



## **POLICY BRIEF**

**(emanating from the FASD Prevention Symposium, 2008)**

Fetal Alcohol Spectrum Disorders in South Africa: A huge challenge requiring multi-faceted prevention strategies

### **Sadly, a common problem in South Africa**

The term Fetal Alcohol Spectrum Disorders (FASD) is used to include the range of permanent conditions that result from exposure to alcohol of the growing fetus, with Fetal Alcohol Syndrome (FAS) being the most severe condition. To diagnose any of the FASD conditions a specialised multidisciplinary team is needed, however, the availability of such teams is very limited across the country. Prevalence studies in high risk areas of South Africa have found rates of FASD that are the highest in the world (up to 119/1000 in one high risk area). Since there is no surveillance system to collect information on the number of diagnosed cases nationally, the prevalence in the general population is unknown. Based on burden of disease estimates it is estimated that the prevalence of FAS in South Africa could be as high as 14/1000.

### **What are the health consequences of FAS and FASD?**

The typical impairments that characterise a child with FAS are related to brain damage, resulting in low intelligence, behavioural disorders, poor social judgement, and general difficulty performing every day tasks. Without specialised intervention and a supportive home environment, secondary disabilities in adolescence and adulthood will follow, leading to increased risk for mental health problems, inappropriate intimate relationships, unemployment and involvement in criminal activity. Use of alcohol by the mother, and the cognitive damage of her offspring, place both generations at higher risk of abuse and HIV infection than the average person in their specific community.

### **Identifying FAS and FASD for intervention**

Since diagnostic and support services are very limited in South Africa, it is unknown how many children, adolescents and adults who utilise health and mental health services, or who end up in correctional services facilities, are in fact people with FASD. The needs of children with FASD are most noticeable in the schools where teachers are often ill-equipped to adapt their teaching and classroom environment to cater for the learning difficulties of FASD children.

There is also limited awareness amongst professionals and lay people about FASD, making it difficult to assess the needs of people with FASD, and evaluate the extent to which services are meeting their needs. The prevention of FASD requires a thorough understanding of the context in which childbearing age women live, and their alcohol and contraceptive use patterns and norms. From prevalence studies, we can infer the typical profile of woman at risk to an alcohol exposed pregnancy (AEP) as being poorly educated and living in poverty. However, this does not hold true in every situation since some women who do not fit this profile may have children with FASD. There is limited screening for AEPs in primary health care clinics, and health service providers often lack the skills to carry out brief interventions where indicated. There are very few alcohol rehabilitation programmes in the country and those that exist are inaccessible, due to location and cost, to most women.

Currently, a number of funded prevention studies are being implemented predominantly in the Western Cape. Findings from these projects were recently presented at a Symposium held on the 9<sup>th</sup> & 10<sup>th</sup> September 2008, at the MRC in the Western Cape. This brief summarises some of results and their implications for interventions and policies.

### ***Prevalence of FAS and characteristics of women at risk of having a FAS child.***

Prevalence studies, mainly in the Western and Northern Cape, have found the prevalence of FAS in high risk areas to be as high as 119/1000. This is more than a hundred-fold higher than other comparable sites in other countries and considerably higher than so-called 'high-risk' populations elsewhere. Where prevalence has been measured more than once, an increase has been found.

Studies of the risk factors for having an alcohol exposed pregnancy (AEP) indicate that the rural, farm based women in the Western Cape are at higher risk than urban women. This risk applies not only to women living on wine producing farms but for all types of farms. Although beer is preferred amongst rural adults, the poorest people drink papsak wine, which is associated with harmful levels of drinking. Other factors associated with the risk of an AEP include smoking, low educational level and unplanned pregnancy. Urban women who are at risk of an AEP may be those who are better educated, presumably have more disposable income, and have access to recreational facilities that include alcoholic beverages.

The rate of contraceptive use among women who use alcohol does not differ from that of women who don't use alcohol, and access to contraceptives is fairly good (65% of women use modern contraceptives, according to SADHS 2003), however, the effectiveness of the use of contraceptives may differ.





