

PARLIAMENTARY INQUIRY QUESTION ON NOTICE

Department of Health

Community Affairs

Effective Approaches to Prevention, Diagnosis and Support for Fetal Alcohol Spectrum Disorder

19 May 2020

PDR Number: IQ20-000380

Subject Question: Australian FASD Register

Type of Question: Written

Senator: Stirling Griff

Question

In response to Senator Askew's question regarding data reporting, the Department said the 580 cases had been reported to the Australian FASD Register from 2015 until funding ended in 2018-19. The Department says it is currently working with a preferred applicant to continue the Australian FASD Register. Has the Register continued to record data since funding ceased at the end of 2018-19, or has data recording (temporarily) ceased?

In the same response, the Department said the Australian FASD Register "will, in time, give national prevalence data which Australia does not currently have". How can prevalence be accurately recorded when many children (let alone adults) with suspected FASD are unable to secure a diagnosis because there are not enough diagnostic services and, according to many submitters, demand for assessment from the few available services and specialists far outstrips supply?

Answer:

The Australian Register has continued to collect data from various sources, including the Diagnostic Services funded by the Australian Government since funding ended in 2019. In June 2020, the Department executed a multi-year agreement from 2019-20 to 2022-23 with the University of Sydney to support the continuation and ongoing maintenance of the FASD Register.

It is widely accepted that prevalence of FASD is higher than reported. Evidence from the National Drug Strategy Household Survey 2016 shows approximately 1 in 4 women continue to drink once becoming aware they are pregnant.

The National FASD Strategic Action Plan 2018-2028 notes around 50 per cent of all pregnancies in Australia are unplanned and the Hidden Harm report stated that as many as two per cent of Australian babies are being born with some form of FASD.

The intention is all FASD diagnoses will be reported to the FASD Australian Register, building a more accurate description of FASD prevalence in Australia. To assist with this, the Register will continue to enhance its data capturing processes, and raise awareness of its existence with health professionals through various methods including the FASD Hub and NOFASD.

PARLIAMENTARY INQUIRY QUESTION ON NOTICE

Department of Health

Community Affairs

Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder

19 May 2020

PDR Number: IQ20-000381

Question Subject: Projects funded over 2019-20 to 2022-23 under the National FASD Strategic Action Plan

Type of Question: Written

Senator: Stirling Griff

Question:

With regards to the projects to be funded over 2019-20 to 2022-23 under the National FASD Strategic Action Plan, please provide information on the scope of resources/services to be provided and where/to whom they will be provided, for the following:

- a. Early Childhood identification guide
- b. Teachers and educational setting resources
- c. Justice and policing resources
- d. Best practice resources for priority groups

Answer:

a) Early Childhood Identification Guide.

Funding: \$600,000 from 2019-20 to 2022-23

Provider: National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD)

Scope

The Early Childhood Identification Guide (the Guide) will be developed to help educators support children and their families in the early childhood education setting. The objectives of the Guide are to:

- provide early years educators with knowledge and skills to identify children who potentially meet the diagnostic criteria for FASD specified in the *Australian Guide to the Diagnosis of FASD*;
- increase the level of understanding within the early childhood education workforce of the child's vulnerabilities and capacity to learn when they potentially have FASD;

- provide early years educators with knowledge, skills and strategies to foster successful and inclusive early childhood education experiences for children who potentially have or have been diagnosed with FASD;
- assist early years educators engage with parents and carers regarding a child's learning and development needs if they potentially have or are diagnosed with FASD; and
- develop an understanding of communication methods that successfully support people with FASD and their parents/carers in an early education setting.

Resources accompanying the Guide will provide information on initiating discussions with parents and carers and options for FASD diagnostic assessment.

Delivery details

The Guide will be produced for use by educators, delivered nationally, be made available on all Australian-based FASD websites (NOFASD will facilitate this) and on early childhood education peak body websites.

b) Teacher and Educational Setting Resources

Funding: \$600,000 from 2019-20 to 2022-23

Provider: The Matilda Centre for Research and Mental Health, University of Sydney

Scope

A suite of resources including guidance materials, tools and templates will be developed to train educators and mentors to recognise FASD and to assist with the management and support of students with FASD. To achieve this the Matilda Centre will:

- undertake a review of current resources within the education sector in relation to education and mentoring for students with FASD;
- develop a suite of resources that align with the Australian Guide to the Diagnosis of FASD to assist the education workforce to identify students who potentially have FASD;
- create resources that improve the capacity of teachers and educational support staff to encourage greater participation of people with FASD in education settings and that align with the Australian Professional Standards for Teachers;
- provide the education workforce with strategies to engage with children who potentially have FASD and their parents/carers; and
- promote and disseminate the newly developed and/or updated resources regarding FASD to ensure that educators and mentors are accessing best practice education tools to support students with FASD.

Delivery details

Resources will be available nationally including in rural and remote schools. It will be the responsibility of each state and territory and their education departments, educators, mentors and schools to utilise the resources in the most effective way for them.

c) Employment Services and Criminal Justice System Resources

Funding: \$600,000 from 2019-20 to 2022-23

Provider: PATCHES Paediatrics

Scope

Employment Services

The Employment Services component of this activity will include reviewing and adapting resources to assist recruitment and employment personnel to understand FASD and to assist people with FASD obtain and retain employment.

The resources will address generalised beliefs people with FASD do not have the skills and attributes to participate in the workforce. The resources will also assist recruitment and employment personnel to shift perceptions, provide support, and guide people with FASD to seek, gain and remain employed.

Criminal Justice System Resources

The Criminal Justice System Resources activity will involve reviewing and adapting resources to assist people in the criminal justice workforce to recognise people who are potentially affected by FASD, and understand the implications of this disorder within the criminal justice system.

The resources will explain the characteristics of FASD, including assessment processes, and strategies to improve the outcomes for the people with FASD, their families and the community. Information on linking people with FASD to employment services will also be included in the resources.

Delivery details

Resources will be available on all appropriate Australian-based FASD and Alcohol and Other Drug websites. In addition:

- the employment services resources will be provided to disability websites and recruitment/employment agencies such as JobAccess or Department of Employment, Skills, Small and Family Business; and
- the criminal justice system resources will be provided to organisations, including state and territory Legal Aid offices; police forces, state and federal courts, and correctional services.

d) Best Practice Resources for Priority Groups

Funding: \$1.3 million from 2019-20 to 2022-23

Provider: These resources are being delivered through the Foundation for Alcohol Research and Education (FARE) FASD Pregnancy and Breastfeeding Awareness Campaign

Scope

This activity will develop a suite of resources supporting women, through their health professionals, at a higher risk of having a child with FASD and target high-risk population groups predisposed to FASD.

The resources will be evidence based and build capacity of multidisciplinary health professional teams involved in supporting priority groups identified in the FASD Strategic Action Plan. The resources will outline appropriate alcohol screening options to educate and

support people in high-risk groups about the harms associated with any level of alcohol consumption during pregnancy.

Resources will be culturally appropriate and will support Aboriginal and Torres Strait Islander People. A review, update and/or development of culturally appropriate FASD information for health professionals working with Aboriginal and Torres Strait Islander women, their partners and families will be undertaken.

Resources will also be developed for health professionals to support women in rural and remote regions. Information for this priority group will be considerate of the lack of referral pathways for maternal health services and alcohol dependency.

Delivery details

The Best Practice Resources for Priority Groups will be delivered by FARE through the FASD Pregnancy and Breastfeeding Awareness Campaign.

These resources will be delivered nationally through a variety of modalities including print and digital media.