

# **Foetal alcohol spectrum disorder: the development of guidelines to inform policy**

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Submitted in fulfilment of the requirements for the degree *Philosophiae Doctor* (PhD), in the School of Public Health, Community and Health Sciences Faculty,

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# KEYWORDS

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Guidelines

Fetal alcohol spectrum disorder

Service providers

Policymakers

Interventions

Services

Women

Development disabilities

Prevention

Management

Alcohol

Pregnancy

Delphi study

Qualitative study

Intellectual disabilities

Children

Fetal alcohol syndrome

Alcohol-related birth defects

Alcohol-related neurodevelopmental disorder



# DECLARATION

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I, Babatope Oluwadamilare Adebisi, hereby declare that this work 'Fetal alcohol spectrum disorder: the development of guidelines to inform policy' is my own work. I declared that this work has not been submitted for any degree or examination in this University or any other University, and that all sources I have used or quoted have been indicated and acknowledged by complete references.

Student



UNIVERSITY *of the*  
WESTERN CAPE

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# DEDICATION

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I dedicate this thesis to my father (Mr. Olufemi Joshua Adebiyi) and my mother (Late Mrs. Janet Ebun Adebiyi).



# ACRONYMS/ABBREVIATIONS

---

FASD - Fetal Alcohol Spectrum Disorder

NPO - Non-profit Organisation

DOH - Department of Health

DSD - Department of Social Development

DOE - Department of Education

COREQ - Consolidated Criteria for Reporting Qualitative Research

FGD - Focus Group Discussions

SANCA - South African National Council on Alcoholism and Drug Dependence

SID - Severe Intellectual Disabilities

CAPS – Curriculum and Assessment Policy Statements

IQ - Intelligence Quotient

USA – United State of America,

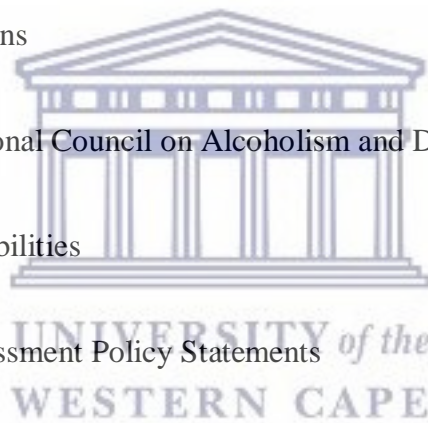
TV – Television,

CHC - Community Health Centre,

SAPS – South Africa Police Service

IEP - Individualised Educational Plan

AEP - Alcohol-exposed Pregnancy



UIF - Unemployment Insurance Fund

CDA - Central Alcohol Authority

USA – United State of America

MRC - Medical Research Council

LDAC - Local drug Action Committees

PSAF - Provincial Substance Abuse Forum

HIV - Human Immunodeficiency Virus

AIDS – Acquired Immunodeficiency Syndrome

FARR - Foundation for Alcohol-Related Research

NDMP - National Drug Master Plan

WCG - Western Cape Government

BMI - Body Mass Index

WCED – Western Cape Education Department

ECD - Early Childhood Development

FAS - Fetal Alcohol Syndrome

TB – Tuberculosis

CBO – Community Based Organisation

NGO – Non-governmental Organisation



CSTL - Care and Support for Teaching and Learning

DPO – Disabled People Organisation

SIAS - Screening, Identification, Assessment and Support

PDF - Portable Document Format.

