Fetal Alcohol Spectrum Disorder in South Africa: Situational and Gap Analysis

March 2008

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Executive Summary

A Situational and Gap Analysis was conducted over a period of one month. Data was collected by means of a literature review and key informant interviews. Since there is very little written on Fetal Alcohol Spectrum Disorders (FASD) in South Africa, the international literature was used for background information. There was some difficulty in getting consent from some key informants, which limited the information that could be gathered on the current service provision to people with FASD related disabilities.

The term FASD is used to include the range of permanent conditions that result from alcohol exposure of the fetus in utero, with Fetal Alcohol Syndrome (FAS) being the most severe condition. The diagnosis of any of the FASD conditions should be made by a specialised multidisciplinary team, however, the availability of such teams is very limited across the country. Prevalence studies in high risk areas of South Africa have shown that some of these areas have the highest rate of FASD in the world (up to 119/1000 school entry aged children in one high risk area). Since there is no surveillance system to collect information on the number of cases diagnosed across the country, 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 14/1000.

The typical impairments that characterise a child with FAS are related to neurocognitive damage, resulting in low intelligence, behavioural impairments, poor social judgement, and general difficulty performing every day tasks. Without sufficient specialised intervention and a supportive home environment, secondary disabilities in adolescence and adulthood occur, leading to mental health problems, inappropriate intimate relationships, unemployment and possible trouble with the law. Since diagnostic and support services are very limited in South Africa it is unknown how many children and adults who utilise various services, such as mental health services, or who are found in correctional services facilities, are in fact people with FASD. The needs of children with FASD are most noticeable in the schools where the teachers are ill-equipped to adapt their teaching and classroom environment to cater for the learning and behaviour difficulties of children with FASD. Due to the use of alcohol by the mother and the cognitive damage of her offspring, both are at a higher risk of abuse and of HIV infection than the average person in their particular community.

There is 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 childbearing age women, and their alcohol and contraceptive use patterns and norms. While the profile of the typical woman at risk of an alcohol exposed pregnancy (AEP) in the high risk areas has been extracted from the prevalence studies, this may not hold true across the country. There is limited screening for AEPs in primary health care clinics, and health service providers 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 to most women. There are currently a number of internationally funded prevention studies taking place predominantly in the Western Cape, but preliminary results are not yet available.

The report concludes with a series of recommendations for research and service development not only to prevent FASD,but to improve the detection of children with FASD and ensure that they are supported to reach their potential in life through multisectoral service provision with adequate protection from negative environmental factors.

We recommend the response process should begin with the strengthening of the National FAS Task Team led by the Department of Health, the provincial Task Teams that exist and the establishment of new Task Teams in other provinces. This should be followed with a series of studies that contribute to better understanding the levels of risk of AEPs and underlying factors across the country, and to identifying the needs of children and adults with FASD, and their families. Simultaneously, it is essential that service capacity and provision be improved, especially in the education, health and social services sectors, so that the complex needs of the many people with FASD can be addressed as a matter of urgency. Raising the general level of awareness of the public of the needs of people with FASD, at the same time as challenging the stigma that people with FASD experience, would improve the integration of adults with FASD into general society and the work place.

Since this review was limited in time and scope, it is also recommended that a further review of policy and service provision in sectors such as justice, labour and correctional services be carried out.

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Abbreviations

ADHD	Attention Deficit and Hyperactivity Disorder
AEP	Alcohol-Exposed Pregnancy
AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal Clinic
ARBD	Alcohol-Related Birth Defects
ARND	Alcohol-Related Neurodevelopmental Disorder
BAC	Blood Alcohol Concentration
BI	Brief Interventions
BMI	Body Mass Index
CDA	Central Drug Authority
CDC	Centres for Disease Control and Prevention
CIFASD	Collaborating Initiative on Fetal Alcohol Spectrum Disorders
CNS	Central Nervous System
DALYs	Disability Adjusted Life Years
DoH	Department of Health
DSD	Department of Social Development
ECD	Early Childhood Development
EPWP	
FARR	Foundation for Alcohol Related Research
FAS	Fetal Alcohol Syndrome
FASD	Fetal Alcohol Spectrum Disorders
HIV	Human Immunodeficiency Virus
ICD 10	International Statistical Classification of Diseases and Related Health Problems 10th Revision
GP	Gauteng Province of South Africa
IOM	Institute of Medicine
IQ	Intelligence Quotient
MI	Motivational Interviewing
MRI	Magnetic Resonance Imaging
MCWH	Maternal, Child and Women's Health
MGEP	
NGO	Non Governmental Organisations
NDMP	National Drug Master Plan
NIAAA	National Institute of Alcohol Abuse and Alcoholism
PAE	Prenatal Alcohol Exposure
PFAS	Partial Fetal Alcohol Syndrome
PHC	Primary Health Care

SA	South Africa
SADHS	South African Demographic and Health Survey
SANCA	South African National Council for Alcohol and Drug Abuse
SBI	Screening and Brief Interventions
SES	Socio-Economic Status
TB	Tuberculosis
TOP	Termination of Pregnancy
UP	University of Pretoria
USA	United States of America

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Chapter 1 Introduction and Methods

This report aims to firstly outline the main issues related to the problem of fetal alcohol syndrome (FAS) and the fetal alcohol spectrum disorders (FASD) in general, with reference to a review of key international literature, and secondly to present the results of the situational and gap analysis focusing on FASD in South Africa (SA).

Due to the limited timeframe for the work, the scope of investigation focuses on immediate issues, such as needs and rights of those affected in relation to health, social development and education, and policies. Research, policies and services that relate to issues such as employment, justice, and liquor controls will be discussed in less detail.

Situational Analysis

The situational analysis reports on the available information for both rural and urban populations.

Objectives

1 To summarise findings of past and current research done in SA on:

1.1 the prevalence of FASD

1.2 risk factors for FASD

1.3 strategies for the prevention of FASD, and the interventions for FASD.

2 To review the current policy frameworks from various sectors that have any bearing on the prevention of FASD and/ or the support of people with FASD.

3 To describe the current status of service provision by the health, social development and educational sectors in relation to the prevention of FASD, and the support to individuals and families with FASD.

4 To develop a conceptual framework of the individual, family and societal level risk factors and outcomes of prenatal exposure to alcohol, in order to map the direct and indirect effects of FASD, and thereby identify the key points of intervention for prevention and support/ rehabilitation.

Methods

Literature review

In order to provide background to the risk factors and context in which FASD occurs, how it presents and is identified and diagnosed, as well as the range of needs of children and

adults with a FASD condition, key international literature was reviewed. Thereafter, all accessible published and unpublished literature related to FASD in South Africa was reviewed to fulfil Objectives 1 and 2. This included searching the PubMed and Cinahl databases using the search terms “Fetal Alcohol Syndrome AND South Africa”. This strategy yielded 22 and 14 articles respectively.

Review of Current Research

The protocols of relevant current research underway in South Africa as well as preliminary results are not yet in the public domain and there are no established provisions for data sharing in publicly funded research in South Africa. However, a summary of current research projects is presented based on interviews or personal communication with the relevant researchers and from research abstracts from internationally funded research projects. Besides summarizing the information, the review identified issues that require future research and/ or service provision strengthening.

Key informant interviews

Three semi-structured interview guides were prepared for three anticipated groups of participants: Researchers, Government officials, and NGOs or advocacy groups (see appendices 1a-c). Eleven key informants were interviewed in person or telephonically, after providing informed consent. A copy of the consent form is included as Appendix 2.

The interview notes were analysed for dominant themes in the areas of the nature of the problem, target populations, service delivery and perceived needs in service provision. A summary of these results is provided in Chapter 6. The information from the key informants is also referred to in the situational analysis of the various issues related to FASD in South Africa.

Policy review

Various national and provincial policies were reviewed to identify those which specifically used the terms FAS and/ or FASD. In addition some of the key informant interviewees were asked questions related to policy issues in order to understand the current implementation levels of the policies, and the extent to which FASD is potentially covered by legislation.

Gap Analysis

Objectives

1 To assess the status of current policy and service delivery in terms of the needs of people with FASD, and women at risk of having a child with FASD, in order to identify geographical and need-based deficiencies in the system.

2 To identify priority interventions that should be further researched or strengthened at a service or policy level in order to facilitate prevention and support.

3 To make recommendations for multi-sectoral developments that would improve the lives of those with FASD and prevent further children being born with FASD.

Methods

A matrix was developed based on the situational analysis for each of 'prevention' and 'support and rehabilitation' needs. Current services and policies were listed in a table to indicate which needs and problems should be addressed, and who is responsible for these.

For each set of factors and needs, a conclusion was drawn regarding the need for further research, policy development or service implementation. These form the basis for the overall conclusion and recommendations.

Final report writing

The report was submitted in draft form to the UNICEF office following a one hour presentation of the main findings. Feedback was received on this report from members of the UNICEF office, and the final report was submitted a week later.

Ethical considerations

The researchers obtained approval from the University of Cape Town (UCT) and University of Pretoria (UP) Faculty of Health Sciences Ethics Committees (058/2008 and 34/2008 respectively) for the key informant interviews. The interviewees provided signed consent to participate in the interviews and were assured that no reference to their name or personal details would be made in the final report. Only the research team will have access to the summary notes from each interview.

Roles within the Research Team

Ms K Rendall-Mkosi (MPH) served as the principal investigator (PI) and co-ordinator of the research team and is based at the School of Health Systems and Public Health, UP. Communication with co-investigators and consultants was by teleconference and e-mail across SA. Four of the team members met once in Pretoria, and another combination of four met in Cape Town once.

Profs L London and C Adnams (UCT), and Dr N Morojele (MRC) served as co-investigators in the research and contributed to the identification of the literature to be reviewed and key informants to be interviewed, as well as the finalisation of the draft and final reports.

Drs J McLoughlin and C Goldstone served as contract researchers for the duration of the one month period, and carried out desk top reviews and key informant interviews, as delegated by the investigators. They jointly produced the draft report, with guidance from the PI and co-investigators

Limitations

Refusal by key informants

It was found that a number of key informants, especially from government services, were not prepared to participate in an interview and either referred the researcher to a colleague, or explained the lengthy process of getting permission within their organisation to participate in such an interview.

Policy review process

Only 2 national government policy documents were identified that used the term FAS and none that used FASD. Additional time and investigation is needed to identify and review relevant policies which incorporate the range of needs of people with FASD in the absence of the express use of the terms FAS and/ or FASD in these documents.

Chapter 2 FASD characteristics, issues of diagnosis and prevalence

How does alcohol affect the fetus?

Alcohol consumed by the mother at any stage in pregnancy may affect the fetus and result in permanent impairments of growth and brain development problems. The more the mother drinks the worse the effect is likely to be.

Alcohol is a potent teratogen and exposure of the developing fetus to moderate to high concentrations of alcohol causes permanent and multi-system damage. If present in the mother's blood during pregnancy, alcohol freely crosses the placenta into the blood and other tissues of the developing embryo or fetus. The developing fetus exposed to high concentrations of alcohol in utero typically demonstrates a constellation of pre and postnatal problems including growth retardation, characteristic facial features and central nervous system (CNS) deficits. The most significant effects are on the developing central nervous tissue and brain and prenatal alcohol exposure is seen as a leading cause of intellectual impairment in the world. Furthermore, it is now known that the damage done to the developing brain may result in a range of neurobehavioural problems in the face of normal intelligence (Hoyme et al., 2005). In the absence of any other features of alcohol damage these may go undiagnosed with potentially severe individual and societal consequences (Sampson et al., 2000).

The gestational timing, frequency, duration and amount of exposure to alcohol which result in central nervous system damage and growth retardation, the nature of the damage and the precise biological mechanisms of harm are the subject of ongoing research. Experimental animal studies and non-experimental human studies have linked the cellular and organ level injury to the typical phenotype of prenatal alcohol exposure (PAE) (Roebuck et al., 1998, Bookstein et al., 2002a, Bookstein et al., 2002b, Manning and Hoyme, 2007, Cortese et al., 2006). Similarly, there is evidence showing the correlation of specific functional domains and neuroanatomical areas in the brain affected by PAE and relating these to the cognitive (intellectual) and behavioural deficits seen in affected individuals (Kodituwakku, 2007, Sampson et al., 2000). A dose-response effect has been observed where higher exposure results in greater damage and lower levels of exposure result in more subtle effects. Binge type drinking which results in a high blood alcohol concentration (BAC) in the mother's blood is associated with particularly severe developmental deficits. A threshold or safe level of alcohol concentration in pregnancy

has not been established thus even low levels of alcohol consumption by a pregnant mother may place her fetus at risk of a permanent, neuropsychological impairment later in life (Jacobson and Jacobson, 1999, Sampson et al., 2000).

They may be a range of other physical abnormalities such as heart defects, skeletal defects, abnormalities of the renal system and visual and hearing problems (Chudley et al., 2005). Odds of survival before and in early infancy birth are reduced due to impaired growth, physical and other risk factors.

The negative effects of heavy PAE were reportedly recognised in ancient times and many traditional societies discouraged the use of alcohol amongst women of childbearing age, yet it was only in 1973 that a clinically distinct syndrome called Fetal Alcohol Syndrome (FAS) was described (Jones and Smith, 1973, Jones et al., 1973). Subsequently FAS, the severest form of FASD, and milder forms of fetal damage due to PAE have been described. The range of effects of PAE has been identified as a major public health issue in both well and poorly resourced countries where alcohol is widely used (May et al., 2006, May et al., 2007, Chudley et al., 2005, US Department of Health and Human Services, 2000). The first descriptions of FAS that we have identified in the medical literature in South Africa were published in 1978 (Hayden and Nelson, 1978, Beyers and Moosa, 1978).

The effect of alcohol on the developing fetus is influenced by additional known and unknown risk factors. For example, good maternal nutrition likely has a protective effect. Similarly, the pattern of exposure, the developmental timing of the exposure, genetic variations, other maternal characteristics, socio-economic status (SES), and synergistic reactions with other drugs (Riley and McGee, 2005) play a role in determining the nature and extent of the effects of PAE. This results in a range of physical, and neurobehavioural disabilities. It follows that not all children who display features consistent with PAE will meet the criteria for a diagnosis of FAS (Hoyme et al., 2005, CDC, 2005). Recognition of these lesser effects led to the use of the term fetal alcohol effects (FAE) (Sampson et al., 2000) in order to collectively describe the features seen in children who did not meet the criteria for a FAS diagnosis but who had some growth and neurocognitive and/or behavioural deficits consistent with PAE. However, use of the term FAE has been questioned particularly as it came to be used incorrectly as a clinical diagnosis (Hoyme et al., 2005), and it has been superseded by more definitive terminology.

What is FASD?

Fetal alcohol spectrum disorders (FASD) is an umbrella term used to categorise the range of effects an individual may have as a result of maternal alcohol use. The most severe diagnostic category is fetal alcohol syndrome (FAS), and others include partial FAS (PFAS), alcohol-related neurodevelopmental disorder (ARND) and alcohol- related birth defects (ARBD).

