



Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

By email: community.affairs.sen@aph.gov.au

Dear Committee Secretary

Re: Goulburn Valley (GV) Health submission to Senate Community Affairs References Committee Inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

Goulburn Valley (GV) Health welcomes the opportunity to make a submission to the inquiry into effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder. GV Health is located in the regional center of Shepparton in central Victoria.

Our submission responds to the Terms of Reference points a), b), c), d), g), h) and p).

GV Health is the Victorian representative of the PATCHES Paediatrics National FASD Consortium. We have worked in partnership with PATCHES Paediatrics since early 2018 to establish the first Victorian clinic dedicated to the assessment and diagnosis of Fetal Alcohol Spectrum Disorder (FASD) for children aged less than 17 years. Funding for this project has included the employment and training of a FASD Clinical Co-ordinator. GV Health has supported clinicians and staff at an operational and administrative level required to establish and run the clinic. PATCHES Paediatrics provided initial training for the clinicians in FASD assessment and diagnosis and ongoing professional support. In line with the requirements of the National Consortium project, GV Health aims to assess 24 children throughout the course of the two year funded period, ending August 2020. The program will be supported after this time through GV Health funding arrangements.

GV Health's three main goals as a member of the National FASD Consortium are to:

1. Establish a regional paediatric FASD Diagnostic Clinic

There have been seven clinics conducted where 12 children ranging from 2-16 years of age were assessed. Of these children, 75% have been diagnosed as having a FASD. 22% of these children were from an ATSI background. 16% of children received a diagnosis of At-Risk of FASD.

2. Work with a Community Reference Group (CRG) to formulate a local FASD Model of Care

We have worked with a group of 25 community stakeholders. A diverse group made up of representatives from a number of local health and welfare services, the Department of



Education and Training, The Department of Justice and Regulation as well as the parent of a child diagnosed with FASD. Our CRG has formulated three local Models of Care for FASD referral, diagnosis and therapy within local Health, Education, Child Protection and Youth Justice systems.

3. Provide education to clinicians, educators and the wider community about FASD including the prevention of, and the lifelong implications of living with a FASD diagnosis.

Since March 2018 the GV Health FASD Clinical Co-Ordinator has facilitated and/or presented at 28 education sessions to more than 500 people. These events have been held at locations across both the Goulburn Valley and Melbourne. Sessions range in format from lectures and workshops to shorter guest speaker roles as part of various whole-day FASD events. Attendees have included professionals from health care, education, justice and welfare, as well as parents and carers of children living with FASD or suspected FASD and interested members of the wider community.

In our submission we will respond to the Terms of Reference which most closely relate to the experiences we have had in FASD education and FASD diagnosis. Our responses will highlight the successes as well as the challenges we have faced, discuss the limitations of our current model and put forward some recommendations for changes that we believe will contribute to improved outcomes for individuals and families affected by FASD.

Terms of Reference

a) The level of community awareness of risks of alcohol consumption during pregnancy

The overwhelming observation in relation to community awareness of the risks of alcohol consumption during pregnancy is the misconception that alcohol is only harmful to a developing fetus if taken in extreme quantities or if the mother has an addiction to alcohol.

b) The adequacy of health advice provided to women planning a pregnancy, pregnant women and women who are breastfeeding about the risks of alcohol consumption

Comments from women who have attended our education sessions:

- "I was told (by a health professional) during my pregnancy that "the odd glass (of alcohol) here and there" is fine." (attendee at Upper Murray Child First Education Session, Wodonga. November 2018)
- "I thought it would only harm a baby if the mother was an alcoholic and drinking alcohol everyday" (attendee at Child Protection Education Session, Shepparton. January 2019)
- "Alcohol was just never mentioned to me (by my health care provider while I was pregnant). He discussed not eating soft cheeses and not smoking but I do not recall a discussion about alcohol." (attendee at NoFASD Education session, FamilyCare, Shepparton. September 2018)

Our project has highlighted the need for more discussion and current education for both healthcare professionals and the wider community about the importance of abstaining from alcohol throughout pregnancy. The risks, lifelong implications and the prevention of FASD needs to become part of the secondary school curriculum, for both boys and girls, as well as being incorporated into the essential coursework for undergraduate students in health, justice and welfare related disciplines.