PFAS - Partial Fetal Alcohol Syndrome

ARND - Alcohol-related Neurodevelopmental Disorders

ARBD - Alcohol-related Birth Defects

CASA - Court Appointed Special Advocates

PAE - Perinatal Alcohol Exposure

AEP - Alcohol-Exposed Pregnancy

SBIRT - Screening, Brief Intervention, and Referral to Treatment

MI - Motivational Interviewing

CRA - Community Reinforcement Approach

WHO - World Health Organization

CDC - Center for Disease Control and Prevention

EPHPP - Effective Public Health Practice Project

SBI - Alcohol Screening and Brief Intervention

PICO - Population Intervention Comparison Outcome



SPSS - Statistical Package for Social Science

PHCP - Primary Healthcare Providers



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# ABSTRACT

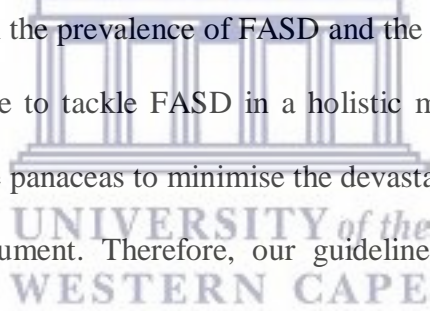
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**Introduction:** Maternal alcohol consumption during pregnancy can result to birth defects, which may be developmental, intellectual and physical. Fetal alcohol spectrum disorder (FASD) is a term used to describe an array of disorders related to alcohol consumption during pregnancy. FASD is a severe public health problem globally, with South Africa having the highest prevalence (29 to 290 per 1000 live births). What makes the FASD problem severe in the country is rife of maternal risk factors and widespread binge drinking during pregnancy. There is no policy specifically addressing FASD despite being pervasive in South Africa. Government programmes to prevent and manage FASD remain limited and fragmental across relevant departments. Herein, we aimed to conduct a multi-method study with a modified Delphi approach to developing a guideline to inform the development of a comprehensive and multi-sectoral policy for the prevention and management of FASD.

**Method and analysis:** We used a modified version of the World Health Organization's approach to guideline development in three phases. In phase 1, we conducted four different studies to design the initial guideline prototype. The studies include an in-depth interview with policymakers and a focus group with relevant service providers on policy requirements for FASD, a document review of policies on FASD and a scoping review of various interventions employed for the prevention and management of FASD. The second phase involved using the initially developed guideline prototype to engage with the local and international experts on FASD for improvement on the content. In the third phase, we refined the prototype using a modified Delphi approach. Framework method and content analysis were used to analyse the qualitative data while the Statistical Package for Social Science (SPSS) software was used to analyse the quantitative data.

**Results:** Our findings revealed there is no specific policy for the prevention and management of FASD in South Africa. However, clauses exist in other related policy documents that could be attributed to

the prevention and management of FASD. We discovered there are effective interventions for the prevention and management of FASD, but they are unevenly distributed among countries. We identified current practices such as general services for women and screening, identification, assessment, and support for children. In addition, we identified policy requirements such as streamlined programmes for the prevention and management of FASD, broad-based preventive awareness programmes, training and support for parents and caregivers. Furthermore, our guideline suggests that FASD policy should be collaborative, holistic, evidence-based and multi-sectoral. We also found awareness and education of the dangers of drinking alcohol, access to treatment for alcohol problems, training of service providers, capacity building related to diagnosis and support for parents and individuals with FASD as the essential components of FASD policy.



**Conclusion:** The persistent rise in the prevalence of FASD and the lack of a specific policy call for a decolonisation of policy discourse to tackle FASD in a holistic manner. Development of a multi-sectoral policy could be one of the panaceas to minimise the devastating effects of FASD considering the importance of a policy document. Therefore, our guideline has the potential to assist the policymakers and service providers to develop a multi-sectoral policy for the prevention and management of FASD in South Africa and beyond.

# FOREWORD

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The language used in this thesis was a mixture of American and British English. This is based on the preferred language of the journal where the articles embedded in the thesis were sent for publication.

The Ph.D. student was the primary/first author and main contributor in all the articles embedded in the thesis. Also, five out of the seven chapters in the thesis have been published in different interventional open access, peer-reviewed journals.



# STUDY OVERVIEW

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This study is presented in four sections and seven chapters.

## Section I

Section 1 consists of only one chapter, which was based on the proposal for the research. The title for this section is: A Modified Delphi study towards developing a guideline to inform policy on Fetal Alcohol Spectrum Disorders in South Africa: A study protocol.

