

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: IQ20-000234

Question Subject: The Hidden Harm Report

Type of Question: Spoken

Hansard Page number: 2

Senator: Wendy Askew

Question

Senator ASKEW: So that was the current action plan, but you mentioned things as far back as the The Hidden Harm report. What sort of measurements did you have coming out of those reports and implementation of programs?

Ms Appleyard: Sorry, Senator; I'll find the right briefing. A number of those activities—I haven't got information in front of me specifically in relation to those evaluation outcomes, so I may take that question offline in order to provide some information. What I guess I would say is that progress against those funding measures would have been articulated as part of the project agreement or funding plan with the funded organisations. And I would probably mention that the fact that a number of those initiatives have been continued in the existing FASD plan—and I'm thinking of things like the Women Want to Know project, Pregnant Pause as well as the FASD Hub, the data collection activity and the FASD register—would be an indication of successful outcomes in relation to the first tranche. But I do apologise for not having the specific information with me at the moment in relation to any evaluation outcomes.

Senator ASKEW: That's okay; that's fine. If you could take that question on notice—it would be interesting to have that statistical report from way back from The Hidden Harm forward with regard to what evaluations have been completed and what improvements have been seen. That leads me to my next question regarding the data and reporting aspect of recording FASD outcomes. What sort of systems are currently in place and what is being done to improve the recording of cases?

Answer:

Part 1

Senator Askew asked:

- What sort of measurements did you have coming out of those reports and implementation of programs?
- If you could take that question on notice—it would be interesting to have that statistical report from way back from The Hidden Harm forward with regard to what evaluations have been completed and what improvements have been seen.

Response

Please refer to the table at [Attachment A](#).

Part 2

Senator Askew asked:

- That leads me to my next question regarding the data and reporting aspect of recording FASD outcomes. What sort of systems are currently in place and what is being done to improve the recording of cases?

Response

The Australian FASD register was initially funded under the 2014 action plan. Since then, a detailed register for recording clinical cases has been developed.

Reporting is still in its infancy, however since 2015, a total of 580 cases had been reported to the register until the funding ceased at the end of 2018-19.

In November 2019, as part of the Department of Health's role in implementing the FASD Strategic Action Plan, a grant opportunity to continue the Australian FASD Register was released. Applications closed on 3 February 2020. A preferred applicant has been identified and the Department is working closely with the Department of Social Services to progress this activity and offer a funding agreement.

The FASD Diagnostic tool, developed with funding provided under the 2013-14 action plan, is used to report cases of FASD to the Australian FASD register which will, in time, give national prevalence data which Australia does not currently have.

