FETAL ALCOHOL SPECTRUM DISORDERS

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ABSTRACT
Alcohol contributes substantially to the global burden of disease. Alcohol consumption is not only associated with an individual’s health in general, but also with all types of injuries. More than half of all homicides and traffic-related deaths in South Africa are associated with alcohol. This Chapter elaborates on one of the hidden effects of alcohol, i.e. the adverse effects (harm/injury) of maternal drinking on the unborn child that may result in a spectrum of disorders referred to as Fetal Alcohol Spectrum Disorders (FASD). FASD is claimed to be the most frequent cause of preventable mental handicap in the world and is devastating in its lifelong effects on the affected person. South Africa, with the highest measured FASD prevalence rate in the world in some high risk communities, has no integrated national strategy or policy to deal with the phenomenon at present, and no ongoing surveillance is taking place in the country. Important achievements in the field of identifying, assessing prevalence and prevention of FASD have been reached through the work and involvement of the Foundation for Alcohol Related Research, constituted in 1997 as a non-profit organisation. Since then, important projects by a range of national and international organisations and universities are being conducted to explore strategies to reduce the harmful alcohol use by pregnant women and women in general.

Keywords: pre-natal alcohol abuse, Fetal Alcohol Syndrome (FAS), FASD, FASD surveillance, FASD prevention

INTRODUCTION
Alcohol contributes substantially to the global burden of disease (4% of total mortality and 4-5% of disability-adjusted life years), and thus is one of the largest avoidable health risk factors (Rehm, Mathers, Popova, Thavorncharoepsap, Teerawattanano & Patra, 2009). There is a clear association between alcohol consumption and the health of individuals. There is also a clear association between alcohol and all types of injuries (Krug, Dahlberg, Mercy, Zwi & Luzano, 2002; Rehm et al., 2004). In South Africa 58% of homicide deaths and 57% of road traffic crash deaths are associated with alcohol use (Matzopoulos, 2005). Despite the fact that many South Africans do not drink alcohol, alcohol abuse results in a considerable health burden in South Africa (Schneider et al., 2007). Household surveys

¹To whom correspondence should be addressed: Sandra Marais, Medical Research Council-University of South Africa Safety & Peace Promotion Research Unit, PO. Box 19037, Tygerberg, 7505, South Africa. Email: Sandra.Marais@mrc.ac.za.
indicate that currently approximately 50% of men and 20-30% of women drink alcohol in South Africa, although this is probably an underestimation (Schneider et al., 2007). While consumption per adult is 7.1 litres of pure alcohol per year, the amount of alcohol consumed per drinker in South Africa is estimated at about 20 litres of absolute alcohol per year (Schneider et al., 2007) – among the highest in the world. In the SA Demographic and Health Survey (SADHS) of 1998 it was reported that one-third of drinkers reported risky drinking over weekends, i.e. five or more drinks per day for men and three or more drinks per day for women. Binge-drinking is a well recognised, problem-drinking pattern in South Africa and refers to more than five drinks per sitting. Alcohol harm accounted for 7.1% of all deaths and 7.0 % of all DALYs (disability adjusted life years) in South Africa in 2000. Alcohol harm ranked third in terms of percentages of total DALYs for 17 risk factors included in the SA Comparative Risk Assessment (CRA) study after injuries and cardiovascular incidents.

However, the full impact of alcohol on the health of the individual and the wider community is difficult to estimate due to many hidden effects resulting from its use. Rehm et al. (2009) state that, for alcohol, the usual epidemiological model should be widened, since drinking can also harm the health of non-drinkers, for instance, maternal drinking can affect the health of the unborn baby, or driving under the influence of alcohol can harm pedestrians and other road users. In this Chapter the focus will be on:

a. Maternal drinking and the adverse effects (harm/injury) this can have on the unborn child.

b. The epidemiology of fetal alcohol spectrum disorders (FASD) in South Africa and globally.

c. Prevention interventions.

d. The role of different state departments in prevention actions.

e. Policy formulation.

FASD is not typically included in the injury prevention literature, but together with the effect of other harmful substances such as paraffin and organophosphates on the body, alcohol ingestion can be seen as a chemical substance which is harmful or injurious to the body (maternal drinking is harmful to an unborn child).