The chapter is available from pages 6 to 32 in this document. The phenomenon of FASD and the significance for conducting the research are initially discussed followed by the aim of the research, which was: To develop a guideline for policy on the prevention and management of FASD in South Africa.

The objectives to reach the aim included:

- To review policies and their contents on FASD in South Africa;
- To explore and describe the content of FASD policies from the perspective of policymakers;
- To provide an update on the interventions on FASD internationally and in South Africa;
- To explore and describe the perspectives of service providers involved in the implementation of identified FASD intervention activities;
- To apply the Delphi technique to guide the development of guidelines for an integrated policy on FASD for the South African context.

## Section II

Section 2 consists of four chapters (chapters 2, 3, 4, 5), which focused on objectives 1-4.

### II.1 Chapter Two

Chapter two is titled: Exploring service providers' perspectives on the prevention and management of fetal alcohol spectrum disorders in South Africa: A qualitative study (**see pp. 35-80**). In this chapter, objective four was achieved by using focus groups with service providers including paediatricians, social workers, occupational therapists and educators in order to explore current practices, interventions and policy requirements for the prevention and management of FASD. A qualitative research approach with the explorative design was used.



### II.2 Chapter 3

The title of chapter 3 is: Policymakers' perspectives towards developing a guideline to inform policy on Fetal Alcohol Spectrum Disorders: A qualitative study (**see pp. 81-118**). Objective 2 was achieved in this chapter. A qualitative approach with the explorative design was used by doing in-depth qualitative interviews on FASD policies, guidelines, practices and interventions with policymakers from the Departments Health, Education and Social Development. Data analysis was done using the Framework Method to describe the findings from this research.

## II.3 Chapter 4

Chapter 4 is titled: To what extent is the Fetal alcohol syndrome disorder considered in policy-related documents in South Africa? A document review (**see pp. 119-174**). Objective 1 was achieved during this process. The researchers used a qualitative research approach to conduct a review of documents on policies and guidelines. Data analysis was done using the framework method to identify specific and generic clauses for the prevention and management of FASD in South Africa.

## II.4 Chapter 5

The title of chapter 5 is: A global distribution of available prevention and management interventions for Fetal Alcohol Spectrum Disorders (2007 to 2017): Implications for collaborative actions (**see pp. 175-224**). The researchers conducted a scoping review to identify the effective interventions for the prevention and management of FASD. Objective 3 was achieved by doing this. A framework and narrative approach were used to synthesise and report on the findings of this process.

## Section III

The prototype guideline was developed and improved during this section. This section is based on section 2 and included in chapter 6 of this document. Objective 5 was achieved in this chapter.

The title included in chapter 6 is: A Guideline for the Prevention and Management of Fetal Alcohol Spectrum Disorder in South Africa: A modified WHO's approach to guideline development (**see pp. 226-261**). A draft guideline was developed from the studies explained in section II. A discursive

approach with local and international experts on FASD was used to refine the initial guideline. The refined prototype was then used in 2 rounds to using a 5-point Likert scale to finalise the prototype.

## Section IV

This section includes Chapter 7 of the thesis with the title: Policy requirements for the prevention and management of fetal alcohol spectrum disorder in South Africa (**see pp. 263-278**). This section is written in the form of policy in brief and contains a summary of the thesis. It contains an overview of FASD, contextualisation of FASD in South Africa, a summary of findings, conclusion and recommendations.



# SECTION I

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## Overview

This section comprises of one chapter (Chapter 1). In chapter 1, the study protocol is described. This protocol was published in the British Medical Journal (BMJ Open) in 2018. This chapter provided a background to the research - the FASD problem in South Africa and highlighted the aim, objectives, approach and methods that were used in the entire project.





