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Where is the South African prevention of fetal alcohol spectrum disorder programme? A call to action

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Fetal alcohol spectrum disorder (FASD) prevalence is high in South Africa, and is a significant public health concern. The long-term consequences of FASD are devastating to the individual, their family and society. Costs associated with managing these patients and the consequences of their disorder are significant. National ownership and multisectorial involvement are required to design and implement a successful FASD prevention programme.

Keywords: fetal alcohol spectrum disorder, pregnancy, prevention, prenatal alcohol exposure, policy

S Afr Med J 2025;115(10):e3278. https://doi.org/10.7196/SAMJ.2025.v115i10.3278

Fetal alcohol spectrum disorder (FASD) is a preventable disease, and an umbrella term describing a spectrum of conditions (fetal alcohol effects, partial fetal alcohol syndrome, alcohol-related birth defects and alcohol-related neurodevelopment disorder) associated with prenatal alcohol exposure (PAE). South Africa (SA) has the world's highest estimated prevalence of FASD (111 cases per 1 000 children and young people),[1] which varies by province. Prevalence is difficult to estimate, partially owing to challenges associated with case ascertainment. Nonetheless, the reported prevalence, which is likely an underestimate, is high, and is of great public health concern.[2]

SA has an FASD prevention and management guideline to inform policy,[3] but there are no national, co-ordinated, multisectoral policies to specifically address FASD and its long-term complications. A modified World Health Organization (WHO) approach to guideline development was applied when preparing this guideline, and a robust process was undertaken prior to finalisation. The guideline proposes a policy that considers lifespan needs, is culturally diverse, collaborative, evidence-based and multisectoral, and addresses social determinants of health. The prevention component highlights education and awareness, access to treatment and training of healthcare providers. Education and awareness include a population-wide approach to addressing stigma, increasing public and healthcare provider awareness and promoting healthy behaviours and social upliftment. Training of healthcare workers to provide appropriate counselling, screen for PAE and establish clear effective referral systems is a key component to a successful policy, as is the enforcement of liquor laws and warning labels. The guideline, published in 2019, has the potential to fast-track a policy under government's custodianship that brings together multiple sectors to provide impactful changes in a holistic and streamlined manner. Here we highlight prevention aspects we consider most urgent.

Lifelong impacts of FASD include developmental, cognitive, learning and behavioural disabilities that may result in mental health challenges, schooling disruptions, unemployment, trouble with the law, including incarceration, inappropriate sexual behaviour and alcohol/drug addictions.[4] Additionally, there is a documented link between mothers of children with FASD and poverty[5] and lower levels of education.[6] Broodryk *et al.*[7] also noted that in rural SA, people with FASD were significantly more likely to be victims and perpetrators of shootings and stabbings than people without FASD. These challenges place a heavy burden on people living with FASD, their families, healthcare systems, legal systems and society. In high-income countries, the mean annual cost for children with FASD was estimated to be USD22 810 (~ZAR415 000), and for adults USD24 308 (~ZAR443 000).[8] These costs included the healthcare, special education, residential care and criminal justice system costs, as well as productivity losses due to morbidity and mortality, and losses to caregivers of children with FASD. In 2009/2010, the average annual SA National Department of Health (NDoH) provider cost per child with FASD was USD841 (~ZAR15 300) (equivalent to USD598 (~ZAR29 000) in 2024) in the Western Cape Province.[9]

FASD prevention

There is no safe trimester in which to drink alcohol, and no safe amount to consume while pregnant.[10] Additionally, there is a strong relationship between the increased length of time and quantity of alcohol intake during a pregnancy and the child's increased risk for FASD.[11]

FASD prevention is complex and requires multisectorial involvement to be successful. Several strategies are theoretically available to prevent FASD or reduce its long-term impact. We present a set of practical strategies that require urgent attention and implementation.

1. Education and awareness

School and peer education programmes and social awareness projects aimed to inform people of all ages about the risks of alcohol use during pregnancy are critical. The programmes should emphasise FASD causes and effects, the long-term complications of FASD, the importance of contraception if sexually active and not planning to fall pregnant, and the signs and symptoms of early pregnancy. These efforts should further promote early pregnancy testing, pre-emptive

cessation of alcohol use if a pregnancy is planned or suspected and the need for early antenatal care and nutritional support throughout the pregnancy. Additionally, the awareness, education and training of healthcare workers providing care to pregnant women requires attention. Healthcare worker training should include extensive education on FASD risks, the range of FASD symptoms and long-term effects, appropriate counselling methods and all potential referral systems.

2. Prevention of unplanned pregnancies

Most pregnancies in SA are mistimed (34%) or unwanted (20%).[12] Women who already have a child with FASD are at high risk of having unplanned pregnancies.[13] The risk of PAE may be lower in planned pregnancies, but the empirical evidence for this is inconclusive.[14,15] However, fewer unplanned pregnancies also mean fewer children with FASD. Prevention of unplanned pregnancies includes education on safe sexual practices, and access to and appropriate use and high uptake of condoms and effective contraception methods. Providing options for women to choose a contraceptive method that aligns with their specific lifestyle may improve uptake.

3. Early pregnancy detection

While PAE affects brain development at any gestational age, the first trimester is particularly sensitive.[16] In 2020, just over 30% of first antenatal visits in SA occured after 20 weeks' gestation,[17] and by the time many women access antenatal care, much of the PAE-related harm has already occurred. As an intervention, early pregnancy detection has important advantages:

- It is a stated aim of NDoH policy directives,[18] irrespective of FASD risks. It empowers women to make informed choices earlier in pregnancy, and enables them to seek early pregnancy termination of unwanted pregnancies, or to access antenatal care earlier, which could make interventions (including those to reduce FASD risks) more effective.
- There is a high demand for early pregnancy recognition,[19] and like early HIV recognition,[20] it can be delivered through self-care.[21] Promoting self-care is again a longstanding policy objective in SA.[22]
- What may be most important for FASD prevention is that early pregnancy recognition empowers women to act on the knowledge that they have after receiving education about the risks of alcohol use in pregnancy.[23] Studies from high-income countries consistently show that most women who drink before pregnancy recognition spontaneously stop drinking after pregnancy recognition.[14,24-28] Less is known about women in low- and middle-income countries, but in 2011, Rotheram-Borus *et al.*[29] showed that two-thirds of pregnant mothers in Cape Town, SA, townships who drank alcohol in pregnancy stopped spontaneously after pregnancy recognition.[29] Findings from other sub-Saharan countries are less encouraging.[30,31]

As the odds of FASD increase the longer a woman drinks alcohol during her pregnancy, earlier pregnancy awareness could dramatically reduce the risk of FASD.[11] If the gestational age at pregnancy recognition could be reduced from the current 10 weeks[32] to 6 weeks' gestation, the rate of FASD could be reduced by >20%. There is a high unmet demand for pregnancy testing. Urine pregnancy tests (UPTs) are widely available at pharmacies in SA, but at a significant cost to women. While free testing is provided in primary health clinics, poor staff attitudes, long waiting times and the rejection of requests for UPTs are recognised access barriers.[18] In a 36-day pilot study, Rossouw *et al.*[19] distributed 314 pregnancy tests in peri-urban Cape Town, SA, of which 17% detected a new pregnancy. This indicates that it is likely that women would test as soon as a menstrual period is missed, or soon thereafter, if the tests were more easily accessible, with increased privacy, decreased stigma and a lower cost. Bulk-bought single-use urine-based home pregnancy tests can be procured at a low price (~ZAR3.00 each), and we argue that home pregnancy tests, like condoms, are essential tools to reduce serious health risks. They should be distributed without question or consultation in clinics or healthcare facilities, and distribution through hotels and bars,[33] and co-distribution with alcohol or sanitary products, should also be explored.

4. Antenatal education and counselling about the risks of PAE

This should include implementation of WHO[34] or SA[35] guidance to discuss alcohol use at *every* antenatal visit, and to counsel pregnant women on the risks of ongoing alcohol use, with appropriate referral to support programmes if needed. The current antenatal care stationery does not allow for extensive documentation of the discussion about alcohol use, and lack of specific counselling aids precludes a standardised assessment of alcohol use. As questions about alcohol use in pregnancy lack sensitivity or specificity,[36] there may be a place for urine tests to detect alcohol consumption within the last 24 hours.[37,38] Likewise, as the capacity to deliver effective in-person counselling on alcohol use is limited, mobile phone-based counselling services using artificial intelligence[39] could be explored. This counselling method could also be included in contingency management interventions (a behavioural-modification method of providing reinforcement in exchange for objective evidence of the desired behaviour), as this is already an evidence-based intervention for many addictions.[40] Early SA-based studies in pregnant women indicate that the combination of contingency management with supportive text messages can help pregnant women with drinking problems to remain abstinent.[38] A large, randomised control of this intervention is urgently needed.

5. Choline supplementation

PAE causes oxidative stress, and antioxidants have been effective in ameliorating this effect. Choline is an antioxidant and essential nutrient required for normal brain development. Over 80% of SA pregnant women have an adequate choline intake,[41] but even in pregnant women who do not drink and have an adequate choline intake, choline supplementation may improve executive brain function in their children aged 7 years.[42] The impact of prenatal choline supplementation on neonatal brain function was studied in a randomised controlled trial in Cape Town, enrolling mothers who continued heavy drinking after the 20th week of pregnancy. Antenatal choline supplementation (2 g daily) significantly improved these children's brain performance at 6 months of life,[43] and normalised brain volumes and structure.[44] Choline supplementation is safe and relatively inexpensive, and potentially has many benefits in pregnancy with or without concurrent alcohol use.[45] However, a recent systematic review of the evidence is inconclusive,[46] and further trials to evaluate the benefits, side-effect profile, cost-effectiveness and implementation in our setting are needed to generate and support evidence-based guidelines.

6. Reducing the use of alcohol among pregnant women through alcohol warning labels

This latter is envisaged in the Foodstuffs, Cosmetics, and Disinfectants Act No. 54 of 1972,[47] which requires that bottles containing alcohol carry at least one health message. One such message is 'Drinking during pregnancy can be harmful to your unborn baby', but the most commonly used message is not related to pregnancy or risks

to unborn children, and reads 'Alcohol may affect your ability to drive'. The effect of alcohol labelling[48] is small, but could possibly be enhanced by making messages more graphic.

7. Reducing the supply of alcohol in general

There is evidence that alcohol restrictions during the COVID lockdown reduced the short-term effects of alcohol use.[49] This could be a game changer in the prevention of FASD if ever generally implemented, but is not a feasible strategy due to the alcohol industry's reported contribution to the economy.

Conclusion

FASD is not only or even mainly a biomedical problem. It should be a priority societal and governmental issue, and as such deserves a broader multidisciplinary approach. There is an urgent need for a national FASD prevention strategy. SA has faced other health crises, such as HIV, and the lessons learnt from the successes of the HIV vertical transmission prevention programmes should be leveraged to fast-track initiatives towards FASD prevention. We need national ownership of the FASD crisis, and collaboration between government, academia, healthcare professionals in the private and public sector, civil society and the alcohol and hospitality industries. This is a call for action to all the abovementioned parties to make a concerted effort to engage on the matter, and make small changes to facilitate big effects on the lives of our country's pregnant women and children.

Data availabilty. N/a.

Declaration. None.

Acknowledgements. None.

Author contributions. All authors contributed to the literature review, drafting, reviewing and editing of this manuscript.

Funding. Wits RHI.

Conflicts of interest. None.

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Received 17 March 2025; accepted 10 June 2025.