There is no national surveillance system for FASD, or extrapolation from alcohol use survey data, on which to estimate national or regional prevalence. However, the rates of risk for AEP (at high levels of alcohol use) found in an urban and a rural area of one study matched the FAS rates found in another study in similar communities. It may be possible to use surveys of female alcohol use to estimate the prevalence of FASD in a community.

### ***Context of the women at risk***

At the symposium it became clear that the majority of women at risk of AEP were living in poverty, and faced daily struggles in difficult circumstances. There was some evidence that many had some level of depression, and substance use was seen as a coping mechanism. Women feel isolated and hopeless in the face of food insecurity, domestic violence and abuse. Typically, the men in the community also used alcohol with many of them using very high amounts in a weekend binge pattern.

Consequently the problems of women and their partners needed to be understood and managed in a more holistic way. Further, people with alcohol-related problems, especially in rural areas, in need of specialist substance abuse rehabilitation services (in or outpatient basis) are unlikely to have access to such services due to the scarcity of such services and the urban bias in their location.

### ***Liquor availability, quality and controls***

Alcohol is readily available in most communities, and in some areas the licensed and unlicensed outlets are plentiful. Although the liquor control legislation differs from province to province, there is sufficient legislation to protect pregnant women and children from use of alcohol in public outlets. However, there is insufficient enforcement of such clauses, and the unlicensed outlets still need to comply with a license application before codes of conduct are adopted.

There is evidence that some wine sold in papsakke or in plastic bottles have unacceptable levels of chemical contaminants such as mercury, phthalates and ochratoxin. The combination of these chemicals and the ethanol in the wine could be responsible for more damage to the fetus than the ethanol alone.

### ***Living with FASD***

Although children with FASD assessed at 7-12 months did not display marked developmental problems compared to non-FASD children at the same age, when a comparison was made at 5 years of age, the difference was marked, showing the FASD is a disorder that affects the child more as they develop. However, in the high risk areas the general level of malnutrition leading to stunting is high, and the level of stimulation for children is poor. These factors affect both FAS and non-FAS children.

Families are offered little support regarding how to manage their FAS child's behaviour and stimulate them appropriately. There is some evidence to suggest that foster parents receive more support from government services than biological parents.

The educational services are too overwhelmed in high prevalence areas to effectively deal with the needs of learners with FASD. It is possible that people with FASD are disproportionately represented in correctional facilities.

## ***PROMISING PREVENTION STRATEGIES***

There is support for a public health approach to the prevention of FASD through a comprehensive model that includes universal (community wide), selected (women of childbearing age) and indicated (high risk women) strategies.

### ***Community -wide***

Raising awareness on a community level, and engaging community members in action around alcohol problems, is an important component of a comprehensive approach to FASD prevention. However, although there is some local government support, communities find it difficult to make appropriate plans and take action as they are struggling with issues of daily survival. Existing programmes (such as Ke Moja) and new initiatives (such as the "Sober SA, Safer SA") could provide resources for community action.

### ***Women in general***

The training of service providers to screen all women of childbearing age for alcohol use, to offer educational information to low risk women, and refer women at high risk of AEP, was tested and results appear promising.

### ***High risk women***

There is growing evidence to suggest that a brief intervention with women at high risk of AEP, and especially those who have previously had a FASD child, can improve contraceptive use and or reduce alcohol consumption. The intervention



can be either before or during pregnancy, and can reduce the exposure to alcohol. Studies made use of standardised screening tools, such as the AUDIT, and 3-5 brief intervention sessions, with educational material. In all the studies presented there was improvement in both the control and intervention groups, however, those receiving the full brief interventions showed the most change. It was recommended that lay counsellors are the most appropriate personnel to carry out the intervention. A similar approach was applied to women who smoke in pregnancy and came to similar conclusions, and recommended the use of peer counsellors.

In assessing outcomes, it is never possible to be sure if women answer truthfully in their responses to questions on substances. A computer assisted self assessment in clinics was discussed as a future possibility, but the consensus was that for now the emphasis should be on establishing an empathetic rapport between service provider and client, increasing the possibility of an honest and fruitful discussion.