**WHAT ARE FETAL ALCOHOL SPECTRUM DISORDERS**

Fetal alcohol syndrome (FAS) was first described by Lemoine in France in 1968 and as an entity in the USA in 1973 by Jones and Smith (Jones & Smith, 1973). The earliest references to specific cases of newborns with FAS in South Africa were made in 1978 by Beyers and Moosa (1978), and Palmer (1978). Following a 12-month survey of births at a Cape Town hospital, Palmer reported the frequency of FAS as 1/281 live births in 1985.

FAS is the severe end of a spectrum of deleterious effects caused by maternal alcohol use during pregnancy and is one of the leading causes of preventable birth defects and developmental disabilities globally (Centres for Disease Control [CDC], 2003). It is viewed as the most frequent cause of preventable mental handicap in the world and is devastating in its lifelong effects and the serious sequelae in affected persons (Viljoen, 2009). The clinical features of FAS include central nervous system abnormalities (resulting in low intelligence, behavioural impairments and poor social judgement), characteristic facial dysmorphology, growth retardation, as well as abnormalities of organs and limbs (Stratton, Howe & Battaglia, 1996; Streissguth, 1997). The term FASD, describes the range of effects that can occur when an individual is prenatally exposed to alcohol. As mentioned, FAS is the most severe category followed by partial FAS (PFAS), alcohol-related neuro-developmental disorders (ARND) and alcohol-related birth defects (ARBD). FAS(D) may also lead to severe social and
psychological consequences for the individual child and for the family because of the child’s mental and behavioural handicap.

South Africa has the highest measured FAS rates in the world (McKinstry, 2005; Rosenthal, Christianson & Cordero, 2005). Prevalence rates in excess of 40 cases per 1000 of school-entry children in targeted towns in the Western and Northern Cape have been measured (May et al., 2005; Urban et al., 2008; Viljoen et al., 2005;). In Gauteng a rate of more than 20 cases per 1000 school-entry children was identified in four at-risk communities (Viljoen et al., 2005). This is in sharp contrast to the average rate of FAS for the USA quoted as between 0.05-2.0 per 1000 children (May et al., 2005) and the average rate for high income settings as 0.97 (McKinstry, 2005). Prevalence rates among selected high-risk groups in the USA are eight per 1000 live births for First Nation Americans; 8.5 per 1000 live births for Northern Plain Indians, and for African Americans in selected inner city areas with a low socio-economic status, 2.29 per 1000 live births (CDC, 2003; Viljoen et al., 2005). In Table 1 FAS prevalence is presented for different countries.

The reasons for South Africa’s high FASD burden are incompletely understood, and relate to risky maternal alcohol consumption and other maternal, personal, social and perhaps genetic factors that increase the risk of FASD – the answers are multifaceted (Urban et al., 2008). Whilst the exact dose that may cause harm is not known, regular binge-drinking (heavy episodic drinking of five or more units of alcohol per occasion) is the most risky drinking pattern for FASD.

The dop or tot system is believed to have played a determining role in entrenching binge-drinking on wine farms in the Western Cape. It had its origins in the early years of colonial settlement in the Cape Colony. It was a particular feature of the agricultural system to pay farm workers with alcohol as part of their wages. This practice was outlawed in 1961, but the legacy of the historical institutionalisation of drinking on farms is still widespread (London, 1999). However, one should be careful of the stereotype that FASD is peculiar to coloured communities that comprise the local workforce in the Western Cape in present times. Research findings show that the FASD rate is higher in De Aar (a sheep-farming area) and Upington (a wine-farming area), and that there was no overall difference in FAS/PFAS between black and coloured subjects in these two towns. Therefore, at present, FASD is not limited to wine growing areas or to a specific ethnic group (Urban et al., 2008).

There is no doubt that FASD is a huge public health problem in South Africa that requires immediate and decisive attention. In a South African Comparative Risk Assessment study for 2000 (Schneider et al., 2007), FAS ranked third at 18.1% (after alcohol use disorders at 44.6% and interpersonal violence at 23.2%) in terms of alcohol attributable disability.

In general, there is limited data on the prevalence of alcohol consumption during pregnancy. Prenatal drinking varies among and within populations

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globally. According to May et al. (2008) 20-32% of pregnant women drink alcohol in the USA, England and Canada. In some European countries the rate is higher, sometimes exceeding 50%. In South Africa different studies reported different consumption levels for alcohol. Reported use of alcohol by pregnant woman varied from 13% (Marais & Jordaan, 2005) to 43% of women reporting varying degrees of alcohol ingestion during their respective pregnancies (Croxford & Viljoen, 1999; Te Water Naude, London, Pitt & Mahomed, 1998). If we presume that almost half of pregnant women in high-risk communities consume alcohol during their pregnancies, it is crucial to introduce basic steps that will identify pregnant women who are risky drinkers. A combination of screening, followed by brief interventions (a time-limited, patient-centred counselling strategy focusing on changing patient behaviour and increasing patient compliance), is widely recommended as a first approach to identification and treatment for mild to hazardous drinking problems (Babor & Higgins-Biddle, 2001; Marais et al., 2010).