FASD \$27m FUNDING ALLOCATION AND ACHIEVEMENTS	
<i>FASD Action Plan 2013-14 to 2016-17 program \$9.2 m over four years</i>	
Program details	Key Achievements
<p><i>Activity:</i> Women Want to Know and Pregnant Pause <i>Total Funding:</i> \$1,895,35 (Between 2012 - 2019) <i>Recipient:</i> Foundation for Alcohol Research and Education (FARE)</p>	<ul style="list-style-type: none"> • Increase of awareness for GPs to have conversations with patients regarding alcohol. • Completion rates of alcohol related GP professional development courses increased. • More women and their support networks were making a commitment to go alcohol free for the duration of pregnancy and breastfeeding.
<p><i>Activity:</i> Indigenous activities <i>Funding:</i> \$4 million (2013-14 – Current) <i>Recipient:</i> Various</p>	<ul style="list-style-type: none"> • Health promotion messages developed and aired nationally through the Brisbane Indigenous Media Association in English and local languages. • FASD prevention and health promotion messages and resources produced. • Training implemented to support national delivery of New Directions Mothers and Babies. • Research funding delivered through the National Health and Medical Research Council (NHMRC) for various projects.
<p><i>Activity:</i> Social media awareness raising campaign <i>Funding:</i> \$435,000 (2013-14 to 2016-17) <i>Recipient:</i> National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD)</p>	<ul style="list-style-type: none"> • Increase of FASD awareness and the risks of drinking when planning a pregnancy, pregnant or breastfeeding.
<p><i>Activity:</i> FASD Hub <i>Funding:</i> \$400,000 (2016-17) <i>Recipient:</i> University of Sydney.</p>	<ul style="list-style-type: none"> • Establishment of a one-stop online resource hub providing a central repository for all information on FASD for clinicians, health practitioners, researchers and consumers.
<p><i>Activity:</i> Data collection of maternal alcohol consumption in pregnancy <i>Funding:</i> \$379,338 (2013-14 to 2017-18) <i>Recipient:</i> AIHW.</p>	<ul style="list-style-type: none"> • The National Maternity Data Development activity (NMDDP) aims to improve data collection of maternal alcohol consumption in pregnancy as well as develop a screening tool to identify women at risk of alcohol misuse, mental health problems and domestic violence. • This activity has been completed and is capturing data for inclusion into the National Perinatal Best Endeavours Data Set (NBEDS).
<p><i>Activity:</i> Australian FASD Register <i>Funding:</i> \$150,000 (2016-17) <i>Recipient:</i> University of Sydney.</p>	<ul style="list-style-type: none"> • The Australian FASD Register has been established and is recording FASD cases nationally. Over time data collected will provide national prevalence data and incidence rates.
<p><i>Activity:</i> Development of a National FASD Strategic Action Plan <i>Funding:</i> \$297,830 (2016-17) <i>Recipient:</i> Siggins Miller</p>	<ul style="list-style-type: none"> • Focus groups and public consultations undertaken to inform development of the National Strategic Action Plan (SAP). • Consultation report developed • Draft SAP developed which informed final SAP

Taking More Action on FASD 2016-17 to 2019-20 program funding \$10.5m over four years	
<p><i>Activity:</i> Telephone and online counselling services <i>Funding:</i> \$1,506,000 (2016-17 to 2019-20) <i>Recipient:</i> NOFASD</p>	<ul style="list-style-type: none"> • Online and telephone support for people affected by FASD. In the last reporting period (Jan to June 2019) almost 600 enquiries received.
<p><i>Activity:</i> Support for parents and caregivers <i>Funding:</i> \$75,000 (2018-19 to 2019-20) <i>Recipient:</i> Russel Family Fetal Alcohol Disorder Association(RFFADA)</p>	<ul style="list-style-type: none"> • As at the last reporting period (1 November 2019 – 31 January 2020) support was provided to 178 families, parents and caregivers of children with FASD. • An estimated 91 participants have joined a support group.
<p><i>Activity:</i> Diagnostic services and models of care projects <i>Recipients:</i> University of Western Australia</p> <ul style="list-style-type: none"> • \$2,569,419 (2017-18 to 2019-20) <p>Patches Paediatrics</p> <ul style="list-style-type: none"> • \$2,724,223 (2017-18 to 2019-20) <p>Griffith University Enterprises</p> <ul style="list-style-type: none"> • \$1,379,245 (2017-18 to 2019-20) <p>Griffith University Health</p> <ul style="list-style-type: none"> • \$1,368,724 (2017-18 to 2019-20) <p>Monash Children’s University</p> <ul style="list-style-type: none"> • \$325,000 (2017-18 to 2019-20) 	<ul style="list-style-type: none"> • Diagnostic clinics are being delivered in multiple locations across the country. • Each clinic delivers different services based on local need. Some clinics are also delivering support through providing referral pathways as well as assessment services. • In the 2018-19 financial year one of the funded organisations assessed over 400 individuals across multiple clinics. (Not all of these individuals were diagnosed with FASD). • A full evaluation of the Diagnostic Services and Models of Care activities is currently underway.
National FASD Strategic Plan (SAP) program funding \$7.2m over four years	
<p><i>Activity:</i> Australian FASD Register <i>Funding:</i> \$400,000 (2019-20 to 2022-23) <i>Recipient:</i> Not yet awarded</p>	<ul style="list-style-type: none"> • Outcomes not yet available.
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<p><i>Activity:</i> Teacher and educational setting resources <i>Funding:</i> \$600,000 (2019-20 to 2022-23) <i>Recipient:</i> Not yet awarded</p>	<ul style="list-style-type: none"> • Outcomes not yet available.
<p><i>Activity:</i> Justice and Policing resources <i>Funding:</i> \$600,000 (2019-20 to 2022-23) <i>Recipient:</i> Not yet awarded</p>	<ul style="list-style-type: none"> • Outcomes not yet available.
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<p><i>Activity:</i> Women Want to Know and Pregnant pause <i>Funding:</i> \$600,000 (2019-20 to 2022-23) <i>Recipient:</i> This activity will now be funded to FARE through the National Awareness Campaign for Pregnancy and Breastfeeding Women.</p>	<ul style="list-style-type: none"> • Outcomes not yet available.
<p><i>Activity:</i> Translation and promotion of revised NHMRC drinking guidelines <i>Funding:</i> \$400,000 (2019-20 to 2022-23) <i>Recipient:</i> Not yet awarded</p>	<ul style="list-style-type: none"> • Outcomes not yet available.

