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Introduction

1.1 'I just want to be normal' are the words of Tristan, a young Australian boy affected by Fetal Alcohol Spectrum Disorders (FASD).[1]

1.2 FASD is the largest cause of non-genetic, at-birth brain damage in Australia. People with FASD have an 'observable abnormality in the structure and size of the brain; that is, a physical condition which causes a change in function'.[2] The National Rural Health Alliance (NRHA) explained that these problems are:

> … primarily the result of impairment of the brain's 'executive functions', including the ability to plan, learn from experience and control impulses. Children affected might be regarded as being wilful or undisciplined when in fact they have little control over their behaviour.[3]

1.3 FASD is the overarching term for the range of conditions that can occur in an individual with prenatal exposure to alcohol. It can result in learning difficulties, a reduced capacity to remember tasks from day to day, anger management and behavioural issues, impaired speech and muscle coordination, and physical abnormalities in the heart, lung and other organs. The effects can range from mild impairment to serious disability.

1.4 Tristan, like many children affected by FASD, experiences a range of these challenges in everyday his life.

1.5 It is likely that if FASD were a preventable disease occurring across Australia causing such lifelong disabilities and learning difficulties in children, there would public awareness campaigns outlining the causes,

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1 Marninwarntikura Women's Research Centre and Nindlingarri Cultural Health Services, *Tristan – Hopes, dreams and challenges of a young boy living with FASD*, DVD directed by M Hogan, produced by J Latimer, The Lililwan Project, 2012.

2 Ashurst Australia, *Submission 49*, p. 8.

3 National Rural Health Alliance, *Submission 40,* p. 4.

symptoms and preventative measures. There would be public advocacy mobilised to fight for the best outcome for babies and the eradication of the condition.

1.6 However, the causes, effects and the prevalence of FASD are largely unknown or hidden in Australia. It is a totally preventable condition which has no place in a modern developed world, and yet in Australia over 60 per cent of women continue consume alcohol when pregnant. It is expected that FASD is becoming more prevalent. There is no cure—there is only prevention. While much remains to be understood how best to prevent, diagnose and then manage the impacts of FASD on the population.

1.7 FASD is caused by prenatal exposure to alcohol. If a woman has zero alcohol consumption during pregnancy, then the fetus has zero risk of developmental abnormalities from exposure to alcohol. While greater exposure to alcohol increases the risk, there are critical fetal developmental stages during which small levels of exposure may carry significant risk.

1.8 Tragically, many Australians are unaware of the risk that prenatal exposure to alcohol poses and the irreversible lifelong damage that may ensue.

International FASD response

1.9 While Australia has lacked a national approach to FASD, internationally efforts to combat FASD are well advanced.

1.10 North America leads the world in the recognition, diagnosis and response to FASD. A parliamentary report on the problems of FASD was tabled in the Canadian Parliament as early as 1992.[4]

1.11 Diagnostic tools and guidelines, early intervention services, and screening programs are available in North America.[5] For example, in the state of Washington, multi-disciplinary diagnostic clinics have been operating since 1993:

> These clinics have helped to raise awareness of FASD among health professionals and improve diagnosis, with 61 to 90 per cent

4 Canadian Government, *Fetal Alcohol Syndrome: From Awareness to Prevention: Government Response to the Fifth Report of the Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women*, June 1992.

5 South Australian Government, *Submission 52*, p. 5; P Walker, *Submission 29*, p. 12; Royal Australasian College of Physicians, *Submission 27*, p. 4.

> of North American paediatricians being able to correctly identify the essential diagnostic features of [foetal alcohol syndrome].[6]

1.12 In Canada, public awareness campaigns about FASD have been conducted since 1999.[7] That same year, funding for FASD was allocated in the Canadian budget, and a FASD Framework for Action subsequently launched in 2002.[8]

Australian FASD response

1.13 Australia currently lags behind other countries in recognising the prevalence of FASD and the impact on the individual as well as social and economic impact on families and society. It is clear that urgent measures must be taken to reduce the incidence of FASD and to better manage those diagnosed with FASD. This parliamentary inquiry and report are long overdue.