# CHAPTER ONE

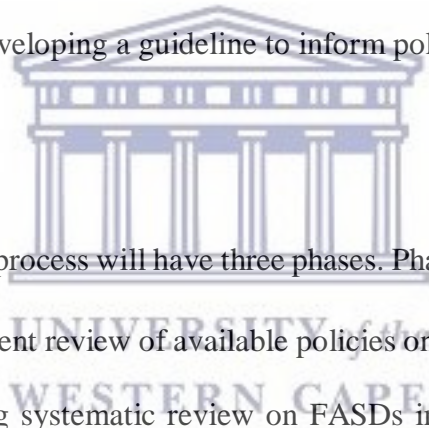
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A Modified Delphi study towards developing a guideline to inform policy on Fetal Alcohol Spectrum Disorders in South Africa: A study protocol. *BMJ Open*. 2018; 8: e019907. Doi; 10.1136/bmjopen-2017-019907

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## ABSTRACT

**Introduction:** Maternal alcohol consumption during pregnancy can result in mental and physical birth defects in individuals. These birth defects are usually described as Fetal Alcohol Spectrum Disorders (FASDs). With an estimated 183- 259 per 1000 children born with FASDs, South Africa is identified to have the highest prevalence of FASDs in the world. Nevertheless, there is a lack of appropriate policies, guidelines, and interventions addressing the issues around FASDs. This protocol outlines a proposed process for developing a guideline to inform policies on FASDs.

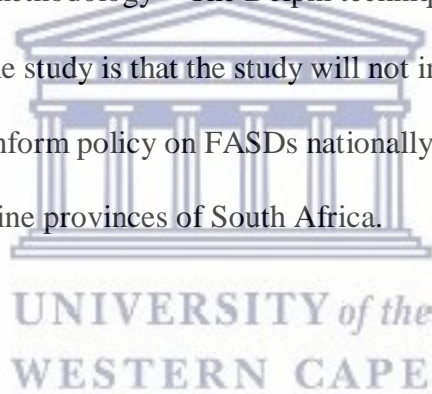


**Methods and Analysis:** This process will have three phases. Phase one will be carried out in three steps; we plan to conduct a document review of available policies on the prevention, and management of FASDs and update the existing systematic review on FASDs interventions. The aim of the two reviews is to explore the availability and content of existing policies and global interventions on FASDs. In addition, we will conduct two exploratory qualitative studies to obtain the perspectives of various stakeholders on the existing or possible guidelines and policies for the management of FASDs and available interventions and services. In phase two, we will aggregate the findings of the previous phase to develop a prototype guideline. In phase three, using the developed prototype, we will apply the Delphi approach with experts on FASDs, soliciting their opinions on the nature and content of the proposed guidelines for policies. The information gathered will be used to modify the prototype to formulate a policy guideline on FASDs. Data will be analysed using thematic analysis and narrative synthesis.

**Ethics and Dissemination:** Ethical clearance has been obtained from the ethics committee of the University and governmental departments. The findings will be disseminated through publications and the guideline will be submitted to relevant departments.

### **Strengths and limitations of this study**

- The study proposes the use of multiple sources for data collection toward developing a guideline to inform policy on FASDs.
- It also proposes a proven methodology – The Delphi technique to develop the guideline.
- A potential limitation of the study is that the study will not include individuals with FASDs.
- This study is expected to inform policy on FASDs nationally; however, it will be conducted in only one province out of nine provinces of South Africa.



## Introduction

Fetal alcohol spectrum disorders (FASDs) refer to an array of birth disorders related to fetal exposure to alcohol during pregnancy. FASDs are classified under four broad groups; fetal alcohol syndrome (FAS), partial FAS, alcohol-related neurodevelopmental disorders (ARND) and alcohol-related birth defects (ARBD) [1]. Of these four groups, FAS is identified as having the most serious anomalies [2, 3].

FASDs may lead to primary and secondary disabilities [4]. Primary disabilities are those that the child is born with [5], usually associated with damages to the brain domains that are responsible for physical motor skills, sensory processing skills, cognition, communication skills, academic achievement, memory skills, executive functioning and abstract reasoning, attention and adaptive skills [6, 7]. The brain damages could also result in physical abnormalities such as ante- and post-natal growth retardation, eye and ear malformations, mouth and jaw deformation, skeletal defects, organ pathology, sensory deficits and impaired immune system [1].