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: IQ20-000235

Question Subject: National Advisory Group information

Type of Question: Spoken

Hansard Page Number: 4

Senator: Malarndirri McCarthy

Question:

Senator McCARTHY: It would be good to know when that next meeting is of the national advisory group. I am looking through my papers here to see if I have the names of people on that advisory group, but I don't seem to have them in front of me. Has that been tabled to the committee?

Ms Appleyard: We can table that. That will not be a problem at all. I have those names in front of me. Also, just to answer your question about the next meeting, at this stage the next meeting is scheduled for November this year.

Senator McCARTHY: What's the breakdown of that committee in terms of state and territory representatives?

Ms Appleyard: I'm looking at my list now in order to tell you that. The list I have in front of me is broken down in terms of qualifications or representation of the organisations that are involved. In state representation, there's a member from Western Australian Health and they're a National Drug Strategy Committee member as well. There's representation, of course, from the Commonwealth, and then you have key paediatric experts like Professor Elizabeth Elliott and Professor Steve Allsop from the National Drug Research Institute, and people like clinical psychologists, neuropsychologists and paediatricians, as well as representatives from peak organisations and research organisations. Parents and community volunteers, I should add, is an important representative group as well. Ms Julie Tongs, who's the CEO of Winnunga Aboriginal health service, which I think is here in the ACT, is also a member, as is Dr Sharman Stone, who was on the previous House of Representatives committee in—

Senator McCARTHY: How many people are on that national advisory group?

Ms Appleyard: There are 15.

Senator McCARTHY: Is Ms Tongs the only Aboriginal representative on that committee?

Ms Appleyard: The best that I can identify from what the list tells me, it would appear that way. If that's not the case, I'll certainly be able to correct that on notice.

Senator McCARTHY: In terms of that national advisory group, if you're tabling the names,

could you also table the terms of reference behind that group being established and what their role is?

Ms Appleyard: I'm very happy to do that, Senator.

Answer:

The FASD Advisory Group was established by the National Drug Strategy Committee (NDSC) in 2019.

The NDSC members are senior department executives from health and law enforcement agencies from all jurisdictions and the Commonwealth. Members of the NDSC nominated individuals for consideration as members of the FASD Advisory Group.

The final FASD Advisory Group composition was endorsed by the NDSC in August 2019. The FASD Advisory Group consists of representatives from clinical backgrounds, as well as research, policy and parent/carer sectors, and representatives of government agencies. Terms of Reference for the Group are provided at Attachment A.

The FASD Advisory Group includes Indigenous representation as well as members who have considerable experience working within Indigenous and remote communities. The names of the Advisory Group members are provided at Attachment B.