**AWARENESS ABOUT FAS(D) AND ALCOHOL USE/ABUSE**

Raising the awareness of the general public through public campaigns is the first and very important step towards prevention. Not many studies have been undertaken on the level of awareness of FASD amongst professionals and lay people in South Africa. Two studies focusing on clinic patients in the Western Cape showed a high awareness of the harmful effects of alcohol to the fetus (Croxford & Viljoen, 1999; Marais & Jordaan, 2005). In one rural and one urban community more than 90% of the women on routine visits to clinics knew about the harmful effects of drinking alcohol and smoking tobacco during pregnancy. More than a third of the women said they had heard of FAS (35%). Of these women, 51% could give a more or less correct description of what FAS is, and a further 21% had some vague idea as to what it is. The clinic staff members were their main source of information (51%), family and friends (25%), television and radio (23%), and the printed media (22%), according to Marais and Jordaan (2005).

Staff members were also asked about their knowledge on alcohol and FAS. All respondents (N=29) knew that the use of alcohol by pregnant women might have a negative effect on the unborn child, and all respondents were familiar with the concept of FAS. Questions on characteristics that could differentiate children exposed to alcohol from other children were well answered by the majority of respondents (Marais & Jordaan, 2005). However, all staff members indicated that they needed further training on the effects of alcohol on the unborn child, as well as to identify, manage, counsel and refer high-risk mothers. They felt unprepared and uncertain about dealing with FAS and giving appropriate advice regarding the use of alcohol and the effects on the fetus. Knowledge alone does not necessarily lead to prevention. Although awareness of the effects of alcohol among clients and staff seems high in these studies, the high prevalence of FAS in those communities indicate that different strategies should be followed by health care services to try and deal with the problem.

An early and correct diagnosis of FASD is of great value in improving opportunities for early intervention and management for the affected child and for reducing fetal exposure to alcohol in subsequent pregnancies (Payne et al., 2005). Staff should not only have the knowledge about FASD, but should also be trained to use screening tools and to administer brief interventions as routine measures to identify and treat risky alcohol drinkers. Until this lack is addressed, opportunities for diagnosis and prevention of FASD will be limited (Payne et al., 2005).
FAS(D) SURVEILLANCE
The success of any public health programme can be measured by comparing the incidence or prevalence of a particular problem before and after implementing an intervention. In the case of FAS(D), the literature indicates that methods to determine the prevalence and epidemiology of FASD is far from consistent or conclusive (Institute Of Medicine [IOM], 1996; Urban et al., 2008). The consistency (and overall epidemiologic) methodology should be improved. Generally, it remains difficult to reconcile incidence and prevalence rates between studies. Key issues mentioned in this regard include: variation in methodologies and definitions in case findings and diagnosis, wide variation in the types of populations studied, inconsistency of data gathered by prospective, versus retrospective methods; and the improvement of surveillance techniques.

The clinical identification of a child with FASD (usually between 3-10 years old) is a specialised procedure because of the complexities of the diagnoses. FASD is usually diagnosed on the strength of abnormalities in each of the following categories:
- Growth retardation.
- Central nervous system abnormalities, such as developmental delay, behavioural dysfunction or deficit, intellectual impairment and brain malformations.
- Structural abnormalities, such as characteristic facial features.
- Confirmation of maternal alcohol consumption, wherever possible (May, 1995; World Health Organization [WHO], 1996).

All of the above characteristics have to be present to make a positive diagnosis of FAS. For instance, diminished structural growth and/or developmental delay on its own may be the consequence of malnutrition, general poor health or lack of stimulation, associated with poverty and/or dysfunctional family structures. Developmental delay, similarly, may be caused by other forms of mental disability. Extreme caution should therefore be taken before labelling a child. It is also necessary to study the social and biological characteristics of the mother. Increased understanding of the maternal characteristics and social variables that influence FAS(D), is important.