The concept and use of the term of fetal alcohol spectrum disorders (FASD) was developed in 2004 (CDC, 2005). FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioural and/ or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis. It encompasses the full continuum of structural anomalies, and neurocognitive and behavioural deficits from mild to severe resulting from PAE. In decreasing order of severity the diagnoses defined within the continuum are FAS, partial FAS (PFAS), alcohol-related birth defects (ARBD) and alcohol-related neurodevelopmental disorder (ARND). While FAS is the most physically recognisable of the conditions, the milder conditions are likely to be more prevalent in the general population, thus an understanding and use of the term FASD ensures that there is recognition and quantification of all of the harmful effects of PAE. All of the FASD conditions would be completely prevented by abstention from alcohol at the time of conception and in pregnancy.

Is there an intergenerational presentation of FASD?

FASD is often intergenerational. A woman who herself was exposed to alcohol in utero, and who had life exposure to an environment of excessive alcohol use, is at a higher risk for early substance (alcohol) abuse and unplanned pregnancies due to her poor cognitive abilities and social judgement. She is therefore herself at risk of having a child with FASD.

Alcohol dependence has been shown to cluster in families both as a result of genetic and environmental influences. International cohort (Rouleau et al., 2003) and South African case control studies (May et al., 2005, Viljoen et al., 2002) have provided evidence that mothers who have given birth to children with FAS were themselves raised in an environment where heavy maternal drinking was prevalent. Mothers of children with FAS

have shown features consistent with the secondary disabilities of FASD such as depression, learning difficulties, suicide attempts and criminality (Rouleau et al., 2003).

Similarly, in South African studies mothers of children with FASD had lower education attainment (Urban et al., 2008 submitted for publication, May et al., 2005, Viljoen et al., 2002) compared to control mothers and greater evidence of social and emotional problems. South African mothers of children with FAS were also reported as being socially more isolated and stressed during the index pregnancy (Viljoen et al., 2002) which may not only have reflected their challenging socio-economic position relative to the controls but also their own neurocognitive and behavioural profile - the latter possibly the result of unrecognised FASD. Further evidence of possible intergenerational FASD is the finding that case mothers were significantly smaller than control mothers for height, weight, head circumference and body mass index (BMI) (May et al., 2005, Urban et al., 2008 submitted for publication) and the authors propose not only that some mothers of FAS children may have FASD but that the behavioural traits associated with FASD, such as impulsivity and poor judgement, could have contributed to their heavy alcohol use and their alcohol use during pregnancy. A further link may be seen between a lack of knowledge regarding the detrimental effects of PAE on the fetus as a result of possible maternal FASD and an increased risk of an alcohol explosed pregnancy (AEP) (Rendall-Mkosi et al., 2007).

The presence of intergenerational FASD suggests a complex interaction of genetic and environmental risk factors for FASD. Early recognition of FASD in a girl child, followed by sufficient support and service provision, may prevent perpetuation of the intergenerational cycle (see Figure 1 on page 22).

What are the characteristics of FASD and how are diagnoses within the spectrum made?

A child is diagnosed with FAS if he or she has specific facial features, is small in growth and head size for age and has deficits in intelligence with behavioural problems. Report of maternal drinking at the time of the pregnancy can help to confirm the diagnosis, but is not necessary. A child with another FASD diagnosis will have a combination of the above defects specific to PFAS, ARND or ARBD. Diagnosis should be confirmed by a multidisciplinary team that includes a specialist doctor and is therefore both costly and largely unavailable in South Africa.

Within the spectrum of FASD there is a constellation of a characteristic pattern of (1) facial and other dysmorphology, (2) diminished structural growth for age and (3) intellectual and behavioural deficits. To meet the criteria for the severest diagnosis, that of FAS, all three categories of problems must be present and non-alcohol related causes of the anomalies must be excluded (Hoyme et al., 2005). Therefore, whilst confirmation of heavy maternal drinking is preferable, in a situation where it is impossible to obtain this information (for example if the mother is deceased and collateral information is not available) a definitive diagnosis of FAS can be made without confirmation of heavy maternal drinking (May et al., 2007, Hoyme et al., 2005).

Diagnostic guidelines and tools which have been published in the recent literature were reviewed. These are the revised Institute of Medicine (IOM) 1996 guidelines (Hoyme et al., 2005), the Washington criteria (Astley and Clarren, 2000), the fetal alcohol spectrum disorder: Canadian guidelines for diagnosis (Chudley et al., 2005), the Centres for Disease Control and Prevention (CDC) guidelines (CDC, 2005) and a FASD guide for healthcare professionals by the British Medical Association (BMA, 2007). There is ongoing refinement and debate as to how to make the most accurate diagnosis of FAS and of the other disorders within the FASD continuum (Hoyme et al., 2005, Astley, 2006). The lack of internationally accepted standardised guidelines and diagnostic criteria result in complications. For example, there is some evidence that individuals within the FASD continuum would be misclassified if guidelines and diagnostic criteria are used interchangeably (Astley, 2006). A lack of a standardised diagnosis affects identification of both diagnostic criteria and risk factors and studies exploring prevalence and risk factors of FASD may not be fully comparable (Sampson et al., 2000) .

Work conducted in South Africa has contributed greatly to the refining of the IOM (1996) guidelines and towards ensuring that they are locally applicable (May et al., 2000). As a result there exists technical expertise within the country in the use of these guidelines and a basis for which to compare the results of future research. Thus it seems reasonable to recommend the continued use of the revised IOM 1996 guidelines for future diagnostic efforts in South Africa.

Facial features and other dysmorphologies

The characteristic facial features of FAS result from an under developed brain and midface in utero and include short palpebral fissures (narrow or small eyes in the horizontal plane), a smooth philtrum (smoothing of the parallel ridges between the nose and upper lip), and a thin vermilion border (thin upper lip). Individually these features occur in other genetic disorders or may even be within the normal range for some populations but it is the simultaneous presence of all 3 facial features that is specific for FAS (Astley, 2006).

The Washington diagnostic criteria require all 3 facial features to be present whereas the revised IOM 1996 criteria require 2 or more (Hoyme et al., 2005). This difference has been seen as one of the reasons for high prevalences of FAS when using the IOM 1996 criteria (Astley, 2006) and is the subject of debate.

Growth retardation

Pre and postnatal growth retardation results in a child's weight and/ or height, and head circumference, being less than expected for age. The usual cut off point for diagnosis of FAS is at or below the 10th percentile according to locally standardised or developed growth reference charts. The stunting is permanent and whilst in adolescence the weights of individuals with FAS may increase towards the average for age, affected individuals will remain short, and with a small head (Streissguth et al., 1991), and typically have a low BMI.

Central nervous system (CNS) abnormalities

Primary disabilities of a person with FASD are intellectual and behavioural impairments that lead to the secondary disabilities of not coping as well as others of the same age and having poor social judgement and emotional problems (Streissguth, 1992). Intellectual deficits may be identified by numerous neuropsychological tests in addition to measurement of IQ.

Besides a smaller brain size overall, specific structural abnormalities of the brain may only be visible using sophisticated imaging equipment such as magnetic resonance imaging (MRI).

Increasing attention has been paid to the neurocognitive (intellectual) and behavioural deficits of FASD as it is the these effects that impact greatest on the lives of people affected by FASD, their families and broader society. Current research is exploring

whether there is a specific observable pattern of mental and behavioural deficits (cognitive-behavioural phenotype) in FASD that is distinguishable from the patterns seen in other causes of neurobehavioural impairments, for example, Attention Deficit Hyperactivity Disorders (ADHD). A proposed FASD cognitive-behavioural phenotype is that of a generalised deficit in processing complex information (Kodituwakku, 2007). To be of diagnostic value the behavioural and cognitive impairments should not be expressed by family members not exposed to alcohol or explained by postnatal influences (Hoyme et al., 2005). The functional problems described in FASD are discussed in detail in Chapter 5.

For a diagnosis of partial FAS (PFAS), affected children must display typical facial dysmorphic features and abnormalities of either growth or CNS structure (or function). As in the case of FAS the diagnosis of PFAS can also be made without evidence of maternal alcohol use, however in both cases the clinical records classification should reflect this (Hoyme et al., 2005).

Children with ARBD display the typical facial features of FAS, but have normal growth and neurodevelopment for age. For a diagnosis they must display specific major or minor structural anomalies such as heart defects or unusual hand creases respectively. At the mildest end of the spectrum ARND applies to children who have neither the typical facial features nor growth delay but who show CNS and behavioural or cognitive abnormalities which have been shown to be associated with PAE. Due to overlaps with conditions with similar features, such as ADHD, a diagnosis of ARBD or ARND can only be made if there was confirmed heavy maternal alcohol exposure (Hoyme et al., 2005). Children with other genetic and dysmorphic syndromes may coincidentally be born to women who use alcohol in pregnancy and a diagnosis within the FASD continuum should not be assigned to a child with disabilities in a reflex manner simply because his or her mother used alcohol during the pregnancy (Hoyme et al., 2005).

Diagnosis is most easily made between the ages of 3-10 years as the facial, neurocognitive and behavioural features are collectively most prominent at this age. The detection of FASD and diagnosis in adolescents and adults is complicated because the facial features become less distinguishable with age (Streissguth et al., 1991, Streissguth, 1993). Some of the typical behavioural features may be most prominent in adolescence because of the complex social demands at this age.

An accurate history of maternal drinking is difficult, and in some cases impossible, to obtain. Mothers of children with FAS often lead disorganised lives and some may be untraceable because they are, for example, at risk of illnesses and trauma which may result in an early death (Viljoen et al., 2002). Many factors, including memory, alcohol drunk from shared containers and feelings of guilt and concerns regarding stigmatisation may cause women to over or under report their alcohol consumption in the index pregnancy. The timeline follow back methodology (Sobell et al in Viljoen et al. 2005) has been used to gather information on maternal drinking in recent South African studies and has shown improved recall of past alcohol consumption over time.

Issues of diagnosis in South Africa

The following issues around diagnosis have particular relevance to research and interventions in South Africa:

- Accurate FASD diagnoses are made by means of highly skilled multi-disciplinary diagnostic teams. Such a team might typically consist of a physician trained in dysmorphology, an educational psychologist, a health therapist and an experienced maternal interviewer with a health science background. These immense human resource requirements can be contrasted with the clinical diagnosis of HIV made by a single clinical nurse practitioner. Diagnostic services for FASD are therefore limited.
- The small skills base of South African health and related personnel who have acquired competence in diagnosis and interventions within the FASD continuum as a result of international collaborative studies may form an important resource for future diagnostic and intervention efforts.
- Currently infants with FAS are identified based on clinical suspicion. For example, growth monitoring and examination for dymorphology are part of the standard clinical assessment of a newborn at infant clinics. Protocols for referral for specialist examination are localised and implemented with variable quality and consistency around the country.
- There are no national protocols for screening and diagnosis of FAS or FASD. Health and education services are best placed to screen for FASD. Visits to community health centres for healthcare for children under 6 years, and attendance at primary schools may be effectively targeted for screening for FASD. Children would then need referral to a multidisciplinary team for diagnosis.

- Errors in diagnosis can have far reaching implications. Under diagnosis leaves those individuals at greater risk of secondary disabilities and the family unsupported. Over diagnosis could result in stigmatisation of individuals and families and failure of appropriate management of the actual underlying condition.

Therefore, despite the typical characteristics and functional problems being well defined, screening for and diagnosing FASD is problematic. This has implications for identification in individuals and for epidemiological research and surveillance. In South Africa specialist skills are both scarce and costly and at present there are no screening tools that would effectively screen for all the FASD conditions. Comparison of the results of research, identification of communities and individuals for interventions, and determination of the effectiveness of prevention and intervention strategies are all hampered by these diagnostic difficulties.

What is the prevalence of FASD in SA?

Most of the prevalence work in South Africa has been undertaken in targeted communities in areas expected to have high rates of FASD. In all the areas where Grade 1 children have been screened for FASD, the rate of positive cases has been higher than reported anywhere else in the world. The areas surveyed are in the Western Cape, Northern Cape and Gauteng provinces and the rates range between 2,7% (FAS only) and 11,9% (FAS and PFAS) of Grade 1 children of those high risk communities.

Soon after the description of FAS in 1973 a case series of 4 newborn babies seen over a 3 month period in the maternity unit at a Cape Town hospital was published. The authors commented “We believe the condition is probably more common than is realized and that minor abnormalities may be easily overlooked” (Beyers and Moosa 1978, p. 575). In 1985 Palmer reported on 14 infants with features of FAS born at the same hospital (Somerset Hospital in Cape Town) over a 1-year period. In that year 1/281 infants born at the hospital had facial and dysmorphology features consistent with PAE (Palmer, 1985) and despite the author’s recommendation it was not until the late 1990s that community level surveys were conducted to determine the prevalence of FAS in high risk communities in the Western Cape.

Population estimates in the United States of America (USA) were that 1% of newborns would fall into the spectrum of fetal alcohol disorders (Sampson et al., 1997). To date there have been no South African population based studies which have reported on the prevalence of the full spectrum of disorders (May et al., 2007). However, in high risk communities in SA the prevalence of FAS is the highest reported in the world (Urban et al., 2008 submitted for publication, May et al., 2000, May et al., 2007, Viljoen and Craig, 2003).

A number prevalence studies of comparable methodology, namely active case ascertainment based on a 2 tier screening methodology and diagnosis by multi-disciplinary and skilled diagnostic teams using the revised IOM 1996 diagnostic criteria, have been conducted in high risk communities in South Africa since 1997. Three of these studies were conducted in the same community in a wine-producing region (Wellington) of the Western Cape Province (WCP) amongst 3 different cohorts of Grade 1 school attendees (May et al., 2000, May et al., 2007, Viljoen et al., 2005). Further studies were conducted in Gauteng (Viljoen and Craig, 2003) and the Northern Cape Province (Urban et al., 2008 submitted for publication). The Dopstop Association also carried out a survey of FAS amongst farm workers in Stellenbosch (Te WaterNaude et al., 2000).

The Wellington studies were conducted in 1997, 1999 and 2002 and measured outcomes of pregnancies from, in general, 6-7 years prior in each case. These are therefore children born around the time of the democratic transition in South Africa. The first study reported a prevalence of FAS of between 40.5-46.4/1000 for Grade 1 children (May et al., 2000), the second a higher rate of 65.2-74.2/1000 (Viljoen et al., 2005) and the third 68.0-89.2/1000 (May et al., 2007). In the case of the third study the prevalence of both FAS and PFAS was determined and reported together which in part explains the higher prevalence. These results may reflect an upwards trend but are probably also influenced by increased diagnostic accuracy. The startling fact is that 9% of children in the primary schools included in the study may have FASD.

Amongst first-graders from 4 schools in Gauteng estimates of median prevalence of FAS ranged from 19/1000 to 26.5/1000 (Viljoen and Craig, 2003). Studies conducted in 2001 and 2002 in De Aar and Upington in the Northern Cape, found an overall prevalence of 67.2/1000 of FAS, and partial FAS of 20.8/1000. The town of De Aar had the highest yet reported prevalence of 119.4/1000 of FAS and partial FAS combined. De Aar is

traditionally a sheep farming area whilst Upington is a wine farming area (Urban et al., 2008 submitted for publication). The high prevalence in Gauteng demonstrated that FASD is not exclusively a problem of wine producing and/ or rural areas in South Africa.

A study in Italy using a comparable methodology reported a prevalence of 3.7-7.4/1000 children for FAS and 20.3 to 40.5/1000 when including FAS, partial FAS and one case of ARND (May et al., 2006), making this the highest reported prevalence of FASD in the developed world. This suggests that prevalence data for the developed world, derived from previous studies with less rigorous diagnostic methodology may have underestimated the problem. Such studies have shown a FAS prevalence of 0.33-2.2/1000 in the USA; an estimated average for the developed world of 0.97/1000 and in high risk American Indian communities in the USA 8/1000 (May et al., 2007).