November 2019

National Drug Strategy Committee (NDSC) Fetal Alcohol Spectrum Disorder (FASD) Advisory Group

TERMS OF REFERENCE

<p>Purpose</p> <p>The National FASD Strategic Action Plan (the Strategic Action Plan) was developed to provide a clear pathway of priorities and opportunities to improve the prevention, diagnosis, support and management of FASD in Australia. The Strategic Action Plan proposes that a National FASD Advisory Group (FASD Advisory Group) should be created to monitor and report on the implementation progress of the Strategic Action Plan.</p>	
<p>Roles and Responsibilities</p> <p>The primary roles and responsibilities of the FASD Advisory Group are to:</p> <ul style="list-style-type: none"> ➤ Monitor the implementation of the National FASD SAP ➤ Oversee the mid-point review and evaluation of the FASD SAP (3, 5 and 9 years) ➤ Identify opportunities and solutions for improvement in the implementation of the National FASD SAP with reference to lessons learned from review and evaluation findings ➤ Oversee the final review and evaluation of the FASD SAP, and provide recommendations towards the development of a new National Strategy to commence from 2028 ➤ Facilitate stakeholder engagement and partnership, including by inviting additional experts and representatives from other sectors and stakeholders to engage on issues of mutual interest ➤ Provide advice to the National Drug Strategy Committee on matters within the advisory group's responsibility ➤ Provide advice to the National Drug Strategy Committee through regular reports on the implementation of the Strategic Action Plan, including challenges and proposed solutions/opportunities for improvement. 	
Chair	Co-Chair: Co-Chair: Assistant Secretary, Alcohol Tobacco and Other Drugs Branch, Commonwealth Health
Membership	Members of the Advisory Group, in fulfilling their roles are expected to: <ul style="list-style-type: none"> • Declare any real or potential conflicts of interest prior to appointment and during membership of the Advisory Group, if and as conflicts arise • Ensure the appropriate and proper use of information obtained through membership of the Advisory Group • Respect the diverse views and capacities of all members • Contribute to consensus decision making
Secretariat	Commonwealth Health to provide secretariat services

<p>Operations</p>	<p>The first meeting of the Advisory Group will be a face to face meeting held in a capital city. Members will be required to cover the costs of their own travel and attendance. Where this is not possible (for those in the not-for-profit sector or parent/carer members), a member may approach the secretariat for assistance.</p> <p>Subsequent meetings will be held twice per year via teleconference to be organised by the Secretariat. A face to face meeting will be scheduled to coincide with the scheduled review points (3, 5 and 9 years) of the Strategic Action Plan.</p> <p>It is anticipated that there will be minimal reading in preparation for each meeting. When the time comes for the mid-point and final evaluations, a small subgroup may be formed with agreement of the Chairs to progress work associated with the review/evaluation.</p>
<p>Decision Making</p>	<p>On the basis of consensus</p>
<p>Reporting</p>	<p>The FASD Advisory Group will report to the National Drug Strategy Committee.</p>

Attachment A

Name	Qualifications
Mr David Laffan	Assistant Secretary, Alcohol, Tobacco and Other Drugs Branch Commonwealth Department of Health
Professor Elizabeth Elliot	Professor, Paediatrics & Child Health and NHMRC Practitioner Fellow Paediatrics & Child Health, Children's Hospital, Westmead Director of the Australian Paediatric Surveillance Unit
Professor Steve Allsop	Director of National Drug Research Institute Director of World Health Organisation Collaborating Centre for the Prevention of Alcohol and Drug Abuse
Professor Carmela Pestell	Clinical Psychologist and Clinical Neuropsychologist Former Director of the state-wide Neurosciences Unit (Health Department of WA) Honorary Research Associate Telethon Kids Institute
Dr Katrina Harris	Paediatrician, Adjunct Senior Lecturer, Monash Health
Louise Gray	Executive Officer, NOFASD
Dr James Fitzpatrick	McCusker Clinical Research Fellow, Aboriginal Child Health Telethon Kids
Stewart McDougall	Research Assistant & PhD Candidate Australian Centre for Child Protection
Dr Tracey Harbour	Parent and Community Volunteer FASD Australia CRE
Dr Marcel Zimmet	Developmental Paediatrician, FASD Service at the Care and Intervention for Children and Adolescents Affected by Drugs and Alcohol Centre NSW Member of the Expert Panel for Australian FASD Diagnostic Instrument and Author of National Diagnostic Guidelines
Mr Gary Kirby	WA Health NDSC Member
Dr Nicolle Ait Khelifa	Addiction medicine specialist
Ms Julie Tongs OAM	CEO Winnunga Nimmityjah Aboriginal Health Service
Dr Sharman Stone	Former politician, chaired 2012 House of Representatives inquiry into FASD
Ms Jess Foote	Branch Head, Health, Wellbeing and Justice Branch, National Indigenous Australians Agency

* Dr Carol Bower (coChair) resigned from the Advisory Group as CoChair and member in March 2020.