The diagnosis of FASD should be made by a specialised multi-disciplinary team, consisting of a professionally trained dysmorphologist (a medical specialist who recognises abnormal features in a person), following strict criteria laid down in the medical literature (Hoyme et al., 2005). The team also usually includes a neuro-developmental psychologist, and a trained counsellor. Diagnostic services for FASD are limited because of the necessity of well-trained and skilled professionals.

In South Africa the prevalence of FASD in the general population is essentially unknown, because there is no surveillance system in the country. So far, prevalence of FAS and PFAS has been calculated for targeted high-risk communities in the Western and Northern Cape, as well as Gauteng. The diagnosis of FAS/PFAS remains clinical, and optimal criteria will remain under debate for the foreseeable future (Urban et al., 2008). There is ongoing refinement as to how to make the most accurate diagnosis of FAS and the other disorders in the FASD continuum.

Diagnostic guidelines and tools have been developed in different countries in the world, including the revised Institute of Medicine guidelines (IOM, 1996), the Canadian guidelines for diagnosis, the CDC guidelines and the British Medical Association FASD guide for health care professionals (Rendall-Mkosi et al., 2008). A lack of standardised diagnosis affects identification of both diagnostic criteria and risk factors and studies exploring prevalence and risk factors may not be fully comparable (Sampson, Streissguth, Bookstein & Barr, 2000). However, work
already conducted in South Africa has contributed greatly to the refining of the IOM (1996) guidelines, as well as ensuring that they are locally applicable (May et al., 2000).

Estimates of incidence and prevalence of FASD as reported in the published literature are usually measured in three different ways: information collected passively for another or for many purposes, such as birth defect registries, information gathered either retrospectively or prospectively from hospital- or clinic-based registries and population-based active case ascertainment as is being done in South Africa (IOM, 1996). Information that measures incidence or prevalence of traits or characteristics associated with FASD and not the incidence of FASD itself is also used, such as alcohol intake by pregnant women. Each of these methods has their advantages and disadvantages. According to Viljoen (personal communication, June 20, 2009) there is scope for surveillance in South Africa to determine prevalence. He suggests the diagnostic assessment of school-entry children who have been randomly-selected from multiple district regions within all nine provinces.

WHAT HAS BEEN ACHIEVED IN SOUTH AFRICA SO FAR?

The achievements in the field of identifying, assessing prevalence and prevention of FASDs in South Africa, cannot be discussed without referring to the involvement and achievements of the Foundation for Alcohol Related Research (FARR). FARR was constituted in 1997 as a non-profit organisation and has evaluated communities in three provinces in the country for FAS/FASD up to the present. The need for this research followed a basic audit of clients investigated at genetic clinics undertaken by the Department of Health (DoH), Western Cape Province, and the Universities of Stellenbosch and Cape Town. It was discovered that 1 in 10 children referred to these specialist clinics had the full stigmata of FAS. The FARR organisation has since used every avenue to inform the general public, health, social and educational planners, and other professionals, funding organisations and research groups regarding FASD. FARR has been fairly successful in garnering support, especially from federally-funded research groups in the USA such as the NIAAA (National Institutes for Alcoholism and Alcohol Abuse) and CDC in researching prevalence, risk factors, social conditions, behavioural pattern changes, genetic factors, speech and language deficits and many other challenges associated with FASD. FARR’s most telling research has emerged in publications revealing the very high prevalence of FASD in several communities studied (see Table 1).

Apart from the contribution by FARR on prevalence studies in certain high-risk communities, other significant research findings by FARR and collaborators are briefly summarised below:

- Maternal risk factors associated with having a child with FASD, have been elucidated. These risk factors include binge drinking of large amounts of alcohol during pregnancy, poor socio-economic circumstances, cigarette smoking, low religiosity, limited education, single parenthood and maternal depression (May et al., 2005; Viljoen, Croxford, Gossage, Koditwakku & May, 2002). Morojele et al.’s (2010) study on predictors of risk of alcohol-exposed pregnancies among women in a rural and urban area in South Africa, add the following factors to those mentioned above: the partner’s and family members’ alcohol consumption pattern, age of onset of drinking, physical characteristics (height, weight, BMI). According to Morojele et al. (2010) these maternal risk factors are similar to risks in other parts of the world. Interestingly enough, though, they found contrasting risks for rural and urban sites. Risks for alcohol-exposed pregnancies in urban areas were a mother...
who smokes, few or no children, minimal religious involvement, high self-esteem, and high reported access to recreational facilities such as bars and shebeens. In contrast, women in rural areas who were at risk for alcohol-exposed pregnancies, were impoverished and marginalised, a smoker with few or no children, low self-esteem and minimal education.