1.14 The Foundation for Alcohol Research and Education (FARE) notes that there has been a 'government policy void' in Australia for the past two decades, that individuals and researchers have been trying to fill.[9]

1.15 The National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) was founded in 1999 as a national peak body to provide support for those with FASD and to lobby for awareness and action. In its submission, NOFASARD pointed out that, over a decade later:

> The true extent of the incidence and prevalence of FASD in Australia is currently unknown. There is no nationally consistent definition; diagnostic criteria for FASD; nor biomarker for all conditions within the spectrum. Children are not routinely screened in infancy or early childhood and data which accurately reflects estimates of FASD incidence and prevalence in Australia are lacking.[10]

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6 Foundation for Alcohol Research and Education and Public Health Association of Australia (FARE/PHAA), *Submission 36*, p. 20.

7 FARE/PHAA, *Submission 36*, p. 12.

8 Public Health Agency of Canada, *Prevention of FASD: The Canadian Experience*, October 2010, <http://www.drogenbeauftragte.de/fileadmin/dateien-dba/DrogenundSucht/Alkohol/Downloads/Prevention_of_FASD_The_Canadian_Experience_Vortrag_Johnston_101005_Drogenbeauftragte.pdf> viewed 18 October 2012.

9 Foundation for Alcohol Research and Education (FARE), *The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013–2016*, September 2012, p. 4.

10 National Organisation for Fetal Alcohol Syndrome and Related Disorders, *Submission 46*, p. 8.

1.16 The Telethon Institute for Child Health Research commenced a research program into alcohol and pregnancy in 2001, which has resulted in Australian-specific information, data and publications on FASD that contribute to public health policies.[11] The Telethon Institute later received funding from the Commonwealth Government to develop a national screening and diagnostic tool.

1.17 In 2006, the Intergovernmental Committee on Drugs Working Party on FASD was established. Their 2009 monograph titled *Fetal Alcohol Spectrum Disorders in Australia: An update* was made public only in June 2012. The Committee is aware that there is now an updated version of the monograph which provides more detail on responses to FASD in Australia.

1.18 It is disturbing that a lack of agreement across levels of government prevented the later monograph from being made available to this Committee to inform the report. National action on FASD will require a significantly more cooperative intergovernmental environment than has currently been demonstrated.

1.19 In recent years, concern has been increasing about the damages that alcohol can cause to individuals, families and society. These harms include long-term mental and physical health problems, absenteeism, crime, domestic violence, violence in and near drinking venues resulting in injury or death, and drink-driving. There has been a recent emphasis on the consequences of Australia's growing culture of risky and binge drinking.

1.20 There has been increasing concern regarding the harmful impacts of irresponsible consumption of alcohol. For example, in 2009 the National Preventive Health Taskforce produced a report on reducing harmful drinking. In 2011, a review of food labelling recommended that alcohol be labelled with warnings about the risk of drinking alcohol when pregnant.

1.21 In 2011, the House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs tabled their report, *Doing Time – Time for Doing: Indigenous youth in the criminal justice system.* The Committee received evidence about alcohol and substance abuse, alcohol reforms and the incidence of FASD in Indigenous communities, and recommended that the Commonwealth Government take action on addressing FASD and refer an inquiry to the Social Policy and Legal Affairs Committee.[12]

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11 Telethon Institute for Child Health Research, *Submission 23*, p. 2.

12 Parliament of Australia, House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs, *Doing Time – Time for Doing: Indigenous youth in the criminal justice system*, June 2011.

1.22 That same year, the Western Australia Parliamentary Education and Health Committee commenced an inquiry into improving educational outcomes for Western Australians of all ages, which included terms of reference to investigate FASD. The Committee published its report, *Foetal Alcohol Spectrum Disorder: the invisible disability*, on 20 September 2012.

1.23 On 12 September 2012, FARE launched *The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013–2016*. The Committee commends FARE for their work on FASD and considers that the actions from this plan are a useful adjunct to the recommendations of this report.

The inquiry

1.24 On 8 November 2011, the Minister for Families, Housing, Community Services and Indigenous Affairs, the Hon Jenny Macklin MP, and the then Minister for Health and Ageing, the Hon Nicola Roxon MP, asked the Committee to inquire into and report on developing a national approach to the prevention, intervention and management of FASD in Australia.

1.25 The Committee was asked to investigate three main areas:

- Prevention strategies - including education campaigns and consideration of options such as product warnings and other mechanisms to raise awareness of the harmful nature of alcohol assumption during pregnancy,
- Intervention needs - including FASD diagnostic tools for health and other professionals, and the early intervention therapies aimed at minimising the impact of FASD on affected individuals, and
- Management issues - including access to appropriate community care and support services across education, health, community services, employment and criminal justice sectors for the communities, families and individuals affected by FASD.

1.26 The Committee received 92 submissions and a number of exhibits from sources including Commonwealth, state and territory government departments, academic and research groups, non-profit organisations, Indigenous representative organisations and communities, and individuals such as birth and foster parents. A list of submissions received by the Committee is at Appendix A and a list of exhibits received by the Committee is at Appendix C.

1.27 The Committee held 13 public hearings and community forums in Canberra, Cairns, Townsville, Sydney, Melbourne, Perth, Mimbi and

Broome, including a videoconference with witnesses from the Northern Territory. A list of public hearings and witnesses is at Appendix B.

1.28 Submissions received and transcripts of evidence can be found on the Committee website at www.aph.gov.au/spla.

1.29 During the inquiry the Committee visited the Royal Women's Hospital in Melbourne and attended the Marninwarntikura Women's Bush Camp in Mimbi, Western Australia.

Scope and structure of the report

1.30 This report discusses how a national approach to the prevention, identification and management of FASD can be developed and achieved.

1.31 Chapter 2 provides an introduction to the history and science of FASD, a spectrum of disorders caused by alcohol consumption during pregnancy. It outlines the effect of alcohol on the developing fetus, and the primary and secondary symptoms including the behavioural impacts observable in those affected by FASD.

1.32 Chapter 2 then addresses the prominent role that alcohol plays in Australian society and the harms that certain consumption behaviours can cause to individuals and those around them. The factors which promote or contribute to high-risk alcohol consumption are discussed.

1.33 The prevention of FASD is considered in Chapter 3. National guidelines on alcohol were recently changed to state that not drinking is the safest option for women who are pregnant or planning a pregnancy. However, statistics demonstrate that much of the general community and the medical profession are unfamiliar with or do not understand these guidelines. This chapter explores strategies for supporting parents, including those with alcohol dependence, to stop or reduce alcohol consumption during pregnancy.

1.34 In addition Chapter 3 examines arguments surrounding the labelling of alcohol products with health warnings and specific FASD awareness campaigns.

1.35 Chapter 4 discusses the complexities of diagnosing and managing FASD. FASD is a spectrum rather than a single medical condition. The need for a national screening and diagnostic instrument is discussed, alongside diagnostic tools and services.

1.36 Chapter 5 addresses the paucity of data on FASD prevalence in Australia, and the importance of such data in mobilising public awareness and informing better management services and resourcing. The Chapter then discusses the challenges in managing young adults with FASD in terms of

their care, education and involvement in the criminal justice system. The benefits of legal recognition of FASD are identified.

Terminology

1.37 Throughout this report, the use of the word 'parent' and 'carer' refers to those exercising a parental role, such as caregivers who live with the child and are the primary caretakers. This includes birth mothers, foster parents and legal guardians.

1.38 The Committee has adopted the accepted medical spelling of 'fetus', rather than the common usage spelling of 'foetus'.

1.39 The Committee uses the term FASD to broadly encompass all conditions associated with prenatal exposure to alcohol. Where witnesses or submitters have used specific diagnostic terms to refer to certain conditions (such as Fetal Alcohol Syndrome which is a subset of FASD), the Committee has retained the terminology provided.

National action required

1.40 In Australia FASD has been the subject of a growing number of inquiries and increased research. There are a small number of dedicated individuals and organisations working in the area of FASD, and it has reached the policy agenda of some states and territories and some federal programs.

1.41 However, national efforts to eliminate FASD and efforts to optimise the lives of those already affected by FASD are inadequate. Essentially Australia's response to FASD is underfunded and uncoordinated. The responsibility for this lies with all levels of government and the medical profession who have failed to recognise the severity of FASD, who have failed to take on the alcohol industry and the general harms caused in society by the abuse of alcohol, and failed to educate the public regarding the risks posed by prenatal exposure to alcohol.

1.42 Fostering behavioural and community attitudinal changes to alcohol consumption during pregnancy will require leadership, expertise and inter-governmental cooperation. The purpose of this report is not to add to the volume of inquiries into FASD, but to establish a national plan to eliminate FASD.

1.43 Eliminating FASD will not be achieved by medication or vaccine, but by ensuring that every woman knows the risk though providing accurate health information and advice, and fostering a changed attitude to alcohol consumption during pregnancy and across the wider community.

1.44 Further, this report sets out to optimise the lives of those who have been affected by FASD. This will be achieved by better therapeutic services, greater understanding of the conditions characteristic of FASD and how these may manifest, enhanced support for carers, and improved pathways for those facing a lifetime disability caused by FASD.

1.45 Accordingly the actions set out in this report are high-level and bold. These actions should constitute the National Plan of Action to prevent, diagnose and manage FASD in Australia. While the plan to effect national change may be long term, the start of this process should be considered immediately and many of the actions should be immediately implemented.

1.46 Progressing the FASD National Action Plan will not be straightforward. It will require oversight across a number of areas: from awareness campaigns to health guidelines and training, alcohol regulation, diagnostic and therapeutic services, and disability support.

1.47 The Committee considers it essential that the Commonwealth Government draw on the research and expertise of professionals currently working in the field. The Committee notes the comprehensive report *Foetal Alcohol Spectrum Disorder: the invisible disability* which was recently published by the Education and Health Standing Committee of the Western Australian Legislative Assembly.[13] A number of the recommendations of that report align with this Committee's recommendations.

1.48 The Committee commends the detailed reports produced by FARE, and in particular the report *The Fetal Alcohol Spectrum Disorders Action Plan 2013-2016*, which details a number of costed actions to address FASD.

1.49 The FARE report recommends, as part of the governance structure of a FASD Action Plan, the establishment of a FASD Expert Advisory Committee whose membership should include representation from a number of Commonwealth Departments, state and territory Health and Justice Departments, consumer and carer groups, academics, clinicians and Indigenous communities.[14]

1.50 The Committee finds similarly that a FASD reference group should be established to oversee and advise on national initiatives to prevent, identify and manage FASD in Australia. The Committee considers that, to function effectively, this group should consist of a small group of

13 Western Australian Legislative Assembly Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: The invisible disability*, September 2012.

14 FARE, *The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013–2016*, September 2012, p. 13.

appointed expert health practitioners and professionals. Departmental, governmental and community consultation can take place under the auspices of the FASD Reference Group and assist to inform them in their development of the detail of the action plan and oversight of implementation.

1.51 However, the FASD Reference Group itself should have a limited number of appointed members in order to have the capacity to conduct regular meetings and to act expeditiously to drive forward the national plan of action.

1.52 It is the considered view of the Committee that the effectiveness of any national actions is dependent on the priority establishment of an oversight FASD Reference Group. The national response to FASD prevention and management must be driven as a coordinated response that garners public support for change and ensures a sustained and coordinated set of policy and regulatory measures.

1.53 For this reason, the Committee sets out the establishment of a National Plan of Action for FASD as its priority recommendation. The Committee recommends that a FASD Reference Group oversee the implementation of the FASD National Plan of Action. In the following chapters the report makes a number of further recommendations as part of the FASD National Plan of Action.

Recommendation 1

1.54 **The actions set out in this report should constitute the Commonwealth Government's National Plan of Action for the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders (FASD). This FASD National Plan of Action should be publicly released by 1 June 2013.**

Recommendation 2

1.55 **The Committee recommends that the Commonwealth Government immediately establish an ongoing Fetal Alcohol Spectrum Disorders (FASD) Reference Group reporting to the relevant Commonwealth Government Ministers, consisting of a select group of appointed practitioners, professionals and stakeholders who are experts in the field of prevention and management of FASD.**

The role of the FASD reference group would be to oversee and advise on the FASD National Plan of Action.

1.56 The Committee considers monitoring and reporting on the effectiveness of implemented actions to be critical. A key issue hampering current initiatives is a lack of standardised data regarding numbers of women who consume alcohol while pregnant, FASD diagnosis and consequently the estimated prevalence of FASD in Australia. Issues associated with the collection of this data are addressed in later chapters.

1.57 The Committee recommends that the Commonwealth Government publicly report annually on the effectiveness of the national action plan for implementing FASD diagnostic and management services and for eliminating FASD in Australia.

Recommendation 3

1.58 **The Committee recommends that the Commonwealth Government publicly report:**

- **within 12 months on the progress of the implementation of a national Fetal Alcohol Spectrum Disorders (FASD) diagnostic and management services strategy, a critical element of the FASD National Plan of Action, and**
- **within five years on the progress towards eliminating FASD in Australia.**