

CHILDHOOD VULNERABILITIES

in South Africa

Some Ethical Perspectives



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CHAPTER 5

THE STIGMATISATION OF CHILDREN LIVING WITH FASD AND THEIR BIOLOGICAL MOTHERS

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INTRODUCTION

The harmful consequences of alcohol exposure in utero are the most common cause of preventable intellectual disability (Gibbard, Wass, and Clarke 2003:72-76). It can lead to various sequelae collectively referred to as Fetal Alcohol Spectrum Disorders (FASDs). These disorders are directly linked to the negative health behaviour of alcohol consumption during pregnancy (Riley et al. 2011:73-80). Ideally it should, therefore, be preventable through positive health behaviour.

Alcohol exposure is not the only risky health behaviour that can have negative impacts on children during pregnancy and afterwards. Many of these dangers, including FASD, can be minimised and managed if a mother, father or caregiver is willing to search out assistance from healthcare providers or other professionals. There are, however, significant barriers in the way of this kind of help-seeking behaviour. Frequently, there are no services available, or the parents/caregivers cannot access these services due to practical, logistical or financial reasons. There are also personal reasons why people don't seek help, with a major reason being stigma (Bell et al. 2016:65-77; Choate & Badry 2019:36-52; Corrigan et al. 2017:1166-1173).

The impact of stigma on health-seeking behaviours has been demonstrated in a number of populations, including South African populations. However, these studies have mostly focussed on HIV/AIDS (Day et al. 2003:665-672; Kalichman & Simbayi 2003:442-447; Meiberg et al. 2008:49-54). Stigma is a personal attribute that leads to an individual being devalued and seen as different to the norm. This leads to negative perceptions of the individual (Bos et al. 2013:1-9). There are various forms of stigma, and although they are interrelated, they can have different antecedents and can impact on health-seeking behaviours in different ways. In this chapter, we will refer to a model that breaks down stigma into four separate manifestations, namely self-stigma, structural stigma, stigma by association and public stigma (Bos et al. 2013:1-9).

We will be looking at how children and women experience and perceive stigma in various contexts. To date, and to our knowledge, there have been no studies in the South African context looking at stigma associated with alcohol use during pregnancy. This chapter, therefore, looks at the qualitative experience of women in communities with high FASD prevalence rates (Olivier 2017). When it comes to FASD, it is not only the mothers who experience stigma with regard to their health and psycho-social behaviours. Children born with FASD are also stigmatised based on their disabilities. We will highlight the impact of the various types of stigma on them as well. It is important that the observations made here are taken further and used as the basis for thorough research on the impact of stigma on FASD prevention efforts.

In reading this chapter it is important to take cognisance of two important facts. In the first place, we admit that in the chapter there is much focus on FARR's work. This focus is necessary to understand the context of the data used in this chapter. As the data was gathered during an intervention by FARR's staff, the reader needs to be aware of the details of said intervention so that they can bear possible sources of bias in mind. These are not interviews conducted with a random sample of participants.

In the second place, the method and focus of the chapter are tied to the data available from the South African context to interrogate. In this case, only data on the mother's lived experiences are available. We admit that children's experiences cannot be understood only as derivative from adults' experiences and that they are part of a bigger system of influences. But, it is also true that the impact of stigma on children cannot be divorced from the impact on their mothers. Therefore, some interferences can be made from the available data about the mothers' experiences. It is important that the observations made in this chapter are taken further and used as the basis for thorough research on the impact of stigma on FASD prevention efforts. Further research into this area is necessary so that more in depth data from children's experience can be obtained.

FETAL ALCOHOL SPECTRUM DISORDER (FASD)

Prenatal alcohol exposure, even in small to moderate amounts, can cause a myriad of adverse pregnancy outcomes ranging from pregnancy losses, preterm labour, still births, neonatal and infant deaths, including Sudden Infant Death Syndrome (SIDS), pre- and postnatal growth retardation and FASD (Grinfeld 2009:179-200; Jones & Smith 1973:999-1001; Jones et al. 1973:1267-1271; Odendaal et al. 2009:1-8; Ornoy & Ergaz 2010:364-379).

The term FASD is used to describe a range of birth disorders, such as Fetal Alcohol Syndrome (FAS), Alcohol-Related Neurodevelopmental Disorders (ARND), Alcohol-Related Birth Defects (ARBD) and Partial Fetal Alcohol Syndrome (pFAS) (Hoyme et al. 2016:1-18). Neurobehavioural Disorder Prenatal Alcohol Exposed, is a psychological diagnostic category, separate from FASD (ND-PAE) and listed in the DSM-5 (Harris 2014:95-97). People with FASD present with varied degrees of cognitive impairment manifesting as life-long learning and behavioural problems, and can also have physical birth defects.

The first FASD studies in South Africa (1997-2001) were undertaken amongst farm workers in a rural, viticulture area in the Western Cape Province (Croxford & Viljoen 1999:962-965; May et al. 2000:1905-1912). The research results and findings were widely published in the lay media leading to the myth that farm workers, especially in wine producing areas, are at specific risk of having children with FASD. It was furthermore linked to the 'dop-system', whereby farm workers were partially paid with food, tobacco and wine (Olivier 2017:13-243). Despite numerous subsequent studies, reporting higher rates in non-viticulture areas and even cities, the misconception remains. It has furthermore led to significant stigmatisation of the condition and perpetuates the belief that others from different cultural and income groups are not at risk of having alcohol exposed pregnancies and children with FASD (Olivier, Curfs & Viljoen 2016:S103-S106).

In a country with the highest reported FASD rates in the world (Popova et al. 2017:e290-e299; Roozen et al. 2016:18-32), this stigmatisation has had a severe impact on service rendering and health-seeking behaviour. With rates ranging between 27 to 282 per 1 000 (Olivier 2017:13–243), the true scale of the epidemic in the country is most probably higher and the urgency for prevention and early intervention therefore dire. Stigmatising the condition, in whatever way, is severely detrimental to prevention, adequate service delivery, help-seeking behaviour and management.

STIGMA AND FASD

Self-stigma happens when an individual internalises the negative stereotypes associated with their perceived negative attributes. This feeds into the fear of being exposed when seeking help (Bos et al. 2013:1-9). This has been shown to be especially relevant in the field of substance abuse, and is a significant barrier to seeking treatment (Hammarlund et al. 2018:115-136; Santos et al. 2016:1-16). Self-stigma also erodes the individual's sense of self-efficacy, one of the key determinants of whether behaviour change will be successful (Orji, Vassileva & Mandryk 2012:40-41).

Even in children with severe disabilities there can still be an awareness that they are different than their peers. This is reinforced by their difficulty in making and maintaining friendships (Sanders & Buck 2010:e308-e322). Mood disorders are also frequently co-morbid with FASD and can reflect low self-image, again possibly exacerbated by self-stigma (Gibbard et al. 2003:72-76).

Structural stigma refers to how stigma towards groups becomes entrenched in societies, institutions and ideology (Bos et al. 2013:1-9). This can be seen when individuals that are stigmatised are treated differently when they access services or ask for assistance. It is also reflected in the discourse around the stigmatised behaviour. Seeking help requires that a person reveals the fact that they have the attribute

that is stigmatised (Cockroft et al. 2019:1-8). This also means that they need to put themselves in the vulnerable position of possibly being stigmatised due to the revelation. They may, therefore, opt to rather protect themselves than to seek help (Meiberg et al. 2008:49-54). This is especially problematic when the public discourse becomes punitive towards those struggling with substance use. With regard to FASD, calls for the incarceration of women have been particularly damaging (Choate et al. 2019:36-52; Pietro et al. 2016:726-732; Reporter 2018).

The future of children with FASD is frequently viewed as bleak and hopeless (Watson et al. 2013:76-93). These beliefs can impact on the amount of effort expended on their schooling and learning. Where these children remain in mainstream schools, they may be seen as lost cases. The system can, therefore, give up due to the label of FASD and not the actual profile of the child which has been shown to be amenable to interventions (Peadon et al. 2009:1-9; Pei & Kerns 2012:308-311).

Stigma by association refers to how those close to the stigmatised person are judged and it also refers to how people close to the stigmatised person feels about being associated with them (Bos et al. 2013:1-9). Stigma by association can erode the support structure of individuals seeking help. It can strain personal relationships and lead to problematic behaviours being hidden from view (Corrigan, Watson & Miller 2006:239-246; Van der Sanden et al. 2013:73-80).

Public stigma refers to the social and psychological reactions people have towards stigmatised individuals. Two factors associated with public stigma that are particularly important in terms of alcohol consumption during pregnancy, are perceptions of norm violation and perceived controllability of the condition's onset (Bos et al. 2013:1-9). The norm against which pregnant women are judged is one of protecting the unborn baby and ensuring their healthy birth. Exposing a fetus to a harmful substance is, therefore, a serious violation of this norm. When it comes to substance use, the perception is that the onset of substance use and substance use disorder can be attributed to the sufferer and is under the control of the sufferer (Yang et al. 2017:378-388). This leads to the perception that substance use during pregnancy is an active choice and the blame can, therefore, be laid at the mothers' feet,

leading to stigmatisation. It is partly due to the fear of this perception that health-seeking behaviours are avoided and delayed.

There are unfortunately very negative narratives regarding individuals with FASD and the danger they pose to society. Even though some of the secondary disabilities associated with FASD includes conflict with the law (Brown et al. 2018:13-19), this is frequently sensationalised leading to statements like: “The nation’s prisons are home to an untold number of convicted killers whose brains were damaged in utero when their mothers drank!” (FASfacts n.d.). This feeds into a narrative of children with FASD being dangerous and unpredictable, further alienating them and their caregivers (Watson et al. 2013:76-93).

It should be a priority to avoid having children born with FASD. However, where this is not possible, one should follow the principles of harm reduction. For this to be possible, we must be able to identify at-risk mothers and we need to be able to reach children already affected. Neither of these two goals will be reachable if we do not combat stigma. If a woman has a substance abuse problem and becomes pregnant, stigma can prevent her from reaching out and receiving effective antenatal care and assistance to cut down on or stop using alcohol. Effective interventions exist that can make a difference at this stage of a child’s development.

If, on the other hand, a child has been born with FASD, there are interventions and support programmes that can improve on their life outcomes in terms of health and development. For these to be effective, the problems have to be identified as early as possible and assistance should be given as early as possible. The fear of stigma may prevent parents and caregivers from acknowledging concerns and make them hesitant to access services.

Tackling stigma surrounding the future prospects of children with FASD can help them better integrate into society. Putting them in a more sympathetic light can help build support networks around them and improve their life outcomes. Failing to do so, relegates them to the fringes of society and makes the idea that there is no hope for them a self-fulfilling prophesy.

FASD STIGMA IN THE SOUTH AFRICAN CONTEXT

Stigma is closely tied to public perceptions of behaviour. If a behaviour has been normalised, it is less likely to be stigmatised. South Africa has a particularly high per-capita level of alcohol consumption and a high prevalence of high-risk drinking behaviour (World Health Organization 2018). It is, therefore, not a given that the same stigma surrounds alcohol use, and as knowledge of FASD is not universal, it is similarly possible that the stigma against drinking during pregnancy is not as prevalent.

OBSERVATIONS AT THE FOUNDATION FOR ALCOHOL RELATED RESEARCH (FARR)

The Foundation for Alcohol Related Research (FARR) is an NPO focused on decreasing the prevalence of FASD through comprehensive awareness and intervention programmes. As part of our efforts, we have worked in five of the nine South African provinces. We, therefore, have access to communities where the prevalence of FASD was determined and where some level of awareness regarding FASD has been established. In all our project sites in these provinces, we are conducting research and implementing an evidence-based prevention programme, the Healthy Mother Healthy Baby[©] (HMHB[©]) Programme (Olivier 2017). In this brief motivational interviewing and support programme, pregnant women receive information, support and guidance to facilitate informed decision making in terms of health and psycho-social behaviours as to ensure healthier pregnancies and healthier babies. To alleviate stigmatisation, women are enrolled irrespective of their alcohol use.

At one of these project sites, in a study on parenting of children with FASD (Drotsky 2019:1-126), qualitative interviews provided rich information on parenting and on the experience of being a biological

mother or caregiver of a child with FASD. Information obtained from these mothers, caregivers, as well as the Project Coordinators of the HMHB© Programme is shared below. Lastly, perceptions of FASD and prenatal alcohol use of participants in FARR's training sessions are also shared below.

CONTEXT OF STUDY POPULATION

In South Africa, unemployment rates as high as 80% are reported in some communities with up to 70% of inhabitants living below the poverty line (Stassen 2012). There are numerous financial, social and emotional pressures exerted on most households. This frequently leads to alcohol abuse and high levels of FASD (Olivier 2017:13-243; Stassen 2012; Urban et al. 2008:877-882). Often the main source of income in these households comes from South African Social Security Agency (SASSA) grants. These include child-care grants, old age pensions and disability grants.

Education is often limited in these communities and less than 65% of mothers of children with FASD have secondary schooling. Depression is common amongst women, with 30% of women presenting with severe depression (Davies et al. 2011:298-305). The combination of poor domestic life and low educational level results in a loss of hope with devastating impact on issues, such as school dropout rates, crime and substance abuse.

Mothering children with disabilities requires unique child-care practices filled with paradox (Bourke-Taylor, Howie & Law 2010:127-136). Mothers are often torn between others' opinions about their children's abilities and their own hopes for a miracle and progress. The mother has to embrace her child in spite of challenges associated with the disability (Larson 1998:865-875). This paradox may be aggravated for the mothers of children with FASD who also face public stigma, struggle with feelings of guilt and self-stigma.

THE EXPERIENCE OF THE BIOLOGICAL MOTHER OF THE CHILD WITH FASD SELF-STIGMA

Zelda¹ joined the HMHB© Programme, during the last trimester of her pregnancy in 2010. At the time, she was alcohol dependent and worked hard to cut down on her alcohol consumption. At nine months her son was diagnosed with FAS. Zelda took her son to an early childhood stimulation group, offered by FARR, until he was three years old. For a number of years, while married to a much older, sickly man whom she cared for during most of their marriage, she was able to stop drinking. After his death she lost her secure home, becoming alcohol dependent again. During an interview in 2018, when her son was eight years old, she became tearful in her remorse for the damage she caused. When asked why she was sad, she stated: “My child is slow and could have been different if I did not use alcohol, but at the time of my pregnancy we knew so little about FAS.” Zelda’s sense of self-stigma seems to erode the sense of self-efficacy needed to change her drinking behaviour in the long term.

STRUCTURAL STIGMA

Women who are drinking are often threatened by service providers that their children will be removed from their care. Such removals are not uncommon in the communities where FARR works. Merely removing a child from the biological mother does not necessarily lead to behaviour change in the woman. Alcohol-dependant women, who are unable to abstain or cut down on drinking, often respond to this with their own fatalistic threat that they will then just produce another child. This narrative disempowers women with substance abuse problems and does not help to prevent children being born with FASD.

Service providers often become frustrated when they cannot change pregnant women’s drinking behaviour and project these

1 Aliases are used to protect participants’ identities.

frustrations on the very people they try to help. Health care workers commented in a recent focus group on FASD and stigma that “I want to strangle her”, and “she should be locked up”. Following a discussion, these health care workers recognised that such an attitude may be the reason why some pregnant women avoid them and their service completely.

STIGMA BY ASSOCIATION

The HMHB© programme described earlier, offers information, support and guidance for healthier pregnancies and healthier babies. In some cases, stigma by association becomes a barrier in the recruitment of clients. Zandi chose not to join the programme which she associated with women who use alcohol, because she did not drink any alcohol. After being diagnosed with HIV, also associated with stigma, she was unable to share her burden with anyone. The only way she could cope was by drinking alcohol to relieve her anxiety. When a community worker again invited her to join the HBMB© Programme, she joined. Although she was now much further along in her pregnancy, the support she received, did help her to abstain from alcohol for the rest of her pregnancy and she found alternative ways to manage her stress.

Even though Zandi herself exhibited stigmatised behaviour, the thought of being associated with those already stigmatised and others’ perception, prevented her from seeking support for a long time.

PUBLIC STIGMA

Public stigma may be expressed in a variety of ways by various people including the partners of pregnant women. While raising FASD awareness on International FASD-Day (9 September) in a small community, on one of the project sites, FARR discussed the role of the partner in preventing FASD, with male partners in the community. A number of the men reacted by blaming the women for “drinking way too much”. According to the men, for fear of conflict and domestic

CHILDHOOD VULNERABILITIES IN SOUTH AFRICA: SOME ETHICAL PERSPECTIVES

violence, the topic of alcohol abuse by the women was not discussed in their relationships. Education is needed to shift this view of blaming to one of collective responsibility where men lead by example, support pregnant partners, and select a partner who does not drink as the mother of their future child.

EXPERIENCE OF THE CHILD WITH FASD

SELF-STIGMA

Some children with learning challenges, avoided tasks by saying “I cannot” during intervention sessions with FARR’s occupational therapist. These children seemed to have internalised the feedback from parents, educators and their peers to such an extent that they chose avoidance rather than experiencing another failure. In the South African inclusive educational system, children with FASD regularly experience failure of the curriculum’s standards, resulting in a pattern of self-stigmatisation. This lack of explorative play has even been observed in pre-schoolers. When the same tasks were broken down into manageable steps and presented in a playful manner, children often surprised with their abilities.

STRUCTURAL STIGMA

During training offered by FARR, educators often blame mothers of children with FASD for being ‘irresponsible’ and ‘damaging their innocent children’. They express hopeless frustration in the educational situation, referring to children as ‘lost cases.’

After obtaining information about FASD and discussing myths, such as ‘women choose to drink’, ‘children with FASD cannot learn’ and ‘people with FASD are violent and criminals’, facts are put into perspective and lead to better insight and empathy.

STIGMA BY ASSOCIATION

Where project funding allows, FARR offers support and/or intervention for children with developmental delays including FASD. In some cases, however, children with FASD avoid these programmes because they do not want to be associated with the ‘dull’ children. As one child put it: “FARR’s children are dull. So, FARR is saying I am dull [by inviting me to their programme].”

PUBLIC STIGMA

Marie (aged 59) is a widow whose 23-year old biological daughter Filida was diagnosed with FAS when she was in Grade 1. Marie used alcohol during her pregnancy to cope with domestic violence. She was unaware of the harmful effect of alcohol. She described this time during an interview in 2018:

I had a heavy battle with my husband. He humiliated me in public and even attacked me physically with a spade or anything he could lay his hands on. He always made sure he got me drunk first, because I could not defend myself when I was drunk.

Marie’s daughter, Filida, was born prematurely and struggled for survival. After her birth, Marie stopped drinking and embraced the challenge of raising her daughter who had significant health problems. Marie stated:

She was tiny, her body fit into my hands. One couldn’t hear her crying, because she had no voice ... only her tears flowing. So, I decided to pull myself together and stop drinking because she needed me.

Children with FASD often find it difficult to form and maintain friendships and can present with anxiety and depression (Gibbard et al. 2003:72-76; Sanders & Buck 2010:e308-e322). According to Marie,

CHILDHOOD VULNERABILITIES IN SOUTH AFRICA: SOME ETHICAL PERSPECTIVES

Filida found school challenging and was often teased that she could not read, write or remember like her peers. She was aware of being different to her peers (self-stigma) and struggled to make and keep friends. Eventually she became so anxious and depressed at school that she dropped out.

Children with FASD are often perceived as being 'different' and are, therefore, bullied and/or humiliated by their peers and others. Marie explained how children teased her daughter for her learning challenges. She explained how she tried to comfort her child and how, with patience, she managed to teach her child to read and write functionally. She expressed her dream to support her child to 'become a success'.

Due to the public perception that children with FASD are 'dull', parents might decide not to seek the help that is on offer. One woman explained her reluctance to share her child's FASD diagnosis with anybody since she feared the effect and backlash on her daughter. She felt that the community might tease her and that she will be excluded from opportunities.

PERSPECTIVES OF FARR PROJECT COORDINATORS

Based on reports from project coordinators responsible for the implementation of the HMHB© Programme, it appears as if there is more stigmatisation in areas with very high levels of alcohol abuse and FASD. In these areas, participation in the HMHB© programme is seen as an indication that the pregnant woman might be a 'drinker'. In areas where there is a lower prevalence of alcohol abuse and FASD, it seems as if the community realises the benefits of the programme in terms of the health outcomes for mothers and babies. Of note is that the communities where the stigmatisation seems to be more prevalent are also the communities where the educational levels are lower and the unemployment and poverty levels are higher. This shows the risk stigma poses to intervention programmes and the value of including individuals not displaying the stigmatised behaviour.

In a number of the project areas, especially in areas where FARR has been operational for a couple of years, it seems as if the communities have grasped the importance and need for support for pregnant women and they, therefore, do not stigmatise participation. In some communities, alcohol abuse is so common that prenatal alcohol use may not appear to be of any concern. The prevalence of stigma varies greatly. Some community members 'with higher educational qualifications' have less empathy for pregnant women who are using alcohol. This is also the case in smaller communities with strong cohesion and pride.

On investigation, it seems as if stigmatisation of children living with FASD differs from community to community based on aspects, such as those mentioned above. In communities with higher educational levels, strong cohesion and knowledge about FASD (especially where FARR has been operational for a number of years) there is empathy towards the needs of the children, but also a strong push against children being born with FASD in the area. This sometimes aggravates stigmatisation. In areas with less knowledge and insight into the challenges pertaining to FASD, the communities seem to be unaware of the consequences and, therefore, do not stigmatise the children.

IMPLICATIONS FOR THE SOUTH AFRICAN CONTEXT

STIGMA AND INTERVENTION PROGRAMMES

In our sample, women were less likely to report feeling stigmatised for drinking behaviour. The general awareness about drinking during pregnancy and the dangers thereof did not necessarily translate into stigma. We are in the position of being able to capitalise on the lack of stigma and to work on preventing stigma from being established. An example of how this can be done is the HMHB© programme run by FARR (Olivier 2017:13-243).

Where women are not afraid of stigma, it is possible to recruit them, even in public settings, to take part in interventions. This is supported by not only recruiting mothers at risk of FASD

CHILDHOOD VULNERABILITIES IN SOUTH AFRICA: SOME ETHICAL PERSPECTIVES

births. Including the intervention into a general programme makes it impossible to attach the stigmatised behaviour to an individual with certainty. The training given to the individuals running the interventions emphasises a non-judgemental and safe environment. It is a foundational principal that all mothers are treated with respect and care, regardless of health behaviours. The importance of this cannot be overstated as, even though it appears to be less prevalent, there is still some stigma towards women with substance use problems and who drink during pregnancy. The insights from the FARR community workers and project managers show that there are women who avoid the programmes out of shame or fear.

CHILDREN AND STRUCTURAL STIGMA

Of the various forms of stigma experienced by children, structural stigma poses the biggest threat to long-term life outcomes. If the structures in the fields of education and social work pre-emptively identify them as possible criminals or as children with no hope for development, they are in effect being primed for exactly those outcomes. Part of FARR's intervention and prevention strategies include comprehensive training for professionals. In these training sessions, it is emphasised how our preconceived ideas about life outcomes must be challenged. It is possible to inculcate a sense of hope in teachers and allied professionals, and that has the potential to turn the narrative around.

DISCUSSION

Based on the literature, it was expected that mothers who used alcohol during pregnancy will be severely stigmatised. Our sample sometimes differed from this expectation since it seems as if stigmatisation was closely linked to the communities' level of knowledge and insight in terms of the harmful effects or prenatal alcohol use and the consequences of FASD. It appeared that in some communities, aspects

such as unemployment, poverty and high levels of alcohol abuse in the general population masked the effects of having children with FASD. In communities with strong cohesion, described as ‘proud’ communities and in areas where a high value was placed on pregnancy and child well-being, women were more inclined to seek support for assistance during pregnancy.

In terms of children with FASD, it was expected that they would be seen as a burden on the community, resources and economy. In our context, it appeared as if this was the case in communities with higher levels of knowledge and insight into FASD and also in areas where the educational level and socio-economic status of the community was higher. Children were labelled as being ‘dull’. In the others, there seemed to be a careless attitude towards children with FASD. This might, however, purely be because these communities are still unaware of the impact of FASD or because they are pre-occupied with daily struggles of basic survival.

This also highlights the questionable utility of diagnostic labels. As we see, the stigma associated with FASD can have a significantly negative impact on children. The ethical question must, therefore, be asked whether it is desirable to have diagnoses made in all cases. This is of specific importance when there are no, or limited resources, for FASD support and/or services. In cases like this, having a diagnosis with no access to services will not benefit the child or mother. By diagnosing a child with FASD, the family, especially the biological mother, is also implicated. The ripple effect thereof might even encompass the other siblings who could then also be under suspicion of having been affected.

It furthermore raises the concern regarding FASD prevalence studies and the publication of research results and rates. Although FASD prevalence rates alert governments and service providers to the existing problem and the extent thereof, especially in high-risk areas needing more resources and support, it can also stigmatise communities. In the past, it was acceptable to identify communities and rates in publications. With increased concern regarding stigmatisation, the current trend is to steer away from naming specific communities.

This unfortunately has a negative impact on the lobbying for resources in areas with very specific needs.

In a country facing the consequences of prenatal alcohol exposure, the need for evidence-based awareness programmes is obvious, but it is essential to acknowledge the double-edged sword aspect of these interventions as mentioned in the surveys above. At some stage, the level of community awareness regarding the link between prenatal alcohol use and the child born with FASD, inevitably leads to the blaming and stigmatisation of the biological mothers. These assumptions ignore other factors that can play a role in alcohol exposure like late recognition of pregnancy, lack of family planning (May et al. 2014:855-866) and unrealistic optimism with regard to the impact of alcohol on the fetus (Louw, Tomlinson & Olivier 2017: 212-229).

If FASD prevalence studies and awareness programmes are implemented without any prevention programmes, as well as lobbying for improved service delivery and a whole-of-society approach in terms of support to women of childbearing age and those already affected, the risk of doing more harm than good is evident. From FARR's experience, it appears as if the level of knowledge of the harmful effects of prenatal alcohol exposure and FASD in a community is coupled with the tendency to stigmatise and blame. With the implementation of evidence programmes and involvement of partners, family members, friends and service providers, the blaming and shaming should ideally be overtaken by a sense of collective responsibility towards the support of women of childbearing age, safe and alcohol-free pregnancies so as to ultimately result in the birth of FASD-free children.

As awareness regarding FASD increases, more government departments and non-governmental organisations are becoming involved in combating FASD. As we have shown, the danger exists that through confrontational language and policies and even the possible criminalisation of mothers, public and structural stigma is increasing. It is troubling that those in positions of power fall victim to the idea that punitive measures can make a positive impact while ignoring the best practice guidelines on improving health behaviours.

The responsibility to prevent this and to change the course of the current narrative falls on all parties involved in FASD prevention. As part of FARR's development, we have re-evaluated our messaging and use of language. Stigmatising messages and language can be subtle and South Africa is lagging behind the international community in acknowledging and condemning this.

These aspects highlight the need for research focused specifically on the South African context.

RECOMMENDATIONS

As indicated, little is known about the stigmatisation of children living with FASD and their biological mothers within the South African context. Surveys and reports from participants in existing programmes indicate considerable differences between communities. Reasons for this can only be speculative until research provides the empirical findings. As to facilitate improved prevention and care, research pertaining to the impact of stigmatisation on help seeking behaviour and utilisation of existing services is essential.

Experience indicates that essential components of service delivery include a non-judgemental service in a safe environment where the focus is not only on the women of childbearing age, but also extends to include her partner, family and friends. To adequately prevent children from being born with FASD, a whole-of-society approach is needed where all members of society embrace the concept of collectively protecting and caring for its off-spring. The African proverb 'You need a village to raise a child', can be adapted to 'You need a village to protect a child from being born with FASD'.

CONCLUSION

In South Africa, numerous children are affected by FASD and they face long-term difficulties because of it. It is, however, possible to make a significant difference in both the prevalence of FASD and in the life outcomes of those with FASD. However, the various forms of stigma are blocking the way. We have shown what some of the negative outcomes of stigma can be, and we have given a glimpse of how women in our country experience this. More importantly, we have also shown how this can be combated. It is up to all interested parties to reject stigmatising language and behaviours. Out of a sense of righteous indignation, we are preventing those who need help from seeking it, and we are putting those with FASD at even more risk of negative life outcomes. This cannot remain and we must have the courage to stand up to all spheres of society, both government and civil society, when they harm intervention efforts through stigma.

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CHAPTER 5

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CHILDHOOD VULNERABILITIES IN SOUTH AFRICA: SOME ETHICAL PERSPECTIVES

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CHAPTER 6

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