- Photogrammetry (three-dimensional photography) has been developed for the possible future diagnosis of FASD and has been demonstrated as remarkably specific and sensitive. The evaluation of several hundred children has been reported in many publications from FARR’s collaborations with the Medical Imaging Unit at the University of Cape Town (Douglas, Meintjies, Vaughan & Viljoen, 2003). Such methodologies can immediately form the basics of surveillance in whole populations.

- Cognitive and motor development in children with FASD has been evaluated amongst high-risk South African populations. Children have demonstrated deficiencies in several neurological domains including speech and hearing, performance, practical reasoning and eye/hand co-ordination. Surprisingly, loco-motor subscales were relatively unaffected (Adnams et al., 2001).

- Genetic effects have been demonstrated in families where polymorphisms of the ADH2 *2 molecule were significantly more common in controls than amongst FASD-affected coloured persons in the Western Cape. This finding suggests that susceptibility in mothers and their offspring to FASD is increased because metabolism of alcohol is slower in these persons leading to higher blood alcohol concentrations compared with control subjects without FASD. These studies were the first reported in the literature to assist in understanding susceptibility to FASD amongst different populations (Viljoen et al., 2001).

- A new biomarker of fetal exposure to alcohol was reported in a study of meconium (first stools passed by the baby after delivery) where ethyl-oleate concentrations were much higher in newborns exposed to recent alcohol use in their mother. This is a highly sensitive and specific indicator of maternal alcohol exposure during the latter stages of pregnancy (Bearer et al., 2003).

- The effect of prenatal alcohol exposure on infant visual acuity was demonstrated amongst children exposed to alcohol in a South African collaborative study. This was assessed by Teller Acuity Cards at six months post-delivery. The finding was consistent with clinical and visual evidence of alcohol-related disruptions of the visual pathways (Carter et al., 2005).

**WHAT IS BEING DONE ABOUT PREVENTION?**

The prevention of FASD is, essentially, a social issue. There is consensus in the literature that alcohol and other substance use during pregnancy is linked to many factors impacting on the lives of mothers, their children, their families and significant others, and that solutions to problems of substance abuse should therefore be anchored in a multi-level, comprehensive and integrated approach of outreach, identification, referral and appropriate support (May, 1995; Roberts & Nanson, 2001). The aim should be to work within a model or framework that includes a broad spectrum of interventions and targets with different levels of intensity depending on the inputs required. A model suggested by Roberts and Nanson (2001) is a stepped care model that allows for a continuum of interventions (May, 1995). This model is based on the premise that intervention starts on the least intensive level first, e.g., with screening of clients and a motivational talk, and then by means of
improved methods, when a less intensive treatment is ineffective. Brief interventions have been effective for some women, while others would require more intensive treatment and/or referral.

Intervention programmes to reduce drinking during pregnancy are usually classified into universal efforts (increasing the general public’s knowledge and awareness of the consequences of alcohol use during pregnancy); selective efforts (screening of all women in their reproductive years who are at risk, for instance women who drink alcohol); and indicated efforts (directed towards the women at greatest risk – women who have a history of drinking during pregnancy or who already have a child or children with FAS(D) (Hankin, 2002).

Because of research initiatives and efforts by the Maternal, Child and Women’s Health sub-directorate of the Provincial DoH over the past decade, the Western Cape has been a focus of raising public knowledge and awareness on alcohol abuse during pregnancy (universal prevention efforts). Many NGOs contribute to these efforts in the area, for instance, FARR, Cape Women’s Forum, Dop-stop, Women on Farms, FAS-facts, Reproductive Research Unit’s adolescent-friendly clinic initiative and LoveLife Programmes. Current research projects fall within the selective and indicated prevention field and researchers are pointing out the importance of introducing a basic screening system at the primary care level that would identify women who have hazardous and harmful drinking patterns.

