

FASD – De Aar mums get beyond the ‘tipping point’



Chairman of the Foundation for Alcohol-Related Research (FARR), Professor Denis Viljoen, and its CEO, Ms Leana Olivier.

Picture: Chris Bateman

When most of the low-income folk in the ‘ghost train’ town of De Aar began remonstrating with any pregnant mother who was boozing, excited campaigners thought they’d broken through the ‘tipping point’.

However, their research colleagues proved they’d gone even further – the dedicated local platoon of social workers, nurses, therapists and volunteers had in three short years reduced the prevalence of fetal alcohol spectrum disorder (FASD) by 30%. This is in a town with the worst recorded FASD prevalence of any single community in the world, where 120 out of every 1 000 residents suffer from FASD (12%).

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From the mid-1990s, when the South African Railways moved its repair and manufacturing yards from De Aar (the country’s most central town) to the major capitals, the community’s social fabric slowly crumpled. Joblessness has now reached 80% and alcohol abuse is rife. According to available data, the only other sites (also South African) that come anywhere close to the town’s FASD prevalence are: Wellington (88 per 1 000), Witzenberg (73), Upington

(69) and Johannesburg (27), with the next worse prevalence recorded in certain sectors of the American Indian population (8) and in Sweden (1.33). This remarkable local achievement, recognised in a slew of appreciative awards by the Northern Cape government,¹ is testimony to a holistic, multi-pronged intervention by the Cape Town-based Foundation for Alcohol-Related Research (FARR).

At last count there were more than 100 shebeens in the local townships. Take away the better-off minority ‘white’ community and you’re left with fewer than 300 people keeping a single shebeen in business. That’s a lot of drinking.

Sustained grassroots campaigning

Chairman of FARR, Professor Denis Viljoen, and the CEO, Ms Leana Olivier, believe the years of intense grassroots campaigning about the dangers of alcohol abuse conducted in the former railway hub of South Africa will soon bear even greater fruit.

The demographics of the area have the majority of the population living on the ‘wrong side of the tracks’ in the coloured

township. However, for FARR this actually means the ‘right side’ of the tracks because that’s where they’ve erected their multi-purpose community centre, loved and known by all as Die Pienk Huis.

‘With all the provincial clinics and Department of Social Development staff on board in our Healthy Mother, Healthy Baby programme we now have 90% of the women of child-bearing age in the community enrolled,’ said Olivier. She believes a major reason their comprehensive programme will drop FASD prevalence even further is that their multi-disciplinary platoon has access to all local antenatal clinics and the district hospital and is expanding its activities monthly. Underpinning all this, FARR has trained local people who have been working in the community at risk for nearly a decade. ‘They’re known and trusted and that’s probably the greatest single factor that’s swung things around for us,’ adds Olivier, a former maternal, child and woman’s health manager for the Western Cape.

De Aar has a population of 30 000. At last count there were more than 100 shebeens in the local townships. Take away the better-off minority ‘white’ community and you’re left with fewer than 300 people keeping a single shebeen in business. That’s a lot of drinking. So it didn’t take much arithmetic – or ‘ghost busting’ – to single out De Aar as the site most worthy of research and intervention as FARR’s inception and growth in the Western Cape tracked in inverse proportion to the town’s decline.

Data alarmed retired medical geneticist

Viljoen, a retired medical geneticist and former deputy head of the discipline at the University of Cape Town and later head at the University of the Witwatersrand, said the crying need for a body such as FARR, at



Proud De Aar mothers at Die Pienk Huis community centre.

least in the Western Cape, became obvious in 1996.

'At first there was anecdotal evidence that one in four women attending antenatal clinics in this province were drinking. Then I found out that one in ten kids being referred to the genetic clinic at Red Cross Children's Hospital in Rondebosch had FASD. And

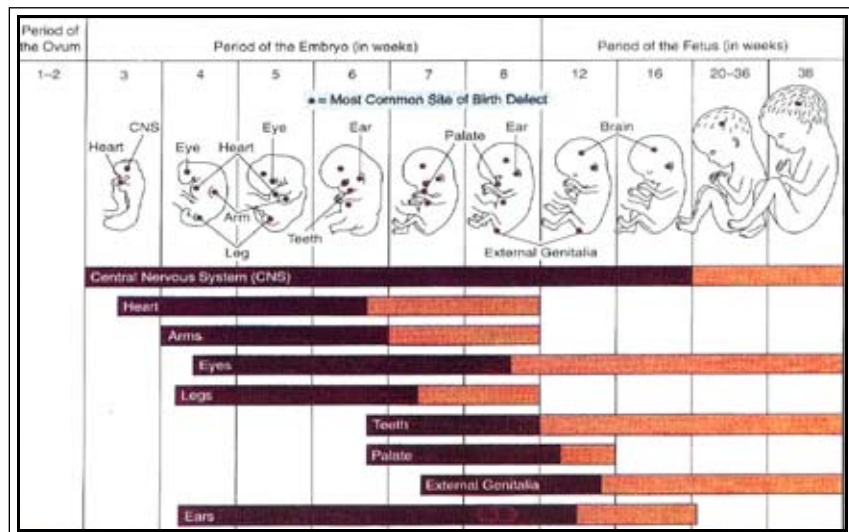
Very few mums intentionally harm their babies, a premise on which FARR builds all its efforts. Adds Viljoen, 'once you empower her with the knowledge of what her drinking could do, she inevitably starts to act out positively'.

when we audited kids attending schools for the mentally disabled, one in four had FASD.' With a funding grant from the Centers for Disease Control (CDC) in the USA and an urgent appeal from the Northern Cape provincial government in 2000, the then mainly research-based body took strength from a pilot FASD prevalence study in Wellington. Once the prevalences in De Aar and Upington were known, it became obvious that a highly focused intervention should be targeted at the hardest hit former railway hub. The first cohort comprised local children born in the past year and evaluated for FASD, followed by those born to women who had previously had children with FASD (in the second year), and finally those born with FASD in the third year were tallied. Preceding this, then running concurrently and expanding, was the FASD intervention programme, radiating outwards from Die Pienk Huis (aka the Joan Wertheim Centre).



The first proud beneficiaries of the Healthy Mother, Healthy Baby programme in De Aar.

Die Pienk Huis echoes with the cries of infants and the excited shrieks of children right up to 15 as they partake in after-school activities, sports, music groups, nutrition schemes, clothes washing or a range of



therapies including speech, occupational and physiotherapy. Mother-child bonding workshops and an early childhood development stimulation programme are vital additional tools. The centre is the new hub of De Aar, providing the stability, support and education so vital to begin turning a community around. Now all the town needs is an economic boost that will provide jobs beyond the current meager pickings in domestic, farm or construction work, the latter two categories often seasonal or temporary.

'Their circumstances are not changing, so it can only mean that women are taking responsibility for their behaviour change.'

Beating the environmental odds

Says Viljoen, who began his career as a paediatrician, 'their circumstances are not changing, so it can only mean that women are taking responsibility for their behaviour change. The anecdotal evidence is that the community has changed so much that they now berate any pregnant mums who drink, especially those who've already had FASD babies. They don't want others to make the same mistakes they did.' Very few mums intentionally harm their babies, a premise on which FARR builds all its efforts. Adds Viljoen, 'once you empower her with the knowledge of what her drinking could do, she inevitably starts to act out positively'. Olivier pens a local front page article in the local weekly newspaper, the *Echo*, centred on



De Aar kids in a typical school supplementary programme run at Die Pienk Huis community centre.

whatever's happening in the local community but with an educational FASD spin (she's also a seasoned contributor to the mass circulation yellow press *Die Son* newspaper). Her biggest contribution however is in training lay people in the prevention, awareness, identification and referral of alcohol abuse and FASD while teaching medical undergraduates and professionals diagnosis and management skills. FARR's two-year-old training academy has accreditation with the Health and Welfare Services SETA (Sector Education and Training Authority) and is fast becoming popular with all categories of students.

Chris Bateman

1. The Premier's Silver Award for Service Excellence, regional and provincial winners of Community Builder of the Year (Department of Social Development), the latter going through to the finals of the national Social Services Department, to be adjudicated later this year.