The Royal Australasian College of Physicians

From the President

15 December 2011

The Secretary
Standing Committee on Social Policy and Legal Affairs
House of Representatives
PO Box 6021
Parliament House
CANBERRA ACT 2600

Via email: spla.reps@aph.gov.au.

Dear Sir/Madam

Inquiry into Foetal Alcohol Spectrum Disorder

The Royal Australasian College of Physicians (the College) welcomes the opportunity to participate in this inquiry.

The College recognises that Foetal Alcohol Spectrum Disorder (FASD) is the leading preventable cause of developmental disabilities and has serious, permanent consequences. The impact on the individual, their family and the community is significant, with the effects ranging from language impairment, growth disturbance and epilepsy, to behavioural issues and a high risk of incarceration.

To help prevent FASD the College recommends:

- raising public awareness in the general population through campaigns that highlight harmful alcohol use as it relates to the unborn child and the general health of girls and women
- targeted education of high risk groups through health and community services
- provision of culturally appropriate recovery and support services for pregnant women with alcohol and mental health problems, including post-partum support
- mandating health warning labels on alcohol products.

Intervention strategies recommended by the College include:

- reviewing and supporting models of rigorous FASD screening processes
- support for and development of formal training programs for health

145 Macquarie Street, Sydney NSW 2000, Australia ■ Tel: +61 2 9256 5444 ■ Fax: +61 2 9252 3310
■ Email: racp@racp.edu au ■ Web: www.racp.edu.au

ACN 000 039 047 ABN 90 270 343 237

professionals about FASD

- adoption of a standardised, well validated diagnostic system across Australia
- encouraging early recognition and community support of individuals with FASD.

For management issues on FASD, the College also recommends:

- formal recognition of the range of needs of individuals with FASD and the lifelong nature of these needs
- review and development of a range of holistic community, education, employment and health services that support individuals and families who are affected by FASD
- support, development and improvement of Aboriginal-specific services in detox and rehabilitation, including support for Aboriginal health workers.

Please find attached the College's submission which provides further detail on these recommendations. I look forward to the outcomes of the Inquiry as a major step towards preventing FASD and improving the lives of those affected by the disorder.

If you have any queries on this submission, please contact Ms Anne Mooney, Senior Policy Officer, on 02 9256 9655, or by email to Anne.Mooney@racp.edu.au.

Yours sincerely

Dr Leslie E Bolitho AM
President-Elect and Acting President

The Royal Australasian College of Physicians

SUBMISSION INTO THE HOUSE STANDING COMMITTEE ON SOCIAL POLICY AND LEGAL AFFAIRS'

INQUIRY INTO FOETAL ALCOHOL SPECTRUM DISORDER

Executive Summary

The Royal Australasian College of Physicians (RACP) recognises that Foetal Alcohol Spectrum Disorder*(* FASD) is the leading preventable cause of developmental disabilities and has serious, permanent consequences.

The impact on the individual, their family and the community is significant, with the effects ranging from language impairment, growth disturbance and epilepsy, to behavioural issues and a high risk of incarceration.

To help prevent FASD the RACP recommends:

- raising public awareness in the general population through campaigns that highlight harmful alcohol use as it relates to the unborn child and the general health of girls and women
- targeted education of high risk groups through health and community services
- provision of culturally appropriate recovery and support services for pregnant women with alcohol and mental health problems, including post-partum support
- mandating health warning labels on alcohol products.

Intervention strategies recommended by the RACP include:

- reviewing and supporting models of rigorous FASD screening processes
- support for and development of formal training programs for health professionals about FASD
- adoption of a standardised, well validated diagnostic system across Australia
- encouraging early recognition and community support of individuals with FASD.

For management issues on FASD, the RACP also recommends:

- formal recognition of the range of needs of individuals with FASD and the lifelong nature of these needs
- the review and development of a range of holistic community, education, employment and health services that support individuals and families affected by FASD
- adoption of a standardised, well validated diagnostic system across Australia
- the support, development and improvement of Aboriginal-specific services in detox and rehabilitation, including support for Aboriginal health workers.

Introduction

The Royal Australasian College of Physicians (RACP) recognises that Foetal Alcohol Spectrum Disorder (FASD) is the leading preventable cause of developmental disabilities and has serious permanent consequences.

Currently, few data on FASD are available in Australia, where the reported overall birth prevalence ranges from 0.06–0.68 per 1000 live births. Rates are consistently higher in subgroups of Indigenous children.[i] [ii] Additionally, underreporting is related to the non-specific nature of clinical features, as well as a lack of awareness by clinicians of the clinical features, of FASD. [iii] [iv]

The impact on the individual, their family and the community is significant. The effects range from language impairment, growth disturbance and epilepsy, to behavioural issues and an increased risk of incarceration.