Current prevention projects

*The Witzenberg Programme*

FARR and the Medical Research Council, funded by the Western Cape Department of Social Development, are involved in a multi-faceted preventative project in the Western Cape’s Witzenberg sub-district. The project includes the following phases: A cluster, randomised trial testing the use of brief interventions during pregnancy to change drinking behaviour (2007); follow-up of all babies at eight months by a medical doctor to evaluate for fetal alcohol outcomes (2008); a prevalence study of FAS/PFAS in the district evaluating a random sample of school-entry children (2009); and lastly, the training of health care workers in clinics to implement the positive effects of brief intervention (BI)s, as proven in the first phase of the project. Results from international studies confirm that BIs have positive results (Marais *et al.*, 2010). This project is important, because it is the first randomised control trial in South Africa showing a significant change in drinking behaviour in the intervention group after applying brief motivational interventions. There were also changes in the control group’s drinking behaviour, although a significant change was not shown. The findings showed that women who are open about their drinking habits are ready to change their drinking habits.

These results are similar to those from other attempts to modify prenatal alcohol consumption reported by Chang, Goetz, Wilkens-Haug and Berman (1999), Handmaker and Wilbourne (2001), O’Connor and Whaley (2007) and the WHO Brief Intervention Study Group (1996) demonstrating declines in both intervention, as well as control groups. It seems to be beneficial to have more than one session of BI, especially in the case of excessive drinking. One to three patient consultations have consistently shown significant reductions in problem drinking in comparison to no consultations (Dore, 2000; Handmaker & Wilbourne, 2001). This study confirms the importance of routine screening for prenatal alcohol use patterns and the necessity of offering information and support during pregnancy in a sustainable way.
Northern Cape FASD Prevention Programme

On invitation from the Northern Cape DoH (and local municipalities), FARR conducted FASD prevalence studies in De Aar and Upington in 2001-2002. Grade 1 learners of all the local schools were assessed and appraised. A prevalence rate of 122/1000 was found in De Aar and 69/1000 in Upington. The De Aar rate is still the highest reported rate, to date, in the world. Following these prevalence studies, FARR started with comprehensive FASD prevention programmes in both communities. This has resulted in an estimated 30% drop in the FASD rate (data currently being analysed). The focus areas outlined below are key components to this programme.

Universal awareness

At the onset of the programme there was very little, if any, knowledge of FASD in the Northern Cape. The Department of Education (DoE) reported high failure rates, truancy and learning disabilities amongst learners, but none of these were linked to alcohol abuse. FARR invested considerable time and effort into raising the awareness regarding FASD through the local media. This drive not only increased the knowledge regarding the problem, but also created more focus on women who are using and abusing alcohol during pregnancy. The support from government departments remain, unfortunately, at a level where the key departments are very interested and supportive of the programme and regularly reports on the work done by FARR.

Selective awareness

Data obtained from the prevalence studies in Upington and De Aar enabled FARR to identify the high-risk communities within these two areas. Intensive awareness programmes are being conducted in these communities involving innovative techniques such as radio dramas, industrial theatre productions, drum majorettes, open days, sport events and motorbike rides. Educators of local schools, especially in De Aar, regularly receive considerable support in terms of training, referrals to the FARR centre and outreach programmes. FARR staff in De Aar work in close liaison with the service providers from the DoH and DSD.

Indicated awareness

FARR has developed an intensive awareness and support programme for pregnant women, based on experiences from the MRC Witzenberg project, research results from the projects in the Northern Cape, and in line with the antenatal and primary health care services of the DoH in the Northern Cape. The programme is called the Healthy Mother – Healthy Baby Project and involves all the pregnant women in the area. The project is currently in its third year. So far, FARR has received positive feedback regarding this intervention.

University of Pretoria, the University of Cape Town and the Medical Research Council Prevention Programme

This programme is funded by the CDC, Atlanta, are involved in a comprehensive FAS prevention programme conducted in Pretoria and the West Coast areas. They are exploring strategies to reduce harmful alcohol use by women in general, reducing alcohol use in pregnancy and promoting the planning of pregnancies. The programme includes general awareness-raising. An article on predictors of risk of alcohol-exposed pregnancies among women in an urban and rural area has been published (Morojele et al., 2010).

University of Nieu-Mexico the University of Stellenbosch and the Medical Research Council Study

This study is funded by the NIAAA, are involved in a comprehensive multi-site prevention study in the Western Cape. This study is based on the FAS prevention programme that is informed by the Institutes of Medicine in the USA and also aims to
address HIV and AIDS risk factors associated with excessive drinking (Rendall-Mkosi et al., 2008).