What are the gaps in prevalence information in South Africa?

There is no national prevalence data on FAS or the continuum of FASD. Given the high rates of FAS in high risk communities, it likely that the rates of the milder diagnoses would be even higher. The magnitude of FASD in SA is essentially unknown.

The studies reviewed show that the prevalence data for FAS and PFAS have been determined in geographically and socio-economically localised areas and in predominantly Coloured communities. Prevalence studies have only been conducted in 3 of the 9 provinces in SA, however there is sufficient information to confirm that SA has a large FASD burden in many high risk areas. It remains unclear what the prevalence of FASD is in the general population and amongst different socio-economic groups and to what extent the diagnoses of ADHD, learning and behavioural difficulties are masking FASD.

Why is it important to diagnose conditions within the spectrum of FASD early?

Screening for and diagnosing FASD as early as possible after one year of age increases the possibilities that a child with FASD will receive appropriate care and stimulation to minimise developmental delays and that the mother will be supported so that she does not have another alcohol affected child.

The earlier identification of FAS/FASD is made the sooner intervention efforts can be implemented. A missed diagnosis conversely has consequences which accrue the longer the diagnosis is missed. There is evidence that an early identification is protective against the secondary disabilities as families can be supported to provide their children with a more stable and nurturing environment. The early diagnosis of FASD and being reared in a stable and supportive environment has been shown to increase the odds of avoiding adverse life outcomes by 2- to 4-fold (Streissguth et al., 2004). Individualised or targeted therapy can be offered to ensure that each infant or child with FASD is able to reach the highest possible level of function within his or her essentially unknown potential. Research based interventions in Wellington have shown that "in spite of cognitive and classroom behavioral difficulties, children with FASD from a vulnerable environment demonstrated significant cognitive improvements following a classroom intervention with a programme that targeted literacy and linguistic skills" (Adnams et al., 2007).

As the mother of a child with FAS is at a high risk of a future AEP, early identification of the index child also enables interventions to be directed towards the mother to reduce the risk of her having further children with FASD. Early identification for an individual may also reduce the economic impact of FASD for example by averting costs of negative behavioural outcomes such as criminality and enabling people to live more productive lives thereby contributing economically both to their families and broader society. However, international experience is that prenatal surveillance for alcohol use is poor. This is in part because prenatal care providers underestimate the number of women with alcohol problems that they see, and fail to use the screening tools which not only are available but have been evaluated and shown to improve the identification and management of women using alcohol during pregnancy (Burd, 2006).

Despite the evidence in favour of early diagnosis, active case ascertainment in the absence of support for families and educational assistance for children with FASD places families and children at risk of stigmatization and may do more harm than good.

Surveillance

The systematic collection of data on FASD could be used to better understand and monitor the prevalence of FASD in South Africa and the impact of prevention efforts, but is not currently being done.

The World Health Organisation (WHO) defines surveillance as “the process of systematic collection, collation and analysis of data with prompt dissemination to those who need to know for relevant action to be taken” (World Health Organisation, 2001, WHO, 2005). This section therefore discusses the surveillance of FAS or FASD at a community or population level in order to describe the FASD burden and trends in FASD prevalence that may help to guide and determine the impact of interventions. Determining the overall FASD burden aids in the allocation of resources for FASD prevention and intervention efforts. There is however no national surveillance system of FASDs and this has been identified as a significant gap area by our informants.

Preliminary findings of local research still in progress has suggested that the screening of women at risk of an AEP is a useful and less costly proxy for screening for FASD than screening for FAS directly. It may thus provide sufficiently accurate and reliable information for surveillance purposes (Rendall-Mkosi et al 2007).

Local research has also explored various biomarkers that may be measured as part of potential screening methods for FAS or for use in surveillance (Jacobson et al., 2008, Bearer et al., 2003). A specific approach, stereo-photogrammetry, involves photographing children and taking measurements from the photographs in order to determine whether they have facial features for FAS (Douglas and Viljoen, 2006, Douglas et al., 2003a, Douglas et al., 2003b, Meintjes et al., 2002). Further work is needed to identify whether this method could provide a suitable and affordable screening format for national surveillance. The surveillance would operate similar to the annual antenatal HIV seroprevalence survey, but through school based sampling as opposed to antenatal clinics (ANCs). Fatty acid ethyl esters which are metabolic products of alcohol and are deposited in the bowel contents of the fetus have been shown to be valid indicators of maternal alcohol use in pregnancy (Bearer et al., 2003). The measurement of these products among new born babies may serve as part of a maternity services and hospital-based surveillance method.

A national hospital-based birth defects surveillance system has been established in SA in line with the National Department of Health (DoH) policy. However, the group of defects included were limited to those that could be clinically diagnsosed at birth or during the period of hospitalisation after birth thus FAS is not included (R Sayed 2008, pers. comm., 7 March).

What are the cost implications of FASD to individuals and society?

In the absence of the knowledge of the true prevalence of all of the FASD conditions it is difficult to determine the economic and other costs of FASD to individuals and society in SA.

In terms of the economic burden, studies exploring the financial costs of FASD have not been published in South Africa to date. Some studies from the USA have estimated total cost due to FAS as ranging from $75 million dollars (Abel and Sokol, 1991) to $9.69 billion dollars (Harwood and Napolitano, 1985) per annum. The relevance of the actual numbers to South Africa is limited because of a substantially higher prevalence of FAS in SA, different health care and social services costs and other factors. It may be more useful to determine estimates of lifetime costs for a single individual than total economic costs as the former method enables assessment of the benefits of prevention policies as the cost saving per case for a particular policy can be determined (Bloss, 1994).

A recent Canadian study explored medical, educational, social services, and patient and family direct costs, as well as productivity losses and the cost of externalising behaviours (such as acts of violence) related to FASD as opposed to FAS alone. The adjusted annual cost per FASD child was over 14 000 Canadian dollars and 19% of the costs were paid by parents caring for FASD children (Stade et al., 2006).

The SA burden of disease estimates of 2000 give an indication of the impact of FAS. FAS was the fourth largest contributor (and totalled 5.5%) in the list of alcohol-attributable Disability Adjusted Life Years (DALYs) for persons, ranking behind interpersonal violence (39%), alcohol dependence use disorders (14.7%) and road traffic injuries (14.3%). No adjustment was made for deaths due to FAS and a prevalence of 14 per 1000 at birth for the general population was used (Schneider et al., 2007). Notably, the rates used in this study are lower than those reported for the Western and Northern Cape and even urban Gauteng. Furthermore, the ICD 10 coding only makes provision for a diagnosis of FAS and not of the continuum of disorders in FASD and as yet there are no estimates for the prevalence of FASD. This study is therefore likely to underestimate the burden of disease from FASD considerably.

Chapter 3 Context of Alcohol and Contraceptive Use

What are the maternal risk factors as far as we know?

Women who are most at risk of having a baby with FASD are those with a cluster of characteristics and behaviours including: older; low socio-economic status; unmarried; low education level; high number of pregnancies; heavy alcohol consumption and binge drinking; and having a partner who drinks heavily.
Factors that seem to protect women include: being more religious; higher educational level; having a better nutritional status before and during pregnancy; and fewer pregnancies.

Only a woman who drinks alcohol when pregnant places her fetus at risk of exposure to alcohol and possible FASD. The prevalence of alcohol use in pregnancy varies substantially. In a Canadian survey 13% of pregnant women had drunk alcohol in the previous week (Dell and Roberts, 2005), whilst 52% of antenatal clinic attendees in Moscow reported alcohol use in the previous month and 85% had drunk alcohol at some time during their current pregnancy (Chambers et al., 2006). In a survey of pregnant women attending antenatal clinics in three areas within the WCP (George/Oudshoorn, Vredenberg/Saldanha and the Cape Metropole), 42.8% reported drinking alcohol during pregnancy. A quarter of the sample were found to drink in a binge pattern and almost a third used both alcohol and tobacco whilst pregnant (Croxford and Viljoen, 1999). A farm based survey in Stellenbosh reported that 41.6% of mothers drank alcohol in pregnancy (Te WaterNaude et al., 2000).

However, a pregnant woman's use of alcohol needs to be understood and addressed within the context of a complex array of inter-related demographic, social, economic, psychological, and biological factors. These factors not only influence women's choice to drink in pregnancy but also appear to increase or decrease the damage to the fetus for a given amount of alcohol exposure.

The necessary condition for FASD is a high maternal BAC, typically achieved by binge drinking[1] (Chudley et al., 2005). The risk factors for an AEP and/or having had a child with FASD have been fairly consistently identified by international and local studies and are

[1] Various definitions of binge drinking are noted in the literature and they range from 3 standard drinks and upwards per drinking occasion.

represented in Figure 1. As shown in Figure 1, the risk factors for drinking in pregnancy do not invariably equate to the risk factors for the birth of a child with FAS, for example whilst adolescents and younger women may be more likely to drink in pregnancy (Chambers et al., 2005), older women who drink heavily in pregnancy are more likely to give birth to a child with FAS (Kvigne et al., 2003). Similarly, in a study conducted in South Africa among children with ARND, those born to older mothers had a lower IQ compared to those born to younger mothers for the same level of alcohol consumption (Jacobson et al., 2004).

Risk factor analyses have used different outcomes such as comparing mothers who have children with FAS with those who do not or comparing women who drink in pregnancy with those who do not. Although numerous risk factors have been identified in bivariate analyses, the lack of large-scale studies of risk factors and the clustering of risk factors make it difficult to provide accurate figures for relative risks (Chudley et al., 2005) for those various maternal risk factors. There appears to be an overall lack of risk factor studies which have used statistical techniques to tease out the clustering of risk factors.

Maternal risk factors for FAS in South Africa have been identified largely by two case control studies which compared the characteristics of mothers of children with FAS with those of mothers of children without FAS in the Wellington area (Viljoen et al., 2002, May et al., 2005). Most of the studies' findings concurred with those of international research.

Mothers of children with FASD were more likely than control mothers to have lived in a rural area at the time of the index pregnancy (OR 7.6 $p<0.001$), to be employed on farms as their usual occupation (35% vs 12%), to have had significantly fewer years of schooling (5 years vs 8.7 years, $p<0.001$), to have had lower incomes when working, and to be single (May et al., 2005). The reproductive variables were consistent with international findings describing a pattern where mothers of FAS children usually have two or three children before the birth of the index child. In this study maternal age was not significantly different for the two groups, prompting the authors to consider other cofactors such as nutrition, body size and general SES to explain why relatively younger mothers in this community also had children with FAS (May et al., 2005).

Regarding drinking patterns, case mothers had drunk alcohol for longer and were more likely to be current drinkers (OR 8.14). Of the case mothers who were current drinkers,

96% engaged in binge drinking[2] and 90% of their drinking was on weekends. Whilst control mothers who drank during pregnancy were more likely to cease drinking during pregnancy, 90% of case mothers drank at least as much during the index pregnancy as their current levels. Almost three quarters of case mothers reported both smoking and drinking during pregnancy compared to 11% of control mothers (May et al., 2005).

The case mothers were surrounded by heavy drinking family and friends and a number of features of case mothers suggested an intergenerational presentation of FASD – that these mothers of FAS children may themselves have unrecognised FASD. Features such as lower education levels, smaller stature (May et al., 2005) and feelings of stress during the index pregnancy which were seen as the cause for heavy drinking in pregnancy (Viljoen et al., 2002, May et al., 2000) would support this hypothesis. Maternal factors which were associated with not having a child with FAS were higher SES, greater religiosity, higher education, being married and having had fewer pregnancies and fewer children.

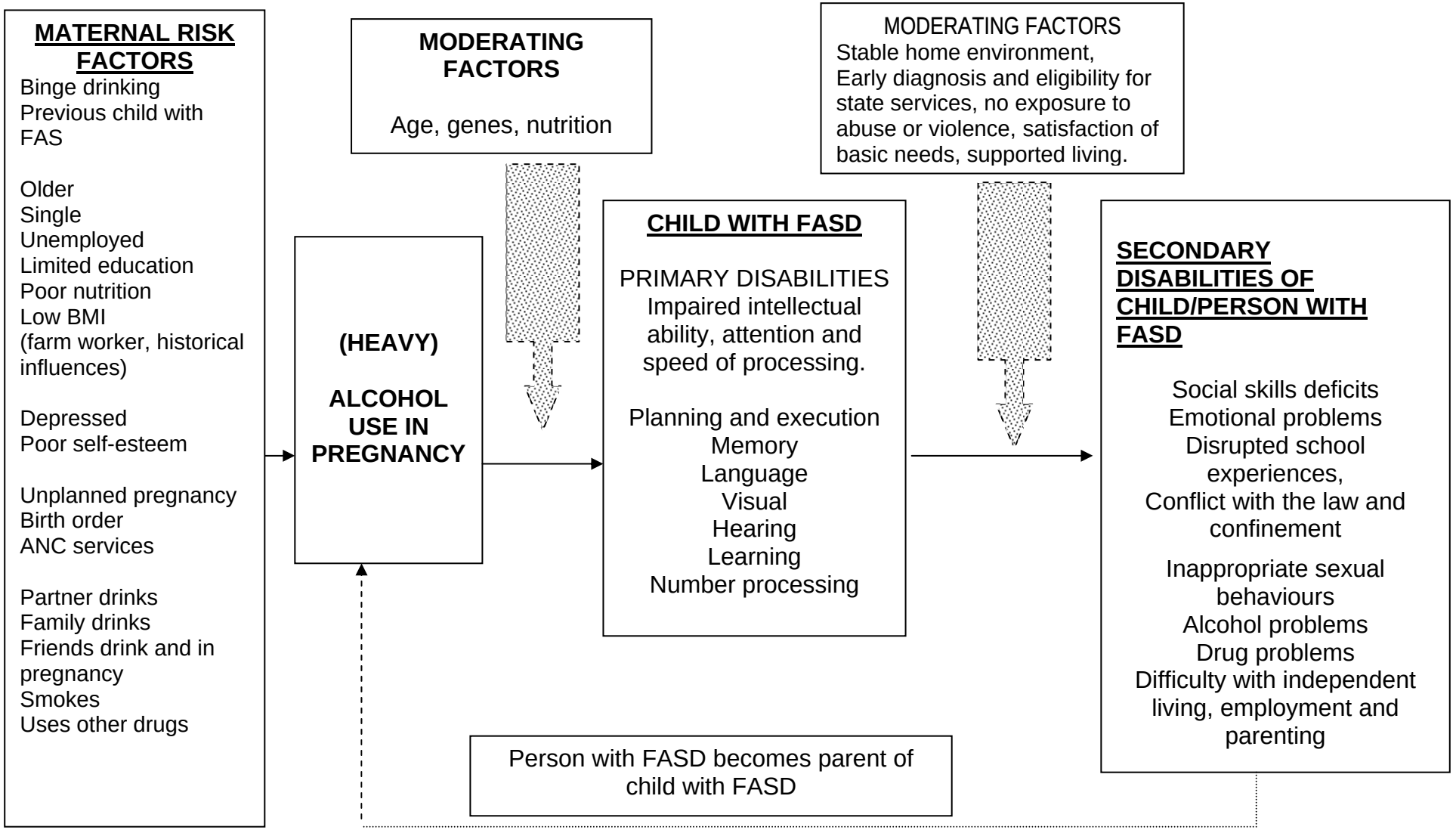
There is ongoing work exploring the genetic risk factors for FAS. Emerging evidence suggests that some genes found in mothers, and others found in mothers and/or their children, may be protective by influencing alcohol metabolism and by being associated with lower BAC levels for the same amount of alcohol consumed in individuals who have the genes compared to those who do (Viljoen et al., 2001, Jacobson et al., 2006).

Further research in a South African farming region pointed to a possible interaction between smoking and alcohol use in pregnancy, and low birth weight. In adjusted analysis maternal smoking and not alcohol use predicted low birth weight (OR 2.67 95% CI 1.69-4.20) but when the effect of smoking and alcohol were considered together the risk of having had a low birth weight baby was increased (OR 4.24 95% CI 1.01-17.76) (Jackson et al., 2007). Similar interactions may occur with environmental exposures (e.g. lead or pesticides) or specific nutritional deficits (e.g. thiamine and iron deficiency) and need to be further explored (May et al., 2004, Mancinelli et al., 2007b).

All these issues and factors are summarised in Figure 1 below, which is adapted from a similar conceptual framework developed by Morojele et al, 2006.

[2] In this study this was 3 or more drinks on 1 or more days in the past week.

Fig 1. Conceptual framework of maternal risk factors and outcomes



Women and alcohol use in South Africa: patterns of use and social context

Since women of all classes in South Africa drink, and the rates are on the increase, it is likely that more women in the future will be at risk of an AEP. Factors such as earlier risk taking behaviour, marketing of alcohol to young women, and the reduction in traditional cultural influences, are promoting the use and abuse of alcohol by more women.

In SA the proportion of adults in the general population who consume any alcohol is lower than that of most developed countries. The patterns of alcohol consumption among women vary in different communities. The South African Demographic and Health Survey (SADHS) conducted in 1998 estimated that 45% of men and only 17% of women 15 years and older were current drinkers[3] (Parry et al., 2005). However, overall a third of women (and men) who drank, did so at risky levels[4] on weekends and 10% of women who drank screened positive for alcohol problems[5]. Among women of reproductive age 9.1% reported risky weekend drinking, however, amongst women risky drinking was highest in the 45-54 year age group. Risky drinking was also highest among women residing in rural areas, those with a low level of education, and coloured and African women. The important implications for FASD efforts are that whilst many women abstain from alcohol, a high proportion of those who do drink do so at levels which pose a risk to their own health.

At the same time treatment facilities for alcohol dependent women tend to be concentrated in urban areas and most are unaffordable and inaccessible for the women who need them most (Myers and Parry, 2005).

International trends show increased female drinking, lowering of the age of first alcohol consumption for women and that the rate of at-risk drinking amongst female teenagers is similar to that of males. In general women show a more rapid progression to risky drinking than men (Mancinelli et al., 2007a, Mancinelli et al., 2007b). In developing countries there has also been an increase in alcohol use among women (Jernigan, 2002). As a rule, per capita alcohol consumption increases as economic development occurs (Jernigan, 2002) and a steady increase in per capita alcohol consumption in South Africa was seen during the last quarter of the 20th century (Jernigan, 2002).

[3] Current drinking was defined as having drunk alcohol at least once in the 30 days preceding the interview.
[4] Risky drinking was defined as 3 or more standard drinks per day for women and 5 or more per day for men.
[5] This was based on responses to the CAGE questionnaire which is a screening test for alcohol problems.

Traditionally, alcohol consumption was prohibited for women of child-bearing age and for adolescents and youth. Changes in the role of women, industrialisation, urbanisation, the availability of higher concentration commercial alcohol (in particularly commercial beer) and emulation of perceived "western" drinking styles have been seen to contribute to an increase in drinking in general and amongst the youth and women in particular in developing countries (Jernigan, 2002); SA is no exception. In addition, alcohol advertisements seem to be increasingly targeting women and beverages (ciders and wine coolers) specifically for consumption by women have been introduced into the market.

In both urban and rural areas alcohol is easily accessible and fairly affordable (NAMC, 2002) and shebeens and taverns are plentiful (Parry, 2005b). Minimum drinking age restrictions are not enforced and a qualitative study in Gauteng noted that some women in drinking venues appeared less than 18 years old. In the same study it was noted that women who drank on a regular or daily basis attributed their drinking to their economic, social and psychological problems (Morojele et al., 2006).

Of further concern is that women in the 20-40 year age group have less activity of the enzyme which breaks down alcohol in the stomach than women of the 41-60 year age group. The consequence is that, all else being equal, a higher BAC is reached for the same amount of alcohol consumed when women are most fertile (Mancinelli et al., 2007a).

The results of the 2003/2004 SADHS are expected to be released shortly and will be helpful in accurately showing general trends of alcohol consumption amongst women in South Africa. It would seem though that findings point towards a general increase in the proportion of women who drink and in the proportion of drinking women who drink at risky levels. An increase in the proportion of adolescents using alcohol has been reported (Parry et al., 2004), and as these cohorts of adolescents age, so the proportion of women who drink is likely to increase. Studies point towards an increase in current drinking and in life-time drinking among young, black African women (Parry, 2005a). The uptake of alcohol at an earlier age by women in SA is likely to result in many more women being at risk of an AEP.

Historical and current influences on alcohol use

The dop system was used for a few centuries in the farming industry in the Cape, and beerhalls were built at the mines and in townships. This promotion of alcohol use has influenced the drinking patterns of South Africans.
Currently the commercial liquor industry strongly promotes drinking through advertising, easy accessibility and relatively low prices. They are also involved in initiatives to promote responsible drinking.

Investigation into the historical influences which have shaped drinking patterns and caused the high rates of FAS and other negative impacts of alcohol use in high risk communities in SA have largely focussed on the dop (or tot) system (McKinstry, 2005, Parry and Bennets, 1998, London, 1999, London, 2000, Te WaterNaude et al., 1998). The dop system involved the part payment of farm workers in wine (Scully, 1992) and evolved into a system of institutionalised alcohol use and social control that was probably unique to SA (London, 1999, London et al., 1998b) and undeniably contributed to the high prevalence of FAS described amongst farm workers in the WCP (May et al., 2005).

The dop system commenced in the late 1600s in the Cape when, in order to secure labour on farms, indigenous populations were induced to work on farms with payment in alcohol, tobacco and bread. The system became entrenched during the 18th century - the time of slaveholding – when poor quality wine was given, as a condition of service, at regular intervals during the working day and on weekends to farm workers and working children as young as 12 years (Scully, 1992). Wine was cheaper than wages and over time the dop system became a profitable mechanism for disposing of poor quality wine (London, 2000). As a consequence generations of predominantly Coloured farm workers have become enmeshed in cycles of poverty and heavy alcohol use (London et al., 1998b, London, 1999). It is argued that heavy drinking, and in particular heavy drinking on weekends, is ritualised and provides a cultural space for farm workers where they experience temporary relief from their desperate circumstances (De Kock, 2002, London, 1999). The prevalence of drinking and potential problem drinking is extremely high for both male (London, 2000, London et al., 1997, Te WaterNaude et al., 2000) and female farm workers (McLoughlin, 2007), the latter with direct implications for AEPs and FAS .

Experience of the dop system by farm workers has been linked to numerous negative health outcomes including greater poverty, growth faltering (London et al., 1998b),

pesticide poisonings (London et al., 1998a) and FAS (May et al., 2007). However the impact of the dop system should be seen in the context of other coercive and paternalistic labour practices and means of social control (such as apartheid) which together shaped drinking patterns amongst farm workers (London, 1999, De Kock, 2002, du Toit, 1992, London, 2000) and South Africans in general and resulted in racially aligned alcohol consumption patterns and preferences (McLoughlin, 2007, Mager, 2004).

The dop system was dynamic (Scully, 1992) and though challenged and outlawed by at least 2 statutes permutations of its practice[6] persisted in the 1990s. At this time public health practitioners played a key role in exposing it and initiating and supporting efforts to end it (London et al., 1998b, Te WaterNaude et al., 1998, London, 1999) in all its forms.

It is erroneous to only associate the dop system with wine farms and wine-growing regions of the Western Cape. The system was widely used in the deciduous fruit industry for example (London et al., 1997), and in agriculture in other provinces. This is extremely pertinent to future FASD surveillance and intervention efforts as there are likely many high FASD prevalence areas which have been subject to similar social, cultural and economic forces as the wine-growing areas of the WCP. The finding of a high FAS and FASD prevalence in the Northern Cape supports this assertion (Viljoen and Craig, 2003).

The dop system depended on the availability of large volumes of cheap wine. In the wake of the dop system there is evidence that poor quality wine sold in inferior packaging such as “papsakke” by legitimate retailers to farm workers has continued to fuel drinking patterns and alcohol-related problems amongst farm workers and in particular, female farm workers (McLoughlin, 2007). New packaging regulations which were gazetted in 2007 have outlawed papsakke. The effects of this recommended policy change (Parry, 2005b) remain to be seen. Whilst beer is the overall preferred drink, papsak wine has been sold widely and in massive volumes throughout the country (NAMC, 2002) and would have been a source of cheap, high alcohol concentration (compared to beer) alcohol for poorer women in general.

Alcohol played a central role in other aspects of labour and social control in South African history (Mager, 2004, Parry and Bennets, 1998) . For example, alcohol was used to

[6] For example some farmers supplied workers with alcohol on Fridays at the end of the working week, whilst technically not considered payment it remained an expectation of employment.

secure labour on gold mines after the discovery of gold in 1886. Here the dilemma of its negative impact on safety and production and a general prohibition of the possession of alcohol by Africans was solved by mine owners being legally permitted to brew and then distribute beer on mine premises. Beer was given at the end of a shift to be consumed on the mine premises, however, its consumption was illegal off mine premises thus theoretically ensuring that workers not only returned to work but also returned sober (Ambler and Crush, 1992).

Government controlled beerhalls and illegal shebeens were central to social networks and featured strongly as means of both control and resistance in both pre-apartheid and apartheid South Africa (Ambler and Crush, 1992). For women, the brewing of and trade in alcohol was an important source of income and conferred social importance. This role was not only a traditional one, it adapted to the social forces of the 1900s and Ambler and Crush argue that the "women who made and sold beer and those who patronized beerhalls and shebeens were engaged in the redefinition of gender" (Ambler and Crush, 1992)31).

Currently the commercial liquor industry strongly promotes drinking through advertising, easy accessibility and relatively low prices. They are involved in initiatives to promote responsible drinking (Parry and Bennets, 1998).

What contraceptive use barriers exist?

The effective use of contraceptives can prevent an alcohol-exposed pregnancy in women who drink alcohol, but many women do not plan their pregnancies for a variety of structural, cultural, social and cognitive reasons.

Women in the reproductive age group who are heavy drinkers but who are reliably using effective contraception are not at risk of an alcohol-exposed pregnancy. It follows that access to and the correct use of modern contraceptives are crucial considerations in FASD prevention.

Household surveys have shown that South African women in the reproductive age group (15-49 years) have good knowledge about modern contraceptives: 97% of women in 1998 and 94% in 2003 knew of contraceptive methods (SADHS, 1998, SADHS, 2003).

Amongst sexually active women,[7] 61% in 1998 and 65% in 2003 were using modern contraceptives. Most women (84%) obtained their contraceptives from the public sector (SADHS, 1998) and the largest group (33%) were current users of injectable methods, making up just over 50% of the 65.2% of women who were current users of any modern method of contraception (SADHS, 2003). Adolescent pregnancies remain common in South Africa despite a decline since the late 1980s. However, 35% of women still experience pregnancy before the age of 20 (Wood and Jewkes, 2006)

Barriers to contraceptive use amongst adult women can be viewed under the following headings, although there are areas of overlap:

Service Infrastructure

In general in South Africa there is reasonable access to points of delivery offering family planning services. However, distances to services create a barrier to accessing contraceptives which is reflected in part by the fact that amongst sexually active women 67% in urban areas compared to 54% of women in rural areas used modern contraceptive methods in 1998 (SADHS, 1998). Traditional norms regarding use may also explain the lower levels of contraceptive use in rural areas. In 1998 the lower use of contraceptives in the rural areas persisted when adjusted for social, demographic and economic risk factors (Burgard, 2004). In 2003 this difference appeared less, 63% rural and 66% urban.

Staff communication styles have also been shown to constitute a barrier and approximately 20% of women reported that staff in public sector facilities either shouted at or scolded them, and did not explain the use of contraceptives enough to meet the needs of their clients, or were unfriendly (SADHS, 1998). Adolescents described some nurses as being rude, short-tempered and arrogant with clients. Clients were scolded for many things, all of which led to erratic use, or the abandoning of use of contraceptives (Wood and Jewkes, 2006).

Historically, family planning services were viewed with suspicion as a result of apartheid policies to restrict population growth especially amongst black South Africans (Kaufman, 1998, Burgard, 2004). However, at the same time there was a high uptake of injectable contraceptives amongst black women as their use was heavily promoted and funded.

[7] Sexually active in the 4 weeks preceding the survey

Fewer years of formal schooling is linked to a lower prevalence of contraception use (SADHS, 1998, SADHS, 2003) with a steady and dramatic increase when a higher education level is attained; 38% of women with no formal education used contraceptives compared to 75% of women with a tertiary education.

Cultural and Social Factors

Notions and the meanings around fertility may influence women not to use contraceptives. Both the choice to use contraceptives and the type used may be influenced by male partners (Stephenson et al., 2007) and by family members. Among adolescents in Limpopo Province pressure from male partners and family members to have a baby and to pre-maritally prove their fertility were described (Wood and Jewkes, 2006). Adolescents have also described nurses as stigmatising and being judgmental of adolescent sex (Wood and Jewkes, 2006, Ehlers, 2003), which possibly reflects the cultural influences on nurses' values and behaviour.

Cognitive Factors

Negative beliefs about contraceptive use, for example, that it may lead to permanent infertility and that the amenorrhoea associated with injectable contraceptives is unhealthy have been identified. Fears relating to the side-effects of contraceptives which are essentially based on a lack of knowledge about them are not sensitively addressed by nurses (Wood and Jewkes, 2006).

Knowledge of emergency contraception and termination of pregnancy (TOP) options are important in avoiding an alcohol-exposed pregnancy. A survey of adolescents showed that only 21% knew of emergency contraception and whilst 46% knew about legally available TOP services, 78% did not wish to make use of them (Ehlers, 2003).

Women with FASD may lack the social skills and judgement to use contraceptives effectively and to negotiate condom use. These barriers would be compounded when they are using alcohol in a risky or hazardous manner. The psychoactive effect of alcohol reduces effective contraceptive use, and alcohol consumption and sexual risk behaviour have been shown to be correlated in a qualitative study (Morojele et al., 2006). It is therefore those women who are less likely to plan their pregnancies who are more likely to use alcohol to the extent that they will find it difficult to give up drinking during pregnancy,

and are more likely to confirm their pregnancy late, having caused harm to the fetus unknowingly.

What is the overlap with risk of HIV for women at high risk of having a FAS child?

A woman at risk for having a FASD child is also at risk of HIV infection due to similar risk behaviours, and contextual factors.
A child, adolescent or adult with FASD is more at risk than others in his or her community for HIV infection due to poor social skills and relationships and vulnerability to abuse.

We were not able to locate any research which directly explored an overlap of risk between HIV and FASD. However, research has shown that adherence to taking antiretroviral therapy for AIDS is negatively associated with alcohol use (Parsons et al., 2007). An overlap of risk is likely to occur at a number of levels. This would be relevant given the magnitude of both the HIV and FAS epidemics in South Africa and particularly for the Western Cape which has a very high seroprevalence in some districts despite the provincial average being low relative to the national average (Shaikh et al., 2006). Three broad areas of overlap are considered in turn.

Risk of HIV for women at high risk of having a FAS child

There are similarities in the socio-economic and demographic profile of women at high risk of HIV and those at high risk of giving birth to a child with FAS. Women at risk of an AEP are of reproductive age, sexually active, not using effective contraception (or using effective methods sub-optimally) and current drinkers. Women at high risk of HIV transmission are of reproductive age, sexually active and not using barrier contraceptives effectively. Additional areas of socio-economic similarities exist.

Risk of infant born with both HIV infection and FAS (FASD)

From the perspective of the fetus the potential for both prenatal alcohol and HIV exposure exists and both HIV and FAS present diagnostic challenges at birth. There is no data available on the risk of FAS in infants and young children with HIV and vice versa.

These areas of overlap present research questions but also may provide a useful entry point for FASD prevention efforts. For example, the PMTCT counselling process may be extended to screen for alcohol use in pregnancy and be a point where brief interventions

(BI) could be offered. Since there are time and attitudinal barriers on the part of some nurses to counselling pregnant women who use alcohol, lay counsellors may be more effective in ANCs (Tversky, 2001).

Vulnerability of adolescents and adults with FASD to HIV infection

Adolescents and adults with FASD may be more vulnerable to HIV infection as a result of their intellectual impairments (such as impaired judgement) and behavioural profile. For example, women with intellectual impairment are more at risk for sexual abuse and dysfunctional relationships. The implications extend to people who are both HIV positive and who have FASD potentially being at greater risk of transmitting HIV as a result of their neurocognitive and behavioural profile – the combination of a lack of knowledge, impulsivity and poor judgement leading to high risk sexual encounters.

In a study which found a link between casual sex and heavy drinking it was found that women engaging in high risk sexual behaviour gave similar justifications for their alcohol use, namely, exposure to abusive and dysfunctional families (Morojele et al., 2006), as women in the maternal risk factors for FAS studies (Viljoen et al., 2002, May et al., 2005). Unidentified FASD may be a common denominator amongst some of these women.

Chapter 4 Prevention of FASD through the prevention of AEP

"… the term 'Foetal Alcohol Syndrome' actually identifies two patients. The 'foetal alcohol' part of the term is relevant to aetiology and is important in recognising that the birth mother is a patient who is highly vulnerable to produce more affected children and to be judged as a poor caretaker of her current children. The diagnosis should direct us to her so that we can support her in her attempts at sobriety for her sake, and for the sake of her children and her unborn children. The 'syndrome' part of the FAS term is relevant to the child who is likely to have complex cognitive and behavioural problems requiring the help of an appropriate team made up largely of educational and mental health professionals". (Clarren and Astley, 1997, p.50)

This chapter considers the complexity of preventing FASD from occurring through reducing alcohol use by childbearing age women and improving family planning.

Co-ordination structures and policies are reviewed first, and then strategies related to the monitoring and interventions with high risk women are discussed. Background information is provided for each sub-section, mainly based on literature from the USA, and then the current scenario in South Africa is described and possible gaps in knowledge and service provision are identified. Very little information was found in the SA literature, so information from key informants, web sites, and grey literature was relied on.

Co-ordination Structures

In the United States of America the Centers for Disease Control and Prevention (CDC) has a National Centre on Birth Defects and Developmental Disabilities which in turn has a Fetal Alcohol Syndrome Prevention Team. The goal of this team is to prevent FAS and other prenatal alcohol-related disorders, and to ameliorate these conditions in children already affected by them (Ceperich et al., 2007). The key strategies include: surveillance systems; epidemiological studies; and prevention programs on all levels. These strategies are divided into six main programmes:

1. Estimate prevalence of FAS
2. Monitor alcohol use in childbearing age women
3. Identify women at risk for an AEP
4. Implement strategies to prevent AEPs in high prevalence settings
5. Create and disseminate public and provider education materials
6. Intervene with individuals living with FASDs and their families (Ceperich et al., 2007).

The CDC was instrumental in the establishment of a National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effects in the USA 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 FAS; to co-ordinate efforts through the Department of Health and Human Services; and to report to the relevant committees of the Congress on a biennial basis (MMWR, 2002).

In South Africa, the Department of Health (DoH) has established a National FAS Task Team with representation from divisions in the DoH, and researchers working on FAS issues. The National Task Team meets about three times a year, and is planning to include other sectors of government in the future. Some provinces – notably the WC and Northern Cape, where there is a reported high prevalence of FAS - have also established multi-sectoral FAS Task Teams to tackle the problem.

According to a report written in 2004 (Rossouw, 2004), a workshop initiated by the Maternal, Child and Women's Health Sub-directorate (MCWH) in 2001 led to the establishment of a Western Cape FAS Task Team. The programme was initiated under the auspices of the Task Team and had the following objectives:

1. To develop policies and implementation plans that would guide regions in FAS awareness and management programmes
2. To conduct baseline surveys on awareness and implementation
3. To monitor and evaluate the impact of the implementation plan

Some of the activities subsequently carried out included the training of trainers in FAS based on a training manual that was produced by the WC DoH. Various research projects (outlined in Chapter 6 of this report) were also noted in this 2004 report, implying that the researchers were consulting with the Task Team regarding their projects.

Regional FAS co-ordinators were supported by the Deputy Director: Health MCWH, and used conditional grant funds to initiate various awareness raising, parent support and teacher training activities throughout the province. Psychologists and occupational therapists were involved in the training programmes and follow-up of children with special needs, and toy libraries were established in various towns. There was collaboration

between NGOs and government departments in some areas. However, no written reports on the progress of these initiatives could be identified. A few key informants stated that since the Deputy Director left her post about 2 years ago, much less attention has been paid to the needs of families with FASD. Some NGOs are now taking the lead in the co-ordination of activities.

According to a key informant, in the Northern Cape, the Task Team met for the first time in late 2006 and has received inputs from all the sectors, except Health, to date. The Task Team includes representation from the Foundation for Alcohol Related Research (FARR) and its main objective is to develop guidelines for FAS in respect of the prevention of FAS; services for children with FAS, and support for families. Some concern was voiced by some of our key informants that the FAS Task Teams lacked political support and that representatives were not senior enough to take decisions that would make a difference.

Policies related to the prevention of FASD

A range of policy documents were scanned for use of the terms FAS and FASD to assess if these terms were specifically used. The documents scanned included: Constitution for South Africa; Prevention & Treatment of Drug Dependency Act; SA Social Security Act; Children's Act 38 of 2005, National Programme of Action for Children; Human Genetics Policy Guidelines for the Management & Prevention of Genetic Disorders, Birth Defects & Disabilities; WCED Draft Drug Abuse Policy (Directorate Specialized Education Support Service); National Guidelines for the Management & Prevention of Drug Use & Abuse in all Public Schools and Further Education and Training Institutions; National Drug Master Plan 2006-2011; Guidelines for Maternity Care in SA; Education White Paper 5 on Early Childhood Development; and Education White Paper 6 on Inclusive Education.

Only two of the documents scanned contained the term FAS, namely, The National Human Genetics Policy Guidelines for the Management & Prevention of Genetic Disorders, Birth Defects & Disabilities (Department of Health, 2001) and the National Drug Master Plan (Deparment of Social Development, 2007) whilst one made specific reference to women and alcohol, namely, the Guidelines for Maternity Care in South Africa (Department of Health, 2002). The latter document notes that use of maternal alcohol, tobacco and other substances should be explored in the history taking.

The Prevention and Treatment of Drug Dependency Act (No. 20 of 1992) provides for the establishment of the Central Drug Authority (CDA). A major function of the CDA is to develop the National Drug Master Plan (NDMP) as a national strategy for managing the demand for and supply of illegal drugs in the country, and for facilitating an integrated approach to service delivery and the coordination of programmes on the management of the drug problem in all spheres of government and civil society. The administration of the Act is entrusted to the Department of Social Development, which is the lead Department in the fight against substance abuse and provides the secretariat to the CDA. National and provincial departments draw up operational plans (mini-drug master plans) which must be submitted to the CDA at the beginning of each financial year. The CDA continuously monitors the implementation of these plans and facilitates coordination and service integration. The NDMP reflects the country's response to the substance abuse problem as set out by the United Nations Conventions and other international bodies. It outlines the role that each department should play in fighting drug abuse. The NDMP has identified 9 national priority areas, one of which is Community Health and is the core competency of the DoH. Substance abuse among women in their reproductive years is mentioned as a special area of concern along with other national issues, namely, teenage pregnancy, FAS, multi drug resistant tuberculosis and sexually transmitted infections including HIV and AIDS (Deparment of Social Development, 2007).

The Human Genetics Policy Guidelines for the Management and Prevention of Genetic Disorders and Birth Defects (Department of Health, 2001), compiled and distributed by the DoH, also identifies FAS as one of the national priority conditions in the context of avoidable birth defects. The guidelines list the following three key interventions for FAS:

- *Educate all women regarding the deleterious effects of alcohol on the fetus*
- *Educate all women to avoid alcohol throughout pregnancy*
- *Offer early detection of FAS, with appropriate referral of affected individuals and their parents for counseling and care* (Department of Health, 2001).

Interventions for the Prevention of FASD

FASD is an entirely preventable range of conditions. Interventions to prevent FASD need to be at an individual, family and community level.

Women can avoid having a child with FASD by adopting one of two general approaches - engaging in abstinence from alcohol use before and during pregnancy and secondly,

preventing pregnancy by engaging in effective contraception or abstinence (Ingersoll et al., 2003). In reality, the success of interventions based on these two mainstays of prevention may be hampered by a number of factors such as a lack of knowledge about the effects of consuming alcohol during pregnancy or an inability to change behaviour even when such awareness is present, especially in high risk populations. Poor access to contraceptive services and poor uptake of these services when they are easily available are contributing factors to women's non-use of contraceptives. It is important to acknowledge the importance of contraceptive use among women of child bearing age as not all women realize that they are pregnant within the first few weeks post conception, and many continue to drink into their first trimester and sometimes even further into the pregnancy, unaware that they are pregnant.

The prevention approach to prenatal exposure to alcohol advocated by the US Department of Health and Human Services (US Department of Health and Human Services, 2000) provides a useful framework. Three levels of interventions are described: Universal – broad, population wide, such as media campaigns aimed at all women of childbearing age regardless of risk; Selective – aimed at women known to be at some increased risk because they are drinking while pregnant or belong to a vulnerable group; Indicated – women who are at highest risk - drinking heavily or have had a FAS child before. The most effective treatment approaches for the women who fall within the 'selected' or 'indicated ' groups include comprehensive social, cognitive-behavioural, medical and referral services. The co-ordination of the services through active case management is considered essential. It concludes by indicating, that establishing the baseline of FAS in a community, and the identification of the high risk women is an essential first step. Thereafter the effectiveness of different prevention approaches must be determined through carefully controlled evaluation studies.

A similar approach for addressing FASD is based on primary, secondary and tertiary interventions proposed by May, in which he suggests that a variety of drinking patterns need to be addressed, through a multiple-level, comprehensive programme (May, 1995). Such a programme should be based on epidemiological studies of social and individual risk factors of women's drinking patterns, FAS literature, and women's health programmes more generally. Recognising that the most profound and permanent changes in behaviour occur as a result of the influence of primary social groups, such as the family and peer groups, it is evident that prevention programmes must be broad

enough to alter the norms of these groups, as well as their access to alcohol. Primary prevention is applied to all members of the population, while secondary and tertiary level preventions are reserved for those women who are heavier drinkers and at greater risk of producing children with FASD. It is also suggested that a comprehensive, community – wide prevention trial would be a suitable research approach to developing prevention approaches (May, 1996).

There is a strong move to expand the range of settings in which women can receive counseling and support for alcohol problems. In the past, in-patient specialised treatment for alcohol dependence was the norm, but over the last couple of decades the role of service providers at the primary level has been developed and extensively documented. Much is also written about the need to work in collaboration with the target group.

Effective prevention programmes tend to employ a multi-component approach combining cognitive-behavioural techniques with norms clarification, education and motivational enhancement interventions. However, even where effective programmes are available, pregnant women and mothers still face significant barriers to accessing help for their alcohol and drug problems (Beckman, 1994). A British Colombia study (BCRP, 2005) found that these included:

- Feelings of shame, powerlessness and low self esteem
- Fear of prejudicial treatment and of having their children apprehended
- Lack of information about what help is available and lack of support to access it

Prevention of Alcohol Exposed Pregnancy in South Africa

The first 5 items listed on the framework of interventions by the CDC (Ceperich et al., 2007) is used to describe the current situation in South Africa and identify the gaps for preventing FASD. A summary of the main contribution that should be made by each of the main government departments towards the prevention of AEP is presented in Fig. 3

1. Estimate prevalence of FAS

The epidemiological studies which were conducted in high risk areas in 3 provinces and which used the 2 tier case ascertainment approach are summarized in Chapter 2. The studies described very high rates and identified common maternal risk factors. Such studies are expensive to implement and should only be done where sufficient support

services can be provided after the diagnosis is made. Where high levels of risk are found prevention programmes must be developed and implemented.

South Africa does not have a national surveillance system for FAS and neither are there local surveillance networks even in areas of high risk. FAS is not a notifiable condition. The establishment of surveillance networks is complicated by a number of factors including screening and diagnostic difficulties, specialist availability and ethical considerations. The limited available information makes it very difficult, if not impossible, to derive a valid measure of national FAS and more importantly FASD prevalence.

2. **Monitor alcohol use in women of child bearing age**

There is insufficient routine data collected on the use of alcohol by women of childbearing age. The only sources of data are from the SADHS which is conducted every 5 years. To date the results for the alcohol related findings of the 2003 SADHS have not been released despite the release of other preliminary findings from this study (SADHS, 2003). We suggest that it may be possible to use some of the variables in the 2003 SADHS dataset to calculate the rate of AEPs in the country, and to extrapolate a national FASD prevalence.

The only survey that has focused specifically on alcohol use by women was conducted in two sites in the country, one rural and one urban (Rendall-Mkosi et al., 2007). While this provided useful information on which to base awareness raising and preventive interventions, the alcohol use patterns and predictors of alcohol exposed pregnancy for these two sites cannot be generalized to other parts of the country.

3. Identify women at risk for an alcohol-exposed pregnancy (AEP)

Universal screening for alcohol use amongst women of reproductive age can help identify women who drink above recommended levels for their own health (no more than seven drinks per week and no more than three drinks on any one occasion). Screening techniques that include measures of quantity, frequency, heavy episodic or binge drinking, as well as behavioural manifestations of risk drinking have proven to be most effective and simple questionnaires have been developed to screen for problem drinking in multiple populations and settings (MMWR, 2005).

Administration of most screening tools takes between 2 and 5 minutes. Examples of screening tools include the TWEAK ; T-ACE; CAGE and AUDIT questionnaires (World Health Organisation, 2002, World Health Organisation, 2005).

Fig 2. Service provider responsibilities towards the prevention of Alcohol Exposed Pregnancies in Women of Childbearing Age

Health	Education	Social Development	Justice and Safety and Security	Labour
Estimate prevalence of FAS and FASD Determine surveillance strategy for AEP Screen for women at high risk for an AEP: binge drinking and not contracepting Implement strategies to prevent AEP in high risk settings e.g. brief interventions at primary level	Secondary and tertiary level education of adolescents and young women Lifeskills training in secondary education	Support of women at high risk and their families Recreational alternatives Access to specialist alcohol rehabilitation	Enforcing liquor laws Regularisation of the industry Women and child protection	Work related skills training Employment opportunities for women
Create and disseminate public and provider educational materials Training of service providers across the spectrum with attention to undergraduate and post graduate curricula and ongoing professional development.				

4. Implement strategies to prevent AEP in high risk settings

Brief interventions (BI) that use time-limited (5-15 minutes), self-help and preventative strategies to promote a reduction in alcohol use in nondependent persons and facilitate referral of dependent persons to specialized treatment centres have been used effectively in persons who screen positive for hazardous alcohol use (defined as a pattern of alcohol consumption that increases the risk of harmful consequences for the user or others) (Babor et al., 1994).

Another author refers to a similar methodology as the 5 “A”s: assess, advise, agree (goal setting), assist and arrange (additional contacts as necessary) and found that it successfully reduces heavy and binge drinking among primary care patients. Multi-contact interventions work better than single contact treatment. Because ANC requires multiple scheduled visits by the pregnant woman, interventions can easily be scheduled into her routine prenatal clinic appointments (Mengel et al., 2006).

Motivational interviewing (MI), a counselling model which was developed for health risk behaviour (Fleming and Manwell, 1999), has shown success in reducing prenatal alcohol use, especially in heavy drinkers and has also been effective in increasing contraceptive use in female drinkers of reproductive age (Mengel et al., 2006, Floyd et al., 2007). SA, however, does not have a standardised Primary Health Care (PHC) tool to screen for women at high risk of an AEP or nationally recommended interventions to reduce AEPs. Various screening tools for risky drinking listed above could be adapted for use in SA. Better counseling and support to increase the planning of pregnancies through the family planning services could also contribute to preventing AEPs.

Once a woman is identified as at high risk of an AEP due to her poor contraceptive use and current use of alcohol, or her current pregnancy with alcohol use, her medical records should indicate her risk status to ensure effective case management. The situation is further complicated if such a woman is HIV seropositive.

The Sensible Drinking Project in the Cape Metropole has provide short training for a few hundred health and lay workers to enable them to use alcohol screening tools (the CAGE and AUDIT) and carry out brief counselling. This training was not focused on screening and counselling for women specifically. Although the training was well received, the

impact on the identification and support of people abusing alcohol is difficult to asses without a longitudinal study (Rendall-Mkosi et al., 2004).

A study conducted at PHC clinics in two districts – one rural site and one urban site - in Limpopo Province reviewed the efficacy of training PHC nurses to conduct alcohol screening and brief interventions (SBI) using a training package developed by WHO (Pelzer et al., 2006). One hundred and twenty one nurses were compared before and after training regarding knowledge and attitudes, and the subsequent practice of SBI in routine clinical practice. At follow up most nurses screened patients during consultation (74%), when they have time (21%) and after consultation (5%) and significantly more cases had been managed as compared to prior the training. Nurses reported as main barriers to SBI: patient caused – disinterested/refused (55%); shortage of staff or work overload (35%); patients at risk do not come to clinic (10%); patients do not use/like the referral services; lack of adequate services to refer alcohol dependent patients (24%).

In the Western Cape FASD prevention research projects are in progress and are testing the effectiveness of the use of brief interventions with women at risk of an AEP or who are currently pregnant and using alcohol. Although the interventions are promising, there are no official results at the time of writing.

Women who are not just practising irregular binge drinking, but who are dependent on alcohol would benefit from in or outpatient specialist rehabilitation. However, there are very few such services in the country, and these are mostly unavailable in the rural areas where most high risk women are found (Myers and Parry, 2005).

Access to, and effective use of contraception.

A study conducted in six African countries outside of SA examined the role of community level factors, besides the availability of services, which influence contraceptive use in women. Contextual factors, as well as demographic and socioeconomic factors, played a significant role. The level of community approval of family planning was an important factor and suggests that a woman's decision to adopt contraception was strongly influenced by how she perceived other community members would judge her actions. Economic development and education level were other significant influencers (Stephenson et al., 2007). If these findings are applied to the areas in SA with a particularly high prevalence of FAS, one would expect to find low levels of contraceptive

uptake. One of our key informants expressed the concern that the mobile clinic service (which would provide family planning services) to the farms in a very high risk community might be stopped adding a further local barrier to contraceptive use.

5. Create and disseminate public and provider education materials

- Educational materials and awareness campaigns:
  - The Dopstop Association has been in existence since the late 1990s in the Stellenbosch area and has done broad programmes with farm workers to educate youth and adults on the dangers of alcohol abuse, offered lifeskills training, and some individual alcohol counselling.
  - SANCA is active in the field of public education on alcohol problems, and offer some in and out patient counselling services mostly in the urban areas across the country.
  - FASfacts is an organisation based in Worcester that provides interactive FAS prevention awareness raising activities to school children and adults mainly in the rural areas of the Western Cape. They also offer information on a website – www.FASfacts.org.za
  - Soul City (Health and Development Communication Institute based in Johannesburg) has materials on alcohol abuse and the current TV series has a focus on the issues around alcohol in pregnancy
  - National DoH is about to finalise legislation regarding warning labels on liquor containers. One of the seven messages being planned focuses on 'no alcohol in pregnancy'
  - A colourful book called Tackling Alcohol Problems: Strengthening Community Action in South Africa is aimed at raising the awareness of people of the range of alcohol related negative consequences and providing ideas for dealing with the problems at community level. A handout type page on managing children with FAS is included, as well as information on FAS in various sections of the book (Brady and Rendall-Mkosi, 2005).
  - The reporting of FAS in the media tends to be rather sensationalised and often accompanied by inaccurate and misleading information. An article published on in 2 major daily newspapers stated that "one drink during nine months or a bottle a day during the same period can lead to a woman giving birth to a baby with FAS (Joubert, 2008). In the same week the DoH published a booklet for circulation in a major national Sunday newspaper. In one of the articles titled

‘Think before you drink’ there was a statement: ‘The misuse of alcohol in pregnancy has also been linked to foetal alcohol syndrome in infants’. Both of these messages are unacceptable, with the former promoting an incorrect and alarmist fact, while the latter understates the cause of FASD.

- Service Provider Training:
  - The Medical Genetics Education Programme (MGEP) training is a programme led by the National DoH, Division for Genetics and Birth Defects, and aims to increase the knowledge and skills of health workers in the screening for birth defects in newborns and infants, and counselling of couples who may be at risk of having a child with a genetically transmitted abnormalities, or who have an affected child. FASD is included but not in much detail.
  - A set of guidelines for the prevention, screening and management of FASD has been drafted by the National DoH and is close to being finalized.

Chapter 5 Interventions with people living with FASD and their families

Early intervention for children with FASD - Preschool and Schooling

Primary disabilities are cognitive/intellectual deficits that reflect the CNS dysfunctions inherent in the FASD diagnosis. Early intervention can ameliorate the secondary disabilities

The primary or cognitive impairments include impairments in intellectual ability, attention and in the speed of information processing, more complex tasks such as planning and goal oriented responses (executive functioning), language, visual perception, visual construction, learning and number processing. These impairments lead to social skills deficits and emotional problems. A high prevalence of disrupted school experiences, trouble with the law, confinement, inappropriate sexual behaviours, and alcohol and other drug problems have been described in adolescents and adults with FASD in the USA (Streissguth 1997). The prevalence of these outcomes have not yet been quantified in South African studies. However, high levels of crime and incarceration amongst the youth, sexual risk taking, and an increase in drug and alcohol problems in South Africa should be considered in part explainable by undiagnosed and managed FASD.

The manifestations of FASD tend to present and become more or less prominent during the various phases of the life cycle as the child progresses into adolescence and adulthood. In this section we describe interventions needed to assist children with FASD, with a focus on what is or is not available locally. We relied heavily on information gathered from key informant interviews as little is published in the literature about the South African situation. The information is predominantly from the Western Cape.

Infancy and Early Childhood

The infant affected by PAE usually presents with the non-specific symptoms of a 'fussy' child - feeding problems, irritability, unpredictable patterns of sleeping and eating and poor weight gain. The irritability and feeding difficulties make babies hard to care for and interferes with maternal bonding (Aase, 1994). The situation is aggravated if the mother and/ or father are still using alcohol resulting in a chaotic family environment with negative impacts on the child with FASD and other family members. The support of extended family is of great assistance.

Figure 3. Identification of the service needs of a person with FASD

Life Stage	**Health**	Education	Social Development	Justice and Safety and Security	Labour
Birth and infancy	PHC Clinics Developmental screening and referral. Diagnosis, feeding support and parenting support		Family counselling for alcohol use problems Support in maternal child bonding		Maternity leave, efficient UIF process.
Early childhood	PHC Clinics: developmental screening – growth and behavioural parameters e.g. routine visit at 3 yr Referral and diagnosis before 6	Creches and pre-schools Teacher and parent training to manage learning, language and attentional problems	Access to social grants. Family support stigma and child management in family. Developing supportive home environment	Vulnerable to abuse – physical and sexual abuse and domestic violence.	
Childhood (school going)	PHC Clinics	Supportive education environment Support for teachers Specific learning interventions. Life skills training			
Adolescence	Contraception services	Drop out		Better awareness by police of FASD vulnerability e.g. Recognition of disability in legal process.	Alternative skills training. Enforcing no child labour legislation.
Adulthood	Mental health services		Supportive community living		Meaningful employment opportunities – sheltered/menial work

The young child with FASD will often present with more specific signs – developmental delay, especially of speech; deficits in verbal learning, language, some aspects of visuospatial ability as well as overall intellectual ability; (Streissguth, 1997) poor growth and behaviour abnormalities. Characteristic behaviour manifestations of FAS include hyperactivity, poor judgment, inability to appreciate consequences of actions, excessive friendliness, difficulty with sequencing, poor short-term memory and learning difficulties (Canadian Paediatric Society, 2002).

Advice on feeding and parenting is accessible at routine well baby (immunization) clinics and babies with low weight for age should be referred for medical assessment. Some of the high prevalence areas, however, are serviced by mobile clinics which only visit once per month.

In general in SA developmental delays in infants and young children are detected at PHC clinics or creches. Developmental screening should be done when children attend the clinics for immunizations. However, most clinics do not have staff such as therapists to perform rigorous screening, so nurses are expected to identify problems and refer the children suspected of an underlying problem to a special clinic at a higher service level for further assessment. In the poorly resourced areas access to specialist developmental assessment clinics is limited. In better resourced areas where a child may have a specialist assessment, the diagnosis of a FASD condition could still be missed since few doctors or therapists are sufficiently aware of the FASD features or trained to make the diagnosis.

One of the policy changes which the Northern Cape FAS Task Team is pursuing is to include an additional clinic visit at 3 years for a developmental assessment, between the 18 month booster and 5 year preschool immunization visits. The developmental assessment would include FAS screening (key informant interview) and referral to a Developmental Clinic for further assessment and support for children with positive screening tests.

In the Northern Cape, fifty community social workers have been trained by FARR. Training included increasing awareness that FAS is a specialist diagnosis and the implications for the child and the families when a child receives a FAS diagnosis. They are sensitized to the possible guilt, anger and sorrow of the mother at past alcohol use

and the fact that her child's (or children's) problems could have been prevented, when assessing a family's environment, stressors and coping strategies.

In South Africa the *Education White Paper 5 on Early Childhood Education,* (Department of Education, 2001) refers to Early Childhood Development (ECD) as a comprehensive approach to policies and programmes for children from birth to nine years with active participation of their parents and caregivers. Although the official definition of ECD includes children up to the age of nine years, children in the six to nine year age group are guaranteed access to grades one to four in primary school by the Constitution. The major problem of access to ECD, therefore, lies with children in the birth to five-year age group.

Besides the Department of Education, other government departments that play a lead role in ECD include Social Development, Health, Nutrition and the Department of Labour (which plays an important role in the provision of free accredited training to ECD practitioners). An important policy document influencing early childhood development is the *White Paper on Social Welfare, 1997* which guides the department's service provision in the social development sector*. The Child Care Act, 1983* provides for regulation of and provision of subsidies to early childhood facilities. *The Guidelines for ECD Services,* 2006, clearly state that if a child with a disability cannot be accommodated, referral to an appropriate center must be made. Several other departments participate in intersectoral ECD programmes.

An audit of over 23 000 ECD services sited throughout the country was conducted in 2001 by the Department of Education. This revealed that *'… the ECD field is dominated by the NGO sector. Where departmental provision exists, it usually caters for children from the age of three years to school-going age. It is estimated that about 90% of children under the age of nine in South Africa do not have access to ECD prior to attending school*' (South African Yearbook 2003/2004) The aim is for all children to have access to Grade R (Grade 0) by 2010 and resources have been made available through the Department of Social Development (DSD) in the form of subsidies for daycare centres and by the Expanded Public Works Programme (EPWP) for ECD training. The situation does not appear to have improved considerably as the 2006/7 edition of the same publication states that *"… by February 2006, 5 103 registered ECD sites were receiving (government) subsidies, providing facilities for some 330 036 children"* yet, the midyear population estimate for children aged 0-4 years is 5 177 200 (South African Yearbook 2006/2007).

From our key informant interviews we identified two organisations (Pebbles, based in Somerset West, and Inclusive Education WC, based in Cape Town) which focus on children with special needs. Inclusive Education WC serves as a national resource centre for children with special needs. Pebbles deals with all children with special needs, particularly those affected by alcohol (biologically and environmentally), but is limited to the Stellenbosch farming area. Both organisations provide:

- Training of ECD staff to raise awareness of children with special needs – identification and how to deal with them
- Parenting skills – including how to deal with difficult children

Schooling

Schooling tends to be a negative experience for children with FASD. The children are active, distractible, "flighty", have poor fine motor coordination, attention deficit, poor short term memory and with or without low IQ require educational assistance. Teachers experience them as uncooperative, difficult to manage and disruptive in class and because of their small stature they are easy targets for bullying by school mates.

The average IQ of the person with FAS is about 80, and the average IQ of the person with ARND is around 90; however, almost all of them suffer neurocognitive impairments of low social skills, emotional immaturity, memory deficits, and most have a need for continued close supervision and support services (Streissguth et al., 1997). Many children with FAS and FASD do not legally qualify as "mentally retarded" (usually defined as an IQ < 70) and therefore have problems accessing appropriate services.

The child who appears physically normal and with an average IQ but who has behavioural difficulties is more likely to be judged harshly than a child with intellectual impairment, and is more prone to the anger and frustration resulting from unrealistic expectations of parents and teachers who do not recognize or understand the neurological origins of the problem behaviours. This chronic frustration is likely to result in depression and/ or aggressive behaviour.

School-aged children will usually be referred because of learning problems, especially in reading and mathematics, or with behaviour abnormalities (Canadian Paediatric Society, 2002). This is borne out by the responses of several SA key informants for this survey.

A chapter in the book *The Challenge of Fetal Alcohol Syndrome – Overcoming Secondary Disabilities* (Streissguth et al., 1997) describes a demonstration classroom for (seven) young children with FAS. Five key concepts were identified: structure, consistency, brief presentations, variety and repetition and specific methods and strategies found to be beneficial are described.

In South Africa, especially in poorer communities, the most common time for a child with FASD to be identified as having serious disabilities is in Grade 1. It may be that the class teacher observes the learning difficulties and behavioural problems and refers to the Educational Clinic. Again, due to poor resources, even if the psychologist, therapist or remedial teacher identifies the particular difficulties of the child, the ongoing remedial support required is not available unless the child is placed in a special school.

In the public school system, where classes are large (officially up to 40 or more learners to one teacher in a classroom), the needs of the learner with a FASD are very difficult to accommodate. The model used in SA schools to support learners with special needs is to assign a learning support teacher per school and try to design some learning support strategy. Ideally this should be done one-on-one, but because of the shortage of learning support teachers, it is done in groups and once or twice per week. Class teachers should be equipped to scale down the work according to the child's abilities, focus on his or her strengths, and provide an emotionally nurturing environment to the child rather than focus on scholastic achievement.

The DoE does do training for teachers on behaviour management of children, with varying degrees of success. Unfortunately the emphasis is still on scholastic achievement (pass rates) and the consequent effects of poor achievement on self esteem cause most of these children to drop out of school (key informant interview).

Research conducted in South Africa has contributed to the understanding of the patterns of neuro-cognitive and motor (specifically fine motor) deficits (Adnams et al., 2001, May et al., 2000) and to the development of classroom interventions involving language and literacy training. The researchers worked on the hypothesis that "the core, or fixed deficit in children with FASD is ameliorable to a degree yet unknown, and that children with FASD can improve in specific academic skills after targeted interventions" (Adnams et al.

2007, p. 405) and they subsequently demonstrated improvements among children with FAS who received language and literacy training, compared to those who did not.

The Education white paper 6 on Inclusive Education for Children with Special Needs (Deparment of Education, 2002), outlines a 20 year programme to develop inclusive education for SA, but does not specifically mention FASD. The idea is to increase support so that children with disabilities can attend mainstream schools in their own communities. Whilst this is in line with the Education for All movement, it does add to the significant challenges teachers face in overcrowded schools and who have poor insight into the underlying neurological deficits underlying the behavioural problems. The researchers could not identify any research or routine statistics documenting a change in school drop out rates since the change in education policy from special schools to inclusive education. There are still special schools, but these only accept children with severe disabilities. Since not all children with FAS would be severely learning impaired, they would be accommodated in mainstream schools.

Parenting a Child Growing Up With a FASD

FASD is a lifelong condition – a child will not 'grow out of it. Parents need support to understand and support their child with learning and behavioural difficulties, and to build on their strengths.

When one considers the primary and secondary disabilities that are the consequence of PAE - intellectual deficits and learning disabilities; hyperactivity; attention and/or memory deficits; inability to manage anger; difficulties with problem solving; and prenatal and postnatal growth deficiencies - it is easy to understand that parenting a child with FASD presents a significant set of challenges throughout the life cycle of the child. As parents age, they must ensure that their role is handed over to other capable adults.

The following recommendations are summarized from Lets Talk FAS (VON Canada, 2005) – a publication of particular relevance to this section as it is compiled **for** parents and families of children with FAS **by** parents of children with FAS. The main principles that need to be conveyed to parents, and anyone else closely associated with a child with FAS are:

- Establish a routine and stick to it, and keep the environment structured and consistent

- Help the child to learn by giving short simple instructions, provide repetition, and demonstrate tasks.
- Help the child to form lasting friendships by helping them to read social situations better
- Parents need support from others with similar experiences and challenges
- Parents may need to take specific steps in self care to avoid burnout: de-personalizing the child's behaviour, taking breaks away from the child, and connecting with community and parents who understand FASD.

Information from key informants suggested that in SA if parents are not capable of looking after their children, the extended family steps in. Even in cases where the Social Welfare places children in foster care it is usually with extended family members. However, there seems to be different practices in different parts of the country. It was found that in five case studies in the Gauteng Province, all of the FASD children were either staying with their grandparents or had been placed in foster care. While in the rural Western Cape, five case studies revealed that all children were still staying with their biological mother, even though some of the mothers continued to abuse alcohol, and some had more than one alcohol affected child (Rendall-Mkosi et al., 2007).

The Parent-Child Assistance Program, (the Seattle model of paraprofessional advocacy) has demonstrated promising outcomes with alcohol- and drug-abusing mothers. In this programme, the home visits are conducted by paraprofessionals who have an historical and cultural background in common with clients, excellent problem solving skills and a strong belief in the potential of a difficult clientele. They form dynamic members of the community provider system when they build long term relationships with families, firmly link clients with professionals in the community and establish strong communication networks among service providers around individual clients. This model is now being adapted to serve mothers who themselves have FAS (Grant et al., 2004) and could potentially be adapted for and integrated into the lay health care worker programmes in SA.

The DSD provides grants e.g. Disability Grant, which is awarded depending on the extent of the disability. Since this is usually a physical disability, a child with FAS is unlikely to qualify; Child Support Grant if the family qualifies; Foster Care Grant – this is mostly kin care; Care Dependency Grant for parents with a child with a disability who is younger

than 16 years old. The FAS child would be treated like 'any other child' in being assessed for any services e.g. deal with behavioural problems; if in conflict with the law would be placed in a diversion programme or placed secure centers.

Adolescents and Adults

Secondary disabilities include mental health problems, disrupted school experience, trouble with the law, inappropriate sexual behaviour, alcohol & drug abuse, difficulty with independent living, difficulty with employment and problems with parenting
Secondary disabilities are those that a person is not born with and which can presumably be ameliorated through better understanding and appropriate intervention

Michael Dorris, author of *The Broken Cord* - about his son with FAS - points out what is seldom noted, that the majority of people afflicted with FASD in this world are not children, but adults. The following two quotations encapsulate very poignantly the frustration and the pain of both the child and the parent when he describes how Abel, his son "…lived for 23 years, endured daily loneliness and confusion and hardship and frustration and in all that time never once did anything that was intentionally cruel to another living creature" and then talks about "…The typical FASD trajectory with which parents and professionals who deal with FASD are too familiar: Things almost always get worse with the passage of time… the steady march from 'small, cute and so affectionate' to an individual's struggle to learn how to tell time, to retain the multiplication tables, to not shoplift. … Behaviors that are tolerable though worrisome at eleven, become unacceptable and criminal at fifteen, prosecutable at eighteen and thuggish at forty" (Dorris, 1997, pp. xx1, xxiv).

No literature could be found that shed any light on the situation of adolescents with FASD in South Africa. It is possible that the problem of school violence and intimidation is exacerbated by learners with FASD – both as victims and perpetrators, but this would need further investigation.

Secondary Disabilities and Protective Factors

Secondary disabilities are those that a person is not born with and which can presumably be ameliorated through better understanding and appropriate intervention. They include mental health problems, disrupted school experience, trouble with the law, inappropriate sexual behaviour, alcohol & drug abuse, difficulty with independent living, difficulty with employment and problems with parenting.

A longitudinal study initiated in 1974 – the Seattle Prospective Longitudinal Study on Alcohol in Pregnancy (SPLLS) – followed approximately 500 offspring exposed to a range of alcohol levels prenatally and during pregnancy. These patients were examined on eleven (11) occasions between day 1 and 25 years. Neuropsychological and neurobehavioral performance measures are correlated with prenatal alcohol dose, without substantial confounding by socio-demographic or rearing conditions, smoking, nutrition, or other drugs. Deficits in attention, arithmetic skill, spatial-visual memory, and IQ, as well as increased alcohol problems and psychiatric disorders are among offspring outcomes correlated at several ages with maternal drinking during and before pregnancy recognition. Findings were not confined to women who believed they had alcohol problems – for the most part, these mothers could be characterized as 'social drinkers' – less than 1% believed that they had an alcohol problem. Not all exposed offspring appear affected (Streissguth, 2007).

a Mental health problems

The most common secondary disability in FASD is mental health disorder, occurring in 94% of the adults in Ann Streissguth's (1997) studies, with clinical depression being the most prevalent diagnosis amongst adults with FASD. Mental health issues include suicide threats and attempts, panic attacks, and auditory as well as visual hallucinations. These problems seem to increase with age and are more like to occur when no protective factors are in place. Protective factors include: An IQ below 70 – as inappropriate behaviour is more easily understood and tolerated; Early diagnosis; Eligibility for state services; Absence of domestic violence; Stable home environment.

From our key informant interviews, it was clear that a co-existing mental problem in persons presenting for treatment for substance abuse and for intervention programmes involving youth in conflict with the law, is not uncommon. However, it was not possible to ascertain whether FASD was a contributing factor to any of the presenting conditions i.e. mental problem, drug/alcohol abuse or problems with the law.

b Disrupted school experience

As discussed in the section on schooling, because of their poor scholastic performance and probably other contributing factors including their family and social environments, many children drop out of school, have poor self esteem and engage in the type of high

risk taking behaviour in the context of FAS e.g. drug (tik) and alcohol abuse and unsafe sexual activity. Some NGOs, notably Pebbles, have after-school clubs to provide alternative occupations. Schools also run awareness programmes – FAS is mentioned as part of the alcohol & drug awareness programme

c Trouble with the law and confinement

People with FASD exercise poor judgment, have problems understanding the consequences of their actions or generalizing from one situation or context to another. As a result they can end up in conflict with the law, sometimes repeatedly and therefore end up in a correctional institution. In our research it was not possible to gain any insight into how many offenders might have underlying FASD in South Africa.

d Inappropriate sexual behaviour (ISB)

Persons with FASD tend to have poor communication skills, find social interaction difficult and therefore may have problems with interpersonal relationships. They may also display inappropriate sexual behaviour. Violence against individuals with FAS/FAE occurred at a very high rate: 72% had experienced physical or sexual abuse of domestic violence. Being a victim of violence increased the odds of ISB fourfold (Streissguth et al., 1997).
Although the researchers could not elicit any statistics linking FASD and abuse, this is a worrying observation in the SA context of violence crime and sexual abuse.

e Alcohol and drug problems

A number of factors contribute to making the person with FASD more at risk to substance abuse. Very often they come from an environment where high levels of alcohol consumption are accepted in the home and binge drinking in the community is a societal norm. This, in combination with low socioeconomic conditions, low levels of education (school dropouts), poor judgment and low levels of self esteem increases their risk.

Attempts were made to establish the extent to which people with FASD are beneficiaries of mental health services by the government or NGOs, but there was no literature, and key informants were unable to discuss this since the FASD diagnosis is seldom known in adults.

f Independent living

Most people with FASD have problems with independent living – have poor memory and limited problem solving skills. An option which has been explored in the USA is the therapeutic community (TC) which has been in existence for the treatment of alcohol and drug addiction for more than 40 years. TCs are drug free residential settings where peer influence is used to assist individuals to learn and assimilate social norms and develop more effective social skills with good results. Research shows that those with special or complex needs can be treated in TCs. Specialised treatment strategies and services are often incorporated as part of the TC for these populations. These may include childcare programmes for mothers; programmes for normalising the developmental processes for adolescents; access to mental health & social services for individuals with concomitant mental illness & substance abuse; attention to changing criminal thinking and behaviour for the offender and links to medical services. Although no references were found in the literature, it may be feasible to adapt the TC model to assisted living for persons with FASD.

g Problems with employment

Persons with FASD have problems with employment, those with FAS, more so. If they are employed, they tend to have low level, menial jobs. In the SA situation with levels of employment as high as 40%, the outlook is pretty bleak for persons with the borderline IQ, behavioural problems and social limitations of a person with FASD. They tend to stay on the farms and have little scope to better themselves (key informant).

The DSD does provide sheltered employment (protective workshops) for persons with disabilities – beading, leatherwork, baskets, but this only employs a small number of persons.

Understanding the secondary disabilities of FASD as well as the risk and protective factors that exacerbate or mitigate the extent of these, should inform the development of interventions to improve the quality of life for people with FASD and their families, and reduce costs to society.

Chapter 6 Summary of Key Informant Interviews and Current Research Projects

Themes from Key Informant Interviews

Key informants were drawn from government (policy makers and service providers, 4), advocacy groups and the non-governmental sector (4) as well as research organizations (3). Except for the government departments, the majority of our informants were from the Western Cape Province.

Prevalence

All informants were very conversant with the high prevalence rates in the areas which have been studied in the Western Cape, Northern Cape and parts of Gauteng. The general opinion is that FASD is prevalent throughout the country although the rate might not be as high as in the 'hotspots'.

Levels of Awareness of FASD

There was consensus that amongst the general public in the high risk areas, the level of awareness was high because research projects have have sensitized the community to the condition. However, some informants felt that the focus on prevalence research as opposed to appropriate responses, has led to an acceptance in the affected communities that it is a situation that they can do little or nothing about. Some were of the opinion that efforts are being spearheaded by doctors who tend to have a medical approach to the problem instead of a holistic 'societal' approach. The concern was voiced that the DSD was neglecting its duty as the lead department in coordinating and implementing interventions for this problem.

Most informants felt that there is a high level of awareness amongst health professionals in the provinces where the prevalence is high. This can and does lead to problems when people who are not competent to make the specialized diagnosis label children as FAS leading to stigmatization of the child and the family. It is unclear whether health professionals give patients the strong message to abstain from alcohol during pregnancy.

Current Services Available to People with FASD

Persons with FASD have access to all the services available to persons with disabilities, provided that they meet the criteria set out by the various departments to qualify for those services e.g. the various social and disability grants, special education, employment in protected workshops. None of the current services or programmes has been evaluated in a systematic way to assess the extent to which people with FASD are served.

There was strong consensus that implementation of policies is a problem, mainly because of a lack of human resources, finances and an appropriate skills base. As an example, the inclusive education policy is meant to accommodate children with disabilities in mainstream schools within their communities. In reality, however, there is very little support available for these children who experience teasing and bullying for being 'slow'. Teachers have up to 40 children per class and there is sometimes only one teaching assistant per school. The emphasis on scholastic achievement instead of the development of each child to his or her potential means that these children drop out of school and are prone to participate in drug abuse and crime or experience teenage pregnancy.

Key Gaps in Current Service Provision for People with FASD

- Support for teachers – in the form of assistant teachers and training to deal with children special needs in the context of overcrowded classrooms.
- Support for parents – professionals are 'occasional visitors in the lives of disabled children whereas parents and families are constant and are not empowered with the skills necessary to deal effectively with children with FASD.
- Community outreach services – some services are provided from academic centres which are difficult for community members (especially those from communities most at risk) to access.
- Essential staff and resources to implement policies effectively – rehabilitation policies, such as those related to community based rehabilitation services are not properly implemented.
- Government services are not coordinated with other services to meet the prevention and rehabilitation needs of families,- links with and support for Alcoholics/Narcotics Anonymous which require no resources, work effectively and can be set up in any community are lacking.

Priority Areas for Future Intervention

1. A dual focus of prevention of FASD and interventions for the children and adults with FASD who are need of services now.
2. Special schools for children with alcohol related problems and residential facilities for pregnant women who abuse alcohol
3. Effective alcohol and other drug prevention programmes should focus on the spectrum of substance abuse and not only addiction which is the tip of the iceberg.
4. Regulation of advertising by the liquor industry
5. Training for all service providers on screening women and management of FASD

Priority Areas for Future Research

1. National surveillance so that we know the situation in the whole country – the use of 3D imaging to screen 10% of grade one pupils was suggested
2. Focus on partial FAS and alcohol related neurodevelopmental disorders which are far more prevalent than FAS
3. Better screening at ANC to identify women who drink during pregnancy as this is usually under-reported
4. Understanding community dynamics and how to build resilience - create an enabling environment in which communities can help themselves

Current Prevention Research Projects

Information on current research was obtained from our key informant interviews, from investigators in our team, and from the database of scientific projects of the National Institutes of Health in the US (http://crisp.cit.nih.gov/).

- University of New Mexico, with University of Stellenbosch and Medical Research Council and funded by the NIAAA. This is a comprehensive, community wide, multi-site prevention study in the Western Province based on the FAS prevention programme defined by the IOM and which has been modified to address common HIV and AIDS risk factors.
- Foundation for Alcohol Related Research with Department of Health and Medical Research Council. This FASD prevention study is testing the use of brief interventions during pregnancy, based in the antenatal services, in the Ceres area.
- University of Pretoria with University of Cape Town and Medical Research Council and funded by the CDC, Atlanta. This is a comprehensive fetal alcohol syndrome prevention programme, conducted in the Pretoria and West Coast areas, which is exploring strategies to reduce harmful alcohol use by women in general, reducing alcohol use in pregnancy, and promoting the planning of pregnancies. Community awareness raising and capacity building is part of the prevention model being tested.
- University of California Los Angeles and funded by the NIAAA which will implement and evaluate a randomised controlled trial of a home-visiting prevention programme delivered by neighbourhood Mentor Mothers of the Philani Intervention Project to clinic based programmes. The study integrates alcohol, HIV and AIDS and nutrition issues.

Other Research Projects

- University of Stellenbosch as part of The Prenatal Alcohol in Sudden infant Death Syndrome and Stillbirth (PASS) Network, NICHD and NIAAA and funded by the NIAAA. The first phase of this study aims to identify early markers of FASD and to build local capacity in neurodevelopmental assessment, research skills and data management. A large prospective study of 7000 pregnancies with an experimental study design to determine the role of alcohol exposure and negative outcomes for the fetus, infant and child will follow. It will explore timing, pattern and amount of alcohol exposure, environmental factors and genetic factors.

- University of Cape Town and the Wayne State University (Detroit) and funded by the Fogarty International Center. This study will introduce new MRI technologies to explore the brain images in relation to the intellectual deficits seen in children with FASD.
- University of California San Diego, the University of California the Collaborating Initiative on Fetal Alcohol Spectrum Disorders (CIFASD) and funded by the NIAAA. Previous work by CIFASD established a standard comprehensive protocol for physical evaluation of children with the broad spectrum of features of FASD. New substudies will utilise sophisticated imaging techniques to explore the full range of structural anomalies in children prenatally exposed to alcohol, the structural defects of FASD in relation to neurobehavioural outcomes and compare various methods of physical examination for FASD. A facial imaging project is included as one of the substudies.

Chapter 7 Recommendations: prevention of FASD, and support for those with FASD.

Overall Goals:

1. Reduce the prevalence of FASD, especially in known high prevalence areas
2. Reduce the impact of the primary and secondary disabilities of FASD on individuals and society

Co-ordination and consensus building

1 **A multisectoral national FAS Task Team** should provide **leadership for a co-ordinated response** to the problem of FASD, including (a) **assessment of the impact of FASD;** (b) a **national consultation** involving **stakeholders** such as industry, NGOs, and community groups to ensure **buy-in** to prevention and support strategies; (c) facilitate **consensus on a minimum package** of services for persons with FASD; and (d) identification of **priorities for FASD research** for South Africa that could be targeted for preferential funding by national funding institutions. The Task Team should establish clear objectives and outputs, and be accountable to the relevant parliamentary committee.

2 Each **province** should host its own **multisectoral provincial FASD task team** to assess the **local situation** and plan prevention strategies and comprehensive support services, especially in the high risk areas. The accountability of the task team should be to either the health or social development sector.

3 The **National Health Department** should establish a committee to develop **guidelines on screening and diagnosis of FASD and women at risk** for use at primary care level. Awareness raising and screening of women at risk for AEP should be **integrated into HIV and TB programmes**.

4 There must be **adequate budgetary and resource commitment** from all relevant sectors in addressing the problems of excessive alcohol use leading to FASD, (including Departments of health, social development, education, labour, correctional services, tourism and industry etc.)

Surveillance and detection of AEP and FASD

1 There should be a national commitment to **ensure support services are available** wherever screening for AEP risk or FASD is undertaken as an ethical and human rights obligation.

2 The **National FAS Task Team** should lead a process to establish the **best methods for surveillance of AEP and FASD,** including (a) the best measurement tools; (b) the value of screening for AEP; (c) possible biomarkers and (d) the feasibility of screening children in Grade 1 for FASD.

3 In addition, (a) the **Demographic and Health Survey** should be adapted to include questions that enable estimation of AEP risks; (b) screening for FASD and AEP risk should be **incorporated in existing programmes**, such as developmental and antenatal screening; and (c) the potential involvement of the **private sector health** service providers and private schools should be explored.

4 It should also be determined to what extent service providers at a **community level** could be trained, and with what tools, in the first level **screening for FASD** so that support services can be provided as soon as developmental problems are detected e.g. would Road to Health cards provide sufficient information to alert a service provider to a possible FASD child; could school nurses or school teachers be trained in basic functional screening?.

5 Surveillance should be established to assess the extent to which juveniles and adults in **Correctional Services facilities are affected by FASD**. This could generate new approaches to managing persons with FASD in the criminal justice system.

6 The **curricula** for the **training of all health and social services professionals** should include skills in screening and brief interventions for women with risk of an AEP, and the features and challenges of FASD people, and raising awareness of the benefit of early detection of children affected by alcohol.

Alcohol use in childbearing age women

1 Clear **national guidelines** should be agreed on and communicated to the public on the **sensible drinking levels for men and women in general** (frequency and amount), and this should include the message that **no alcohol in pregnancy is safe**. The negative influence of a **partner's drinking habit** on a woman's use of alcohol should also be highlighted.

2 The **effectiveness of warning labels** to be introduced on alcohol products must be evaluated for their influence on the knowledge of the negative consequences of alcohol use, and in particular the effects of alcohol on the fetus.

3 There should be legislation urgently developed to **restrict the promotion of alcohol use** that targets young women, particularly advertising alcohol products using the image of young women.

4 The liquor licensing regulations should be more strictly applied to **reduce the density of liquor outlets**, especially in high risk areas. Mandatory training of liquor outlet staff should include refusal to serve pregnant women with alcohol.

5 **Recreational activities** that do not include drinking alcohol should be promoted and relevant facilities made available, especially in high risk areas.

6 Further research should be conducted to better understand the service provision and attitudinal factors that prevent women from **planning pregnancies better and using contraceptives** effectively.

Identification of and intervention with women at risk of AEP

1 Research should be done to establish the **best screening tool** for screening for AEP in terms of validity and reliability across different populations.

2 **Standard screening and brief interventions for women** at risk of AEP should be developed for integration in all health and social services programmes, and the necessary training of service providers to follow the protocol carried out. This should include consideration of the **viability** of the screening and interventions stated in point 1 being carried out by **lay counselors, community health workers and home based care workers. Cost-benefit and cost-effectiveness** of these interventions should be evaluated.

3 The **training of health professionals** at under- and postgraduate levels and for **Continuing Professional Development** should include skills training to carry out screening and brief interventions for AEP, and to use ‘teachable moments’ during their daily service provision.

4 **Alcohol rehabilitation programmes** should be strengthened particularly to increase access for women who are typically poor, have many life responsibilities and poor self esteem.

Public education and awareness

1 Surveys should be conducted to establish baseline **knowledge and attitudes of young people** regarding using alcohol in general and in relation to pregnancy prior to the launch of awareness campaigns.

2 Targeted awareness programmes framed specifically for **youth, men and women** should be developed, focused on specific target groups such as students at tertiary educational institutions; women in female dominated trade unions, etc.

3 The inclusion in **national (school) educational curriculum** of appropriately targeted information and learning objectives around use of alcohol and FASD.

4 More support should be given to **civil society organizations** to take up the issues around **FASD as human rights issues**, and mobilize people to challenge the stigma attached to the spectrum of conditions.

Intervention and support for those with FASD

1 A comprehensive review should be undertaken of all **policies across sectors** affecting people with FASD applicable throughout the life cycle, including adolescence and young adulthood. Where the rights and needs of people with FASD are not adequately catered for, **advocacy for their inclu**sion in services and policy should be made, particularly regarding mental health services.

2 With regard to **schooling**, there should be (a) re-evaluation of the **resources allocated** to training for children with special learning and support needs; (b) development of a **standardized and accredited training programme for crèche and school teachers to address** the needs of FASD children; (c) development of a **standardized training and support programme for parents of children** with FASD, including parenting skills and behaviour management.

3 Research should be conduced to (a) **establish the costs to society of FASD** in terms of service provision as well as opportunity costs to the individual and family; (b) explore the role of FASD in contributing to the growth of **criminal gangs**; (c) the **vulnerability of people with FASD to exploitation** should be investigated through case studies and longitudinal studies; and (d) **identification of effective strategies** for maximizing behavioural and cognitive potential and thus long term outcomes, of persons with FASD. This research should contribute to better protective mechanisms

such as alternative appropriate work and life skills training programmes for young people.

4 The families and communities affected by FASD should be encouraged to **openly campaign for the rights of their affected family** member, and make demands for the appropriate service provision. Family advocates should be represented on the National Task Group.

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Appendix 1a

UNICEF FAS STIUATIONAL AND GAP ANALYSIS

SEMI-STRUCTURED QUESTIONNAIRE

FEB/MARCH 2008

Government Officials

1 **What is your understanding of the extent of the problem of FAS and partial FAS in South Africa/ your province?**

2 **What would you say is the level of awareness of the problem of FAS in the country/ province?**

3 **What service needs do people with FAS have?**

4 **In what way does your sector offer any services that people with FAS could benefit from?**

5 **Are any of the specific primary and secondary disabilities that people with FAS have included in any of the policies of the sector?**

6 **Is your sector involved in the prevention of FAS at all, and in what way?**

7 **Is there collaboration between different departments and NGOs to deal with the prevention of FAS, and can you give examples of these?**

8 **In what way are FAS related policies and programmes evaluated?**

9 **If you had new funding to work on research and/ or programme implementation related to FAS what would you do with the funding?**

Appendix 1b

UNICEF FAS STIUATIONAL AND GAP ANALYSIS

SEMI-STRUCTURED QUESTIONNAIRE

FEB/MARCH 2008

Researchers involved in FAS studies

1. **What is your understanding of the extent of the problem of FAS and partial FAS in South Africa/ your province?**

2. **What would you say is the level of awareness of the problem of FAS in the country/ province?**

3. **What is the research that you are busy with hoping to understand?**

4. **What is the geographical site in which the study is taking place?**

5. **What broadly is the study design, and when are results likely to be published?**

6. **Is there collaboration between your research team and government departments and NGOs during the study, and in what way?**

7. **If you had new funding to work on additional research and/ or programme implementation related to FAS what would you do with the funding. i.e. what do you think are the research gaps in FAS prevention and support?**

Appendix 1c

UNICEF FAS STIUATIONAL AND GAP ANALYSIS

SEMI-STRUCTURED QUESTIONNAIRE

FEB/MARCH 2008

NGOs and advocacy groups

1. **What is your understanding of the extent of the problem of FAS and partial FAS in South Africa/ your province?**

2. **What would you say is the level of awareness of the problem of FAS in the country/ province?**

3. **What service needs do people with FAS have?**

4. **In what way does your organisation offer any services that people with FAS could benefit from?**

5. **Is your organisation involved in the prevention of FAS at all, and in what way?**

6. **Is there collaboration between different departments and NGOs to deal with the prevention of FAS, and can you give examples of these?**

7. **In what way do you evaluate the impact of your work on the needs of people with FAS, or on the prevention of FAS?**

8. **If you had new funding to work on further programme implementation or advocacy, related to FAS, what would you do with the funding?**

Appendix 2

12 February 2008 UP Letterhead

Dear Interview Participant

Project: Situational analysis of fetal alcohol syndrome in South Africa (UNICEF)

You are invited to respond to some questions that the interviewer will pose to you related to the situation of fetal alcohol syndrome (FAS) in the country, its prevention and management. This letter is to inform you of the research being undertaken by a group of researchers during February and March 2008, sponsored by UNICEF. You will then be asked to participate in an in-depth interview, and if you consent to this, then you will sign on the last page.

Purpose of the interview
The project is a literature and stakeholder review in order to describe the prevalence and needs of people with FAS, and the extent to which the various policies and services are responsive to these needs. It is also focusing on the prevention of FAS. Therefore, the interview with you will provide us with additional insights and ideas about the current situation and how things could be improved. A summary report, with recommendations for service improvements and further research, will be given to UNICEF on 17 March 2008.

Procedures
The interview will last between 30 and 60 minutes, and will not be tape recorded. Notes will be taken by the interviewer from which a summary of the discussion will be made and used as research data. The interview may be telephonic or face to face.

Ethical approval
The research project has received approval by the University of Pretoria and University of Cape Town Ethics Committees.

Your rights as a participant
Your participation is this interview is entirely voluntary and you can refuse to participate, or may stop participating at any time, without stating any reason.

Risks to you
There should be no risk to you in participating in this interview as you will be asked for the facts on the topics, and for your perceptions on the strengths and weaknesses of the current service provision.

Benefits to you and the broader community
You will not benefit directly by participating in this interview. However, the results of the research that is presented to UNICEF may lead to funding being made available for specific relevant programmes to be established. In the long run the benefit may

be that fewer babies are born with FAS, and those already with FAS will live a more fulfilling life.

Source of additional information
The principal investigator of this research project is Kirstie Rendall-Mkosi. If you require any clarity on the project, please call her on 021 354 2066.

Confidentiality
All your answers to the questions will be added to the data that is gathered for the whole project. None of the interview summaries will be available to anyone outside the research team. No names of participants will be written in the report, and it will be impossible for your responses to be traced to you.

If you agree to assist us by answering the questions that the interviewer will pose to you, please could you sign the attached 'Informed Consent" form and fax it back to the number given to you by the interviewer.

Yours sincerely

Kirstie Rendall-Mkosi
Senior lecturer

UNICEF FAS Situational and response analysis.

Informed consent

I hereby confirm that I have been informed by the investigator, Ms Rendall-Mkosi, or her co-researcher, about the nature, conduct, benefits and risks of answering these questions. I have also received, read and understood the above written information.

I am aware that the information gathered in this interview, including my personal details, will be anonymously processed into the report.

I may at any stage, without prejudice, withdraw my consent and participation in the interview. I have had sufficient opportunity to ask for clarity and declare myself prepared to participate in responding to these questions.

Participant's name _____

Participant's signature _____

Investigator's name _____

Investigator's signature _____

Date: _____