

# Fetal Alcohol Spectrum Disorder Among Australian Aborigines: Barriers to prevention, diagnosis and treatment in the Western Desert

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## Problem Statement

Fetal Alcohol Spectrum Disorder (FASD) has garnered much attention and research over the last 20 years in the United States. FASD is the leading non-genetic cause of mental impairment (Astley, 2004). The disorder is most easily recognized by a group of facial characteristics that are unique to the disease, including a smooth philtrum and thin upper lip (Astley and Clarren, 1996) and is also linked to neuropsychological deficits (Conry, 1990). Early reports of FASD have also noted that babies with the disorder have inadequate sucking reflexes and fail to thrive due to feeding difficulties and poor appetite (Smith, Jones and Hanson, 1976; Clarren, 1981). Within the US, there has been an emphasis on sub-populations such as Native Americans and Alaska Natives who have been shown to be at increased risk for the disorder (Egeland et al, 1998; Duimstra et al, 1993; Christenson, 1990). Research in Canada has followed suit, with a parallel set of studies on aboriginal Canadians (Robinson et al, 1997; Wong, 1983; Asante et al, 1985). Australian aborigines exhibit many of the same risk factors as native populations in North America, yet research on FASD within Australia is scarce, and studies focusing on aborigines are almost non-existent (Elliott, 2004). There is clearly a need for further studies on the prevalence and incidence of FASD among Aboriginal Australians. In addition to basic statistics however, there is also a need for deeper studies that investigate why aborigines are at increased risk for FASD. Understanding the cultural dimensions of both alcohol use and pregnancy among aborigines is critical not only to getting better enrollment in studies but also in developing feasible and efficacious prevention, diagnosis and treatment programs.



## FASD Statistics for Indigenous Populations Worldwide

Research Study	Population	Study Design	Prevalence/ Incidence per 1000 individuals *
Bower et al. (2000)	Australian Aborigine (WA)	Descriptive	2.76 (0.02) P
Harris and Bucens (2003)	Aboriginal Australians	Retrospective Cohort	1.87-4.7 (0) P
Egeland et al. (1998)	Native Americans	Descriptive	1.4-4.1 (0.2-0.4) I
Christenson (1990)	Alaska Native	Cross-Sectional	1.7-5.1P
Wong (1983)	First Nation Canadians	Long-term Surveillance	6.6 I

\*Reference population for each study are non-natives from the same general area, whose prevalence/incidence is shown in parentheses. Prevalence studies are marked with a P, incidence studies with an I.

## Projected Future Research

I will be returning to the field in August of 2008 to conduct preliminary research on FASD at three Western Desert outstation communities. The main objective of this study is to investigate the socio-cultural barriers that have hindered adequate public health research on FASD among indigenous Australians and to determine, through participatory research, an agenda for improving FASD related services to Aborigines living in remote communities in Australia's Western Desert. The specific aims are: 1) to determine awareness of the cause and effects of FASD among aborigines living in the Western Desert; 2) to understand how cultural perceptions relating to pregnancy and alcohol affect current health services uptake; 3) to obtain community opinion on ways to prevent, diagnose and treat FASD through culturally sensitive pre- and post-natal care services that emphasize indigenous participation; 4) to develop a plan of action for future research, community partnerships and training relating to FASD in this population.

## ELEMENTS OF CONCERN

### Binge Drinking

Aborigines are more likely to be non-drinkers than the rest of the Australian population, but when they do drink, they do so at much greater rates than non-indigenous Australians (AIHW, 2002). In an in-depth study on alcohol use in the Kimberley region of Western Australia, also part of the Western Desert, aborigines were classified as either constant, intermittent or episodic drinkers (Hall, Hunter and Spargo, 1993). Constant drinkers drink most of the time. Intermittent drinkers were those who drank around pay-day while episodic drinkers would drink heavily for a period but then have withdrawal periods lasting a month or more. The latter two of these categories can both be considered "binge drinking" which means that all three drinker categories put babies at high risk for FASD.

### Insufficient Pre- and Post-natal Care

Although the birth of a baby is an important event, pregnancy remains a more discrete matter. Women rarely publicly acknowledge their pregnancies to anyone other than close female relatives until the condition becomes visible. Public speculation can precede the mother's acknowledgement by weeks or months. This sense of privacy can extend to health care workers as well, particularly if they are male. This sense of shyness and cultural discretion surrounding pregnancy can have important effects on prenatal care and therefore on opportunities for education about FASD. Aboriginal mothers are less likely to receive prenatal care than non-aborigines (Stewart and Li, 2005; Cass, 2004; Gray and Khalidi, 1990). Brady (1991) reports that in the communities she worked with as a medical anthropologist in South Australia, many women did not receive prenatal care until 8-12 weeks before delivery. Although statistics are not easily found in the literature, it can be assumed that the same factors preventing mothers from seeking prenatal care might be affecting newborn doctor's visits as well. This dearth of prenatal and postnatal care means that prevention, diagnosis and treatment of FASD are all less likely to occur for aboriginal women.

### Remote Location

Australia is the least densely populated continent in the world and aborigines are more likely than their non-indigenous counterparts to live in the most remote regions of the country. Close to 20% of indigenous Australians live in areas classified as "very remote," compared to 1% of the non-indigenous population (AIHW, 2002). In a medical context this means that access to hospitals is either by a long drive to town on unpaved roads or, in emergencies, by plane with the Royal Flying Doctor Service. Outstation communities typically have a clinic staffed by a registered nurse and an aboriginal health worker but only larger communities have doctors in residence. It would be unlikely that outstation clinicians were trained in the diagnosis of FASD and babies would go to the hospital only if they needed emergency treatment or suffered from a diagnosed chronic condition.

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