

FOETAL ALCOHOL SYNDROME SITUATIONAL AND GAP ANALYSIS Summary of Findings

Background

In its work to ensure protection and development of orphans and vulnerable children, and following concerns expressed by both government and civil society partners about the impact of foetal alcohol syndrome on the lives of South African children, families and communities, UNICEF South Africa commissioned the University of Pretoria to conduct *A Situational and Gap Analysis* on the prevalence of foetal alcohol syndrome in South Africa over a period of one month, during March of 2008.

The study was conducted by a team including, Kirstie Rendall-Mkosi (University of Pretoria) Dr. Neo Morojele (Medical Research Council), Drs. Jo-Ann McLoughlin and Cheryl Goldstone and Professors Leslie London & Colleen Adnams (University of Cape Town).

Issue

Fetal alcohol spectrum disorders (FASDs) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. FASDs include FAS as well as other conditions in which individuals have some, but not all, of the clinical signs of FAS. Three terms often used are fetal alcohol effects (FAE), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD).

Full blown FAS is the most severe effect of drinking during pregnancy. It is a lifelong condition that causes physical and mental disabilities. FAS is characterized by abnormal facial features, growth deficiencies, and central nervous system problems. People with FAS might have problems with learning, memory, attention span, communication, vision, hearing, or a combination of these. These problems often lead to difficulties in school and problems getting along with others.

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.

The research revealed that there is no national prevalence data on FAS, but prevalence studies undertaken in certain high risk communities have found prevalence rates are higher than reported anywhere else in the world. One study of Grade 1 children undertaken in (the wine producing region) of Wellington, Western Cape, found that 9% of children suffered from full-blown or partial FAS. While South Africa does not have a surveillance system to collect information on the number of cases diagnosed across the country; based upon burden of disease estimates, the national prevalence of FAS in South Africa could be 14/1000. 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. REPETITION

The dop (or "tot") system, which involved the part payment of farm workers in poor quality wine, is thought to have contributed to the high prevalence of FAS described in agricultural communities in the Western Cape. Although formally banned in 1961, the practice has persisted in various permutations into the 1990s.

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. For women, the brewing of and trade in alcohol was an important source of income and conferred social importance. Currently the commercial liquor industry strongly promotes drinking through advertising, easy accessibility and relatively low prices but are also involved in initiatives to promote responsible drinking.

It is noteworthy that a woman at risk of 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.

Recommended Action

- 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.
- 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.
- There is a need for service capacity and provision to 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.
- Engage in vigorous marketing strategies to raise the general level of awareness of the public of the needs of people with FASD, as well as challenging the stigma that people with FASD experience. This would improve and enhance the integration of adults with FASD into general society and the work place.
- A further review of policy and service provision in sectors such as justice, labour and correctional services be carried out.