(LACK OF) POLICY RELATING TO THE PREVENTION OF FASD

There is no integrated national strategy or policy to deal with the problem of FASD in South Africa. In the Western Cape FASD was declared a provincial health priority between 2001 and 2002 as a result of the initiative of the Western Cape DoH, specifically the Maternal, Child and Women's Health sub-directorate that has been active in the management and coordination of FASD initiatives since the 1990s. A provincial FASD-reference group was established at that stage and regional coordinators were identified and appointed in different regions of the province. A provincial standardised training manual was developed by the FASD-reference group. The manual was launched in 2003 when the first 20 health workers were trained. At present, the importance of FASD prevention is acknowledged by the Western Cape DSD and attempts to address this concern via their Provincial Substance Abuse Programme, which is aligned to its National Drug Master Plan (NDMP) of 2007. National priority areas defined by the NDMP are, amongst others, substance abuse among women in their reproductive years, teenage pregnancies, FASD, multi-drug resistant TB and sexually transmitted diseases such as HIV/AIDS.

A range of relevant policy documents were scanned by Rendall-Mkosi et al. (2008) for the use of the terms FAS and FASD to assess if these terms were used specifically. Only two of the documents scanned contained the term FAS, i.e. The National Human Genetics Policy Guidelines for the Management & Prevention of Genetic Disorders, Birth Defects & Disabilities (DoH, 2001) and the National Drug Master Plan (DSD, 2007) – a result of the Prevention and Treatment of Drug Dependency Act (No. 20 of 1992 specifying the establishment of the Central Drug Authority). One document from the DoH made specific reference to women and alcohol, i.e. The Guidelines for Maternity Care in South Africa (DoH, 2002).

In some high-income countries legislation and task teams for action to prevent FASDs have been established. In the USA the CDC was instrumental in the establishment of a National Task Force on FAS and FASD in 2000, after a specific Public Service Act directed the establishment of such a task force. The main aims of the task force are to provide advice to all relevant persons in various programmes on the prevention and support required in relation to FASD; to coordinate efforts through their health department; and to report to the relevant committees on a regular basis (Rendall-Mkosi et al., 2008).

In Canada the Government takes a holistic, integrated approach to FASD, recognising that FASD is not just a health issue but has long-term societal and economic implications. Federal departments work in an integrated manner on prevention and awareness approaches, as well as on advancing joint work around FASD-related data collection and reporting. Federal FASD work is undertaken in partnership with provinces and territories, first nation organisations, communities and stakeholders. In the UK the national organisation on FAS (NOFAS-UK) works with the DoH to initiate new FASD research strategies, information, care and support.

ROLE OF STATE DEPARTMENTS IN THE PREVENTION AND MANAGEMENT OF FASD

The identification, management and prevention of FAS and FASD require an inter-sectoral and multi-disciplinary task team. It also includes the mother, her affected child, her spouse and their immediate community. More than one department needs to be involved in this multi-faceted task, i.e. at least the DoH, DSD, DoE, and the Department of Agriculture. Given the lack of comprehensive prevention
strategies in South Africa, a first step would be to inform personnel in the above four departments about the magnitude of the problem and propose suggestions for possible interventions. Experience and research findings have shown that primary health care staff, social workers and especially educationists working with affected children do not have the necessary skills and knowledge to cope with the problem. FARR, through their training academy, offers training to professionals, by capacitating them to develop FASD prevention and management programmes. But most importantly, it will require the commitment of policy makers and planners, as well as the motivation of staff, to really make a difference in the coming years.

Research in the Witzenberg sub-district of the Western Cape has shown that, with basic and detailed information and support, mothers were willing to change their drinking behaviour during pregnancy (Marais et al., 2010). On the other hand, children with FASD have a range of developmental, cognitive, behavioural and communication problems that can benefit from early intervention strategies. The needs of children with FASD are most noticeable in the schools where the teachers are ill-equipped to adapt their teaching and classroom environments to cater for learning and behavioural difficulties of children with FASD. However, interventions have shown that despite cognitive disabilities, children with FASD have shown significant cognitive improvements following a classroom intervention targeted at literacy and linguistic skills (Adnams et al., 2007). Ideally, these interventions should become routine.

Unfortunately, as documented results reveal, the South African government departments and social organisations have been slow to respond to the pandemic of FASD found in susceptible communities (Viljoen, 2009). Due to the other disorders prevailing in our country (HIV/AIDS, malaria, TB and malnutrition) health planners appear reluctant to part with significant resources to combat FASD.

**FASD AND THE JUSTICE SYSTEM**

It has been mentioned earlier that alcohol abuse during pregnancy leads to central nervous system abnormalities, resulting in low intelligence, behavioural problems and poor social judgement. Because of reduced ability to think abstractly, FASD-affected individuals do not understand cause and effect, including an appreciation of the consequences of their actions. They are easily influenced by others and frequently are forced to engage in criminal activity. Statistics show disproportionately high rates of incarceration among people with FASD as a concomitant factor (Mitten, 2004). Their high susceptibility to negative peer influences, as well as being vulnerable to victimisation, make artificial settings such as incarceration inappropriate deterrents for them. No research on this topic has been conducted in South Africa yet.

A related, but different issue, is whether a FASD-affected child should be seen as a victim of abuse by the mother and whether her drinking behaviour and the effect on the fetus should be criminalised. It is argued that, by exposing the fetus to a teratogen, the mother is causally and arguably morally, responsible for the outcome (Mukhergee, Eastmen, Turk & Hollins, 2007). This suggestion is also being put forward by some criminologists, notably Michele Ovens (Ovens, 2009). Although a substantial body of research is being done on FASD in South Africa, the link between maternal alcohol use/abuse and child abuse is unique. Ovens states that maternal drug abuse can be viewed as a social welfare issue within the harm reduction approach, or it can be criminalised within the punitive approach. It is therefore a debate whether the mother should be held responsible for the adverse results of her drinking on her unborn child. The question whether the mother is aware of the consequences of her actions, would obviously be an important one,
if punishment in any form is considered. This is an interesting and novel idea in the field of FAS research. Ovens further proposes the development of a drug policy dealing with drug dependency in pregnant women. She states that “research is also necessary to determine whether a drug policy should include the criminalisation of substance abuse by pregnant women” (Ovens, 2009, p. 503).

Drug-related child abuse is defined as the deliberate or unintended physical and/or emotional abuse and/or neglect of a child by a drug-dependent parent (Ovens, 2009). This can be reflected on three levels, namely drug abuse affecting the cognitive and/or emotional abilities of the parent, which contributes to the parent abusing the child; the child may become a victim to tranquillisers given by the mother to keep the child docile; and damage done to the fetus in the case of prenatal abuse of drugs by the mother. Ovens argues that the fetus has limited rights – while the Child Care Act 1999 protects the child from abuse, no protection or rights are offered to the fetus of the substance-abusing mother in South African legislation. This is also the case in UK and USA law – the fetus does not possess rights equivalent to those of a person. This implies that a mother in these countries can currently not be held criminally liable for fetal injury (Mukhergee et al., 2007). The crucial question remains whether child abuse should include drug-related abuse by the mother.

RECOMMENDATIONS AND CONCLUSION
The impact of alcohol on the lives of ordinary citizens in South Africa is devastating. More than half of homicide and traffic-related deaths are associated with alcohol. The hidden effects resulting from the use of alcohol such as FASD and its impact on the lives of affected persons are not yet fully grasped by different state departments and policy makers in this country. It is estimated that one million individuals in South Africa suffer from FASD. Great strides have been made as far as research and awareness-raising is concerned, but more work is needed on all levels of prevention to bring down the prevalence rate in this country. The following are recommended to reach this goal:

- Universal prevention by way of awareness campaigns by NGOs are very important and will continue. Most of this work is presently concentrated in the Western Cape and Northern Cape. NGOs should expand their work to other provinces as well.
- Involvement of the National DoH is crucial. Important research findings should be incorporated into the routine tasks of health care workers in the country, such as screening and brief motivational interventions for women at risk of experiencing alcohol-affected pregnancies.
- A countrywide surveillance system should be developed. This Chapter suggests that school-entry children are randomly selected from multiple district regions within all nine provinces and tested for FASD. Setting up such a surveillance system is another task requiring buy-in from the National DoH.
- Children with FASD and the teachers teaching these children need support. The DoE should become involved to make use of training packages on FASD so that their staff members understand what the handicaps of these children are and how to deal with them.

Key messages
- FAS is 100% preventable, but 100% irreversible.
- FASD is a huge public health problem in South Africa with the highest prevalence in the world.
- Brief motivational interventions with pregnant women have been shown to change their drinking behaviour.
- Because children with FAS do not distinguish between right and wrong, they are often lured into criminal behaviour. Incarceration is the worst penalty they can receive.
- FASD is a hidden effect of the impact of alcohol on the health of individuals and the community.
REFERENCES


Fetal Alcohol Spectrum Disorders