The risks of alcohol consumption throughout pregnancy need to be discussed routinely with all expectant mothers throughout their antenatal appointments. The range of education health care professionals need includes ways to sensitively initiate the conversation about alcohol use in pregnancy, and ways to respond supportively in the event a pregnant woman does disclose alcohol consumption.

c) Barriers that may prevent women receiving accurate, timely and culturally/ethnically appropriate information or advice on alcohol and pregnancy

- Disengagement with the healthcare service and failure to access antenatal care
- Unplanned pregnancy
- Health care professionals who find the topic of alcohol use in pregnancy too difficult or awkward to raise.
- Health care professionals who are concerned that discussing alcohol use in pregnancy may cause women to feel judged and therefore be disinclined to access their service in future.
- Women not knowing where or how to access accurate help and advice
- Women experiencing fear of judgement or shame, fear of social isolation or fear of child protection involvement if they were to disclose alcohol use during pregnancy

d) Provision of diagnostic services in Australia including capacity, training, integration and diagnostic models currently in use

The GV Health Diagnostic Clinic currently has the capacity to assess 12 children per calendar year (2 children per clinic x 6 clinics per year). This is drastically insufficient for our region. The current wait list for an assessment is close to two years. This means there is a long period of uncertainty and missed opportunity for support and intervention for children waiting for an assessment.

Furthermore, the scope of the GV Health FASD Clinic is limited to assessing and diagnosing FASD. Currently, families receive their report and attend a single follow-up appointment at the clinic. The GV Health FASD Clinic does not currently have the capacity to provide ongoing therapies and supports that these children need long term. Few allied health practitioners and child-welfare workers, including DHHS workers, are sufficiently FASD-informed, making it very difficult to link families in with appropriate therapies and supports after diagnosis.

Being a regional center and the 6th most populous city in Victoria, Shepparton is ideally located for a FASD Diagnostic clinic. It is important that families can access assessment within a reasonable proximity of their home. For regional families, accessing assessments with multiple practitioners in Melbourne would require several visits, transport and accommodation expenses on top of the stress and difficulty of making that journey with a FASD affected child. However, our long waiting list means many families, desperate for answers and support, continue to look elsewhere for assessment. In an attempt to keep waiting lists somewhat manageable, we have limited our service catchment area to the Greater Hume Region, meaning many families who enquire about our service have to look elsewhere. There is currently no other regional FASD diagnostic clinic in Victoria.

g) Awareness of FASD in schools, and the effectiveness of systems to identify and support affected students

The GV Health FASD Clinical Co-ordinator has worked with many schools in the Greater Hume Region providing FASD education to staff, and working with teachers to prepare a child for their FASD assessment. School effectiveness and willingness to support students with FASD has been incredibly varied. Continued education is required for teachers and school-based wellbeing staff about what FASD is, and how to manage challenging behaviour associated with FASD in an inclusive classroom environment.

Currently the Victorian Department of Education and Training, does not recognise FASD as a diagnosis eligible for funding under the Program for Students with Disabilities. Often students with a FASD diagnosis also do not qualify under the requirements for intellectual disability. This leaves students with FASD in a position where it is incredibly difficult for schools to supply them with additional supports.

h) The prevalence of, and approaches to, FASD in vulnerable populations, including children in foster and state care, migrant communities and indigenous communities

At our clinic, FASD diagnosis has been disproportionately represented by vulnerable cohorts within the Greater Shepparton community, with every child assessed to date having been in the care of somebody other than their biological parents, and having some form of history of complex trauma. These findings also indicate that biological mothers whose children were exposed to alcohol in-utero may need more education and support to seek help. A focus on decreasing the stigma and shame for mothers who consumed alcohol during pregnancy should be a future action in our community.

p) Any other related matters

At our clinic, a significant challenge we have experienced in assessing children for FASD, has been establishing confirmed in-utero alcohol exposure. The obstacle here is twofold. Firstly, there is very poor compliance with professionals who work with expectant mothers in terms of asking about alcohol consumption and then documenting this in the mother's medical record. Secondly, if pre-natal alcohol consumption it is recorded on the mother's medical record, it is crucial that this is also documented in the baby's medical record, which currently seldom happens. Clinicians assessing for FASD are often not able to gain consent to access the mother's medical record, and, especially for children in the care of the state, there is often no reliable source who can confirm pre-natal alcohol exposure, meaning these children largely miss out on receiving the help that a diagnosis could potentially bring them.

Thank you for considering our submission. Please feel free to contact Kim Cowen, FASD Clinical Co-ordinator at GV Health if you have any further queries

Kim Cowen

FASD Clinical Co-ordinator
Child & Adolescent Unit
Goulburn Valley Health
Graham Street
SHEPPARTON VIC 3630