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: IQ20-000237

Question Subject: Allocation of \$27 million for FASD programs

Type of Question: Spoken

Hansard Page number: 8

Senator: Anne Urquhart

Question

Senator URQUHART: What I'm interested in is the \$27 million allocated to programs since 2014. What's the measure of success of those programs? Is there information about the success? Are we seeing reduced rates? I'm not seeing that. Do you have a program of where the successes are from that \$27 million?

Ms Appleyard: As we have mentioned, the FASD Strategic Action Plan going forward contains a very comprehensive evaluation framework linked to the strategy. The measure of success in relation to previous funding measures would generally be captured through program evaluation activity. But I think it's fair to say that our data in relation to FASD—both its prevalence and the success of the measures—could be improved, which is exactly why we are seeking—

Senator URQUHART: Sorry to interrupt. So we've spent \$27 million but we really don't have an eyeball on what that's actually achieved. Is that what you're saying?

Ms Appleyard: I think we do have some idea based on the factors I mentioned before: we are continuing a number of the initiatives that were funded because they have been successful and we've been building on them. For example, the FASD hub has been a very successful service directory and also provides a lot of information to service providers and families. We would have information from the reports we get in relation to the contracts we manage in relation to individual programs. All of that has fed into the development of the current strategic action plan, so that's—

Senator URQUHART: Just to save time on the hook-up today, are you able to provide, on notice, the information around the allocation of that \$27 million and what the achievements have been from that? Can you break that down into programs?

Ms Appleyard: Yes, we can do that.

Answer:

Please refer to the attached *FASD \$27 m Funding Allocation and Achievements* table

FASD \$27m FUNDING ALLOCATION AND ACHIEVEMENTS

FASD Action Plan 2013-14 to 2016-17 program \$9.2 m over four years

<i>Program details</i>	<i>Key Achievements</i>
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	<p>misuse, mental health problems and domestic violence.</p> <ul style="list-style-type: none"> This activity has been completed and is capturing data for inclusion into the National Perinatal Best Endeavours Data Set (NBEDS).
<p><i>Activity:</i> Australian FASD Register <i>Funding:</i> \$150,000 (2016-17) <i>Recipient:</i> University of Sydney.</p>	<ul style="list-style-type: none"> The Australian FASD Register has been established and is recording FASD cases nationally. Over time data collected will provide national prevalence data and incidence rates.
<p><i>Activity:</i> Development of a National FASD Strategic Action Plan <i>Funding:</i> \$297,830 (2016-17) <i>Recipient:</i> Siggins Miller</p>	<ul style="list-style-type: none"> Focus groups and public consultations undertaken to inform development of the National Strategic Action Plan (SAP). Consultation report developed Draft SAP developed which informed final SAP
Taking More Action on FASD 2016-17 to 2019-20 program funding \$10.5m over four years	
<p><i>Activity:</i> Telephone and online counselling services <i>Funding:</i> \$1,506,000 (2016-17 to 2019-20) <i>Recipient:</i> NOFASD</p>	<ul style="list-style-type: none"> Online and telephone support for people affected by FASD. In the last reporting period (Jan to June 2019) almost 600 enquiries received.
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<p><i>Activity:</i> Translation and promotion of revised NHMRC drinking guidelines</p> <p><i>Funding:</i> \$400,000 (2019-20 to 2022-23)</p> <p><i>Recipient:</i> Not yet awarded</p>	<ul style="list-style-type: none">• Outcomes not yet available.
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