## PROPOSED KEY STRATEGIES FOR FASD PREVENTION AND SUPPORT

Surveillance and monitoring	<ul style="list-style-type: none"> <li>• Extrapolate from surveys to estimate AEP</li> <li>• Improve registration of diagnosed cases</li> </ul>
Screening and brief interventions	<ul style="list-style-type: none"> <li>• Introduce standardised screening for substance abuse in all health services</li> <li>• Introduce a protocol for brief interventions that match the level of risk</li> <li>• Improve routine record keeping of screening and brief interventions</li> <li>• Strengthen the referral chains and follow-up of women at risk of AEP to ensure continuum of care</li> </ul>
Awareness raising and education	<ul style="list-style-type: none"> <li>• Build capacity in key categories such as teachers and religious leaders to be able to educate people on the prevention of FASD</li> <li>• Include FASD prevention messages in other campaigns and services where relevant</li> <li>• Build capacity in key categories such as teachers, social workers, and police, to understand and support families with a alcohol-related FASD member</li> </ul>
Liquor controls	<ul style="list-style-type: none"> <li>• Consider diagrammatic warning messages on alcoholic beverages + standard drinks</li> <li>• Improve the testing of all alcoholic beverages and the removal of those found with unacceptable levels of various chemicals</li> <li>• Improve the enforcement of liquor serving controls i.e. not to pregnant or breastfeeding women, and youth under 18 years.</li> <li>• Introduce universal training of liquor sellers on strategies to prevent alcohol abuse</li> <li>• Integrate substance abuse prevention activities with broader poverty alleviation programmes and life skills programmes</li> <li>• Use positive role models to convey messages of hope and success especially in areas seriously affected by substance abuse.</li> </ul>
Research Gaps	<ul style="list-style-type: none"> <li>• What screening tool should be introduced across the country?</li> <li>• What is the ideal number of brief sessions with women at risk of AEP, and who should deliver this?</li> <li>• How can screening and brief interventions for substance abuse be integrated into other health programmes such as VCT?</li> <li>• In what way can the partner or other family member be incorporated into the brief interventions?</li> <li>• How can specialist rehabilitation services be made more appropriate and locally available to the highest risk women/ families?</li> <li>• What role could religious leaders play in the prevention of FASD?</li> <li>• What training needs to be provided to Educare and school teachers to enable them to support the needs of FASD learners?</li> <li>• What support needs to be provided to families with a FASD member in order that they reach their potential?</li> </ul>

## PRESENTATIONS INFORMING THE POLICY BRIEF

Davies, L	Neurodevelopmental functioning among infants with FASD in the N Cape
Davies, L	The pattern of maternal depression amongst women with a FASD infant within a community in the N Cape
Jacobs, N	Local action: FASD community awareness raising and mobilisation
Jordaan, E	Confirmed and unconfirmed drinking in pregnant women: does this affect the intervention outcome in the Ceres FAS study?
London, L	If the alcohol doesn't get you, then the other toxins will: Potential role of contaminant toxicants in high FAS prevalence in the W Cape
Marais, S	Preventing FAS: effects of screening and brief interventions on the drinking behaviour of pregnant women - a cluster RCT
Marais, S	Proposals to change drinking behaviour in pregnant women: findings from a Ceres FAS study
McLoughlin, J	Fetal alcohol spectrum disorder in South Africa: situational and gap analysis.
Moodley, S	Reducing the risk of alcohol exposed pregnancies in the W Cape: a randomised controlled trial evaluating motivational interviewing and life skills training.
Morojele, N	Predictors of risk of alcohol exposed pregnancies among urban and rural women in South Africa
Mwanza, J	The evaluation of a service provider short course on the prevention of FASD
Olivier, L	Epidemiology of FASD in the N Cape
Parry, C	FAS prevention study (FASER-SA)
Rendall-Mkosi, K	The barriers to preventing and managing FAS in South Africa
Steyn, K	The development and evaluation of a smoking cessation intervention for disadvantaged, pregnant women attending public sector clinics in Cape Town.
Viljoen, D	Epidemiology and risk factors for FAS in the W Cape



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URL link to UP website where FASD Symposium Programme and Proceedings docs can be found:  
<http://research.newsbeat.co.za/projects/FAS.html>