Comments against Inquiry Terms of Reference

1. 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 consumption during pregnancy

The National Health and Medical Research Council's (NHMRC) most recent guidelines recommends abstinence as the safest option for women who are pregnant or planning a pregnancy.[v] However, a lack of consistency and consensus between expert bodies on safe level of alcohol in pregnancy can cause public confusion.[vi] [vii]Furthermore, very low rates of knowledge of the NHMRC drinking guidelines aimed at the general population have been demonstrated in urban Aboriginal communities in Sydney.

Overall, young women may remain unaware of the risk of alcohol on the foetus and unaware of the level of alcohol consumption that poses a risk.[viii] However, knowledge of FASD has been shown to reduce the risk of pregnant women drinking.[ix] Evidence has shown that targeting drinking behaviours in the general population is associated with decreased occurrence of FASD.[x] This includes current attitudes and behaviour in relation to alcohol. Prevention programs should therefore be targeted to the wider population on the risks of alcohol to the foetus.

High risk groups, including women who have multiple births, young women and Indigenous women, should also be targeted. For example, young women undergoing antenatal assessments could be educated on appropriate maternal nutrition, folate supplements as well as reducing alcohol, tobacco and illicit drug use in pregnancy. This has shown to have benefits for the unborn child and decreased the prevalence of some features of FASD. [xi] [xii] [xiii]

There is also evidence to support General Practitioner's educating women on the harmful effects of alcohol on the foetus.[xiv] Targeting high risk groups also includes intensive family support as this has been effectively used in community interventions for other high risk issues.[xv]

The RACP also supports the Federal Government's recent announcement to develop pregnancy health warning labels on alcohol products. This includes the recommendation to mandate for pregnancy warning labels on alcohol products sold in Australia. The RACP believes that mandatory health labels will help women make more informed choices about their health and the health of their unborn baby.

RECOMMENDATIONS

1. *Raise public awareness in the general population through campaigns highlighting harmful alcohol use as it relates to the unborn child, and the general health of girls and women*
2. *Targeted education of high risk groups through health and community services*
3. *The provision of culturally appropriate recovery and support services for pregnant women with alcohol and mental health problems, including post-partum support*
4. *Mandating health warning labels on alcohol products.*

2. 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.

The early identification of children with foetal alcohol syndrome through thorough screening activities is an integral intervention strategy that will reduce the effects of FASD. This begins with a more rigorous approach to identifying women whose babies are at risk.

For example, screening should occur for:

- all children discharged from a drug dependency service in any obstetric unit
- all children apprehended into child protection
- all juveniles going through justice, into probation, community/first line sentencing.

This rigorous approach to screening occurs in North America and should be applied in Australia. The screening of families in this way has also reduced harmful exposures of alcohol in subsequent pregnancies. That is many children diagnosed with FASD will often have a younger sibling whereby FASD can be prevented. This will require adoption of a systematic, well validated diagnostic system.

There is also a need for formal training of a range of health professionals including community nurses, allied health professionals, general practitioners, paediatricians, physicians and psychiatrists to better identify and diagnose FASD and to recognise the needs of the diagnosed individuals.[xvi] [xvii] [xviii] [xix]

RECOMMENDATIONS

5. *Review and support models of rigorous screening processes*
6. *Support and develop formal training programs for health professionals on FASD*
7. *Adopt a standardised, well validated diagnostic system across Australia*
8. *Encourage early recognition and community support of individuals with FASD.*

3. 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 impacted by FASD.

The effects of FASD last a lifetime. Individuals, families and communities need access to appropriate community care and support services across education, health, community services, employment and criminal justice sectors.

Health service involvement will often include vision and hearing services, psychiatric and psychological intervention as well as monitoring of growth and specific organ abnormalities, for example, congenital heart disease. Additionally, teachers require special skills and training to educate children who suffer from FASD.[xx] [xxi]

For Aboriginal people, holistically treating alcohol problems can help the drinker, the family and the entire community. In this case, Aboriginal-specific detox and rehabilitation services need greater improvement. For instant, there are no Aboriginal specific residential detoxification/rehabilitation services in the Sydney region, despite an Aboriginal population of more than 40 000. Other barriers to services for Aboriginal people include:

- transport, even in cities
- lack of family-friendly services and the need to caring for family
- cost of treatment
- language barriers, particularly if from a remote community
- General Practitioners not always being comfortable or willing to offer treatment.

Improving appropriate services for Aboriginal people includes the continued development of the Indigenous health workforce such as health education and leadership support.

RECOMMENDATIONS

9. *Formal recognition of the range of needs of individuals with FASD and the lifelong nature of these needs*
10. *Review and development of a range of holistic community, education, employment and health services that support individuals and families who are affected by FASD*
11. *The support, development and improvement of Aboriginal-specific services in detox and rehabilitation, including support for Aboriginal health workers.*

[i] Greenbaum RL, Stevens SA, Nash K, Koren G, Rovet J. Social cognitive and emotion processing abilities of children with fetal alcohol spectrum disorders: a comparison with attention deficit hyperactivity disorder. Alcohol Clin Exp Res. 2009 Oct;33(10):1656-70.

[ii] Bower C, Silva D, TR H, Ryan A, Rudy E, . Ascertainment of birth defects: the effect on complete-ness of adding a new source of data. . J Paediatr Child Health 2. 2000;36:574-6.

[iii] O'Leary CM. Fetal alcohol syndrome: diagnosis, epidemiology, and developmental outcomes. J Paediatr Child Health. 2004 Jan-Feb;40(1-2):2-7.

[iv] Morleo M, Woolfall K, Dedman D, Mukherjee R, Bellis MA, Cook PA. Under-reporting of foetal alcohol spectrum disorders: an analysis of hospital episode statistics. BMC Pediatr. 2011;11:14.

[v] National Health and Medical Research Foundation. Australian Guidelines TO REDUCE HEALTH RISKS from Drinking Alcohol. Canberra: National Health and medical Research Foundation,2009.

[vi] O'Leary C, Heuzenroeder l, Elliott E, Bower C. A review of policies on alcohol use during pregnancy in Australia and other English-speaking countries, 2006. med J ustralia. 2007;186(9):466-71.

[vii] Peadon E, O'Leary C, Bower C, Elliott E. Impacts of alcohol use in pregnancy--the role of the GP. Aust Fam Physician. 2007 Nov;36(11):935-9.

[viii] Payne J, Elliott E, D'Antoine H, O'Leary C, Mahony A, Haan E, et al. Health professionals' knowledge, practice and opinions about fetal alcohol syndrome and alcohol consumption in pregnancy. Aust N Z J Public Health. 2005 Dec;29(6):558-64.

[ix] Henderson J, Kesmodel U, Gray R. Systematic review of the fetal effects of prenatal binge-drinking. J Epidemiol Community Health. 2007 Dec;61(12):1069-73.

[x] Astley SJ. Fetal alcohol syndrome prevention in Washington State: evidence of success. Paediatr Perinat Epidemiol. 2004 Sep;18(5):344-51.

[xi] Chersich MF, Urban M, Olivier L, Davies LA, Chetty C, Viljoen D. Universal Prevention is Associated with Lower Prevalence of Fetal Alcohol Spectrum Disorders in Northern Cape, South Africa: A Multicentre Before-After Study. Alcohol Alcohol. 2011 Oct 27.

[xii] Masotti P, George MA, Szala-Meneok K, Morton AM, Loock C, Van Bibber M, et al. Preventing fetal alcohol spectrum disorder in Aboriginal communities: a methods development project. PLoS Med. 2006 Jan;3(1):e8.

[xiii] Tough S, Clarke M, Cook J. Fetal alcohol spectrum disorder prevention approaches among Canadian physicians by proportion of Native/Aboriginal patients: practices during the preconception and prenatal periods. Matern Child Health J. 2007 Jul;11(4):385-93.

[xiv] Thanh NX, Jonsson E. Drinking alcohol during pregnancy: evidence from Canadian Community Health Survey 2007/2008. J Popul Ther Clin Pharmacol. 2010 Summer;17(2):e302-7.

[xv] Olds D, Robinson J, O'Brien R, Luckey D, CR H, Ng R, et al. Home Visiting by Paraprofessionals and by Nurses: A Randomized, Controlled Trial. Pediatrics 2002;110(3):486-96.

[xvi] Peadon E, Rhys-Jones B, Bower C, Elliott EJ. Systematic review of interventions for children with Fetal Alcohol Spectrum Disorders. BMC Pediatr. 2009;9:35.

[xvii] Brems C, Boschma-Wynn RV, Dewane SL, Edwards AE, Robinson RV. Training needs of healthcare providers related to Centers for Disease Control and Prevention core competencies for fetal alcohol spectrum disorders. J Popul Ther Clin Pharmacol. 2010 Fall;17(3):e405-17.

[xviii] Payne J, France K, Henley N, D'Antoine H, Bartu A, O'Leary C, et al. Changes in health professionals' knowledge, attitudes and practice following provision of educational resources about prevention of prenatal alcohol exposure and fetal alcohol spectrum disorder. Paediatr Perinat Epidemiol. 2011 Jul;25(4):316-27.

[xix] Payne JM, France KE, Henley N, D'Antoine HA, Bartu AE, Mutch RC, et al. Paediatricians' knowledge, attitudes and practice following provision of educational resources about prevention of prenatal alcohol exposure and Fetal Alcohol Spectrum Disorder. J Paediatr Child Health. 2011 Oct;47(10):704-10.

[xx] Koren GI, Fantus E, Nulman I. Managing fetal alcohol spectrum disorder in the public school system: a needs assessment pilot. Can J Clin Pharmacol. 2010 Winter;17(1):e79-89.

[xxi] Kalberg WO, Buckley D. FASD: what types of intervention and rehabilitation are useful? Neurosci Biobehav Rev. 2007;31(2):278-85.