Secondary disabilities relate to those disabilities that develop because of untimely and inappropriate interventions to primary disabilities – consequences of unaddressed primary disabilities. These include fatigue, frustration, anxiety, fearfulness, rigid, resistant, argumentative behaviour, becoming overwhelmed, shut down (withdrawn), a poor self-concept, feelings of failure, low self-esteem, isolation, acting out, aggression, family and/or school problems, depression and other mental health problems, trouble with the law, drug and alcohol problems, problems with employment and homelessness [8].

A systematic review conducted to identify maternal risk factors for FASDs showed that the maternal demographic (socioeconomic status, employment status, educational status, marital status, religion, living area, income and age) and psychiatric - including neuropsychological (psychiatric

comorbidity, identified stressful, physical aggression and sexual abuse) factors play significant roles [9]. The review also showed that family, social (family lifestyle, drinking habit, alcohol use, illegal drugs use and tobacco use) and pattern of alcohol consumption could predispose women to have babies with FASDs [9].

In South Africa, the national prevalence of FASD ranges from 29 to 290 per 1 000 live births [10]. Some provinces such as the Northern and Western Cape provinces of South Africa have particularly registered high FASDs prevalence. In the Northern Cape province, an estimated 88 per 1,000 of first-grade pupils were reported to have FASDs in 2008 [11]. In 2015, although the prevalence had dropped to 63.9 per 1,000, the prevalence was still relatively high [12]. In the Western Cape province, the prevalence of FASDs among primary school pupils was estimated at 89.2 per 1,000 in 2007 [13]. By 2013, the prevalence of FASDs among first-grade pupils had doubled (135.1 to 207.5 per 1,000) [14], and another increase (170 to 233 per 1,000) was recorded in 2015 [15].

There is evidence that strategies designed to prevent FASDs and to care and support persons affected by FASDs are not effectively implemented, particularly in developing countries [16]. Peadon et al. [17] and Reid et al. [18] also reported the lack of good quality studies and limited strong evidence for specific interventions in managing FASDs. The authors, therefore, advocated for interventions targeting the specific clinical and neuropsychological deficits usually seen in individuals with FASDs.

## **Background**

South Africa is reportedly having escalating levels of alcohol consumption [19], particularly in the informal settlements of the Northern and Western Cape provinces [20–23]. The prevalence of alcohol use among pregnant women in the Cape Metropole of the Western Cape province of South Africa is

estimated at 19.6% and in poor communities of the Western and Northern Cape provinces of South Africa, FASDs are endemic [13, 24]. Maternal alcohol drinking during pregnancy, especially in rural and informal settlements, has led FASDs becoming an increasing concern in South Africa.

Generally, FASDs are relatively unknown among health professionals and have not been given adequate consideration in policies, programmes and interventions [25]. This is probably because FASDs remain unformalised medical diagnoses since they were first identified and described 40 years earlier [25]. Despite the apparent lack of interest in FASDs, efforts toward developing guidelines for the diagnoses [26, 27] and management [28] of FASDs have been made, especially toward recognising FASDs as a public health problem. Because FASDs are preventable, there have also been advocacy efforts for the implementation of various prevention programmes. These advocacy strategies call for the availability of adequately resourced alcohol control services, support for pregnant women and a sustainable commitment from communities, service providers and the government in addressing alcohol-related health and psychological problems [29, 30]. Nevertheless, for these strategies to be effective and sustainable, a governing policy and coordinated efforts are required.

Globally, there is inadequate policy and guidelines for the management and prevention of FASDs. A review on FASDs in Africa reported gaps in policy and service implementation [31]. In South Africa, only two of the national policy documents namely, the National Human Genetics Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities (2001) and the National Drug Master Plan (2007) mentioned the term FAS and none mentioned FASD [32]. In addition, the South African Guidelines for Maternity Care (2002) only suggests that maternal alcohol, tobacco and other substances use behaviours should be taken into consideration when taking a medical history of a pregnant woman [32]. The limited occurrence of issues related to FASDs in policy documents offers a reflection on the extent to which FASDs are (not) being considered in policy.

Current national hospital-based birth defects surveillance