech pathologist may confirm a severe language disorder.

In summary, we can, in some situations, make a FASD diagnosis through telehealth assessment. If facial photos are taken locally in the correct way, they can be used for the facial feature photo analysis, without meeting the child. Facial feature recognition through accessible smartphone technology, is being investigated worldwide, but is not yet clinically accurate or feasible, although is likely to be in the next decade.

Prior to COVID-19, Royal Far West completed almost all assessments face to face. Since COVID-19, Royal Far West has relied solely on telehealth for assessments, reviews and therapy. Where possible, we have completed assessments and diagnoses, but in many cases children are still waiting for completion of assessments face to face.

IS THERE A WAITING LIST?

Unfortunately, yes. The waiting list is the same as for our PDP program which includes children referred for a wide range of common neurodevelopmental disorders (including FASD), such as autism, ADHD, learning disorders, mental health disorders, intellectual disability. This waiting list has been significantly exacerbated by COVID-19 impacts on the service, as well as increased demand.

Prior to COVID-19, this was sitting around 30 weeks from acceptance of referral to first 'admission' (visit to Royal Far West in Manly) with a plan in place to reduce this to 20 weeks. Following COVID-19, the waiting list has increased significantly, reflecting the difficulties assessing new clients with complex developmental issues, like FASD, without a face to face component. It is currently at 56 weeks.

It is critical to note that the neurodevelopmental disorders mentioned above are common manifestations of the brain injury from prenatal alcohol exposure. They form part of the diagnostic criteria for FASD. There is no defining neurodevelopmental profile for children with FASD, rather there is a 'spectrum' of potential neurodevelopmental effects (the criteria for diagnosis requires 3 domains of severe neurodevelopmental impairment, with a confirmed history of prenatal alcohol exposure (PAE).[ii]

At this stage, there are few children specifically referred to RFW for FASD assessment. This is for several reasons:

- Often the prenatal alcohol exposure is *only* identified during RFW clinical assessment interviews with parents, typically with birth mothers. Common reasons for the absence of information about prenatal alcohol exposure (PAE) in referral information to RFW include:
    - No documentation of PAE in birth records or child protection records, even if other prenatal drug exposure is documented.
    - Ongoing gaps in clinicians' knowledge, skills and confidence in discussing drinking in pregnancy with caregivers/parents before, during and after pregnancy, particularly discussing alcohol use prior to pregnancy awareness.
    - The absence of reliable clinical testing for alcohol in newborn drug screens, and the absence of any blood or other tests from a mother or baby to confirm PAE in early or mid-pregnancy.

- For children in out-of-home-care, despite the high rates of prenatal alcohol exposure, referring GPs or paediatricians often have not had the time, capacity or resources to track documentation to confirm PAE, either through child protection, hospital or other records, or speak to the birth families directly who have witnessed the birth mother drinking in pregnancy. Speaking with birth families is complex practically and ethically, and requires considerable time, sensitivity and support (e.g. from social workers).

QUESTION 2

YOU NOTE THAT "RURAL CHILDREN WITH POTENTIAL FASD NEED EARLIER ASSESSMENT THAN IS CURRENTLY OCCURRING" – WITH THE AVERAGE AGE BEING 8 (RANGE 3-13) YEARS. HOW DO YOU SUGGEST THIS COULD BE ACHIEVED?

This requires identifying children with a history of prenatal alcohol exposure as early as possible, then having the monitoring and assessment systems and resources in place to follow them through to track their development, provide supports and therapy and complete relevant assessment. All of these requirements need specific research and piloting into models of care that can be delivered in a rural context to ensure equitable access to FASD informed assessment and care.

This could be achieved by:

- In the prenatal period, better methods and processes for identifying children in regional and rural areas who will be at risk of FASD, including improving documentation of prenatal alcohol exposure (PAE) in health records during pregnancy and at birth.
- Enhancing primary developmental surveillance to identify developmental problems early – e.g through child/family community nurses, GPs and early childhood educators who are more likely to have contact with children in regional and rural contexts than other traditional services.
- Enhancing capacity of secondary developmental paediatric assessment services in regional centres and their outreach,
- Better prevention of PAE/FASD through better public health programs to communicate the risks of drinking in pregnancy (for everyone), and targeted support for at-risk mothers to ensure their next pregnancy is safer, with no or less PAE. This should include communication that is responsive to identified risk factors for harmful drinking, including those specific to regional and rural communities.

QUESTION 3

IN THIS INQUIRY, WE HAVE MAINLY FOCUSSED ON FASD IN URBAN COMMUNITIES AND IN INDIGENOUS COMMUNITIES. WHAT ABOUT RURAL AND REGIONAL COMMUNITIES MORE GENERALLY – DO YOU HAVE A VIEW ON THE SPECIFIC CHALLENGES OR APPROACHES THAT WE SHOULD CONSIDER IN ORDER TO IMPROVE EDUCATION OR REDUCE HARMFUL DRINKING IN RURAL AND REGIONAL COMMUNITIES?

As per our submission, the nature of rural and remote communities can be quite specific, so the approach needs to be nuanced, with strong community engagement.

We know that regional and rural Australia have higher reported rates of harmful drinking than cities.[iii] We also know that regional and rural Australia face greater and unique stressors from birth compared to people living in cities – including higher rates of unemployment and other disadvantage, including poorer access to and use of health services.[iv] These stressors are compounded by uniquely prevalent environmental stressors such as drought, fires and floods. We also know these unique environmental events are likely to increase in frequency and severity in the future,[v] and that they add to the complexity of stressors faced by families in regional and rural communities. These compounding inequities experienced by regional and rural communities highlight the need for a tailored and contextually responsive approach to FASD education, prevention, diagnosis, support and care.

Improving education and reducing harmful drinking in rural and remote communities **primarily involves understanding and addressing the drinking culture in individual communities, then providing sensitive and clear public health messaging and programs**, which understand bush cultures and services, as well as utilise and build on existing expertise and therapeutic relationships.

This requires investment in research in action which comprises sociological and medical approaches to understanding and changing bush drinking cultures (e.g focus group qualitative research, mixed with studies from antenatal clinics/GPs tracking drinking in pregnancy), **ensuring implementation, trialling of strategies/programs, and follow-up research occurs early.**

It also requires research on how to leverage the ingenuity, creativity and resilience of regional and remote communities and families to lead these responses.

Identifying a strong lead organisation in each community that is respected and able to represent the whole community to be a champion, and then working with and through them, will be key.

QUESTION 4

HOW CAN GOVERNMENTS BETTER SUPPORT PEOPLE WITH FASD LIVING IN THE BUSH?

Key strategies include:

- Support and funding mechanisms that enable a **coordinated approach** in the bush to FASD care **within** and **across the health, education, disability, child protection and juvenile justice systems.** This is especially important for children in out-of-home care or who have a history of early life trauma, as these vulnerable children are particularly at risk of FASD.
- Identify gaps in current FASD informed educational, disability, therapeutic and vocational services, and fill those gaps. That means increased services locally and also via telehealth
- Improve clinical skills in supporting people with FASD and developmental disability in primary and secondary health care ie. capacity building, clinician education.

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[i] Bower C, Elliott EJ 2016, on behalf of the Steering Group. Report to the Australian Government Department of Health: "Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD)".

ii Lange S, Shield K, Rehm J, Anagnostou E, Popova S. (2019) Fetal alcohol spectrum disorder: neurodevelopmentally and behaviorally indistinguishable from other neurodevelopmental disorders. BMC Psychiatry. Oct 28;19(1):322. doi: 10.1186/s12888-019-2289-y. PMID: 31660907; PMCID: PMC6816158

iii Australian Institute of Health and Welfare 2019. Alcohol and other drug use in regional and remote Australia: consumption, harms and access to treatment, 2016–17. Cat. no. HSE 212. Canberra: AIHW

[iv] Arefadib, N. and Moore, T.G. (2017). Reporting the Health and Development of Children in Rural and Remote Australia. The Centre for Community Child Health at the Royal Children's Hospital and the Murdoch Children's Research Institute, Parkville, Victoria. https://www.royalfarwest.org.au/wp-content/uploads/2017/12/Murdoch-Report.pdf

[v] Intergovernmental Panel on Climate Change. Climate, Change and Land: an IPCC special repost on climate change, desertification, land degradation, sustainable land management, food security, and greenhouse gas fluxes in terrestrial ecosystems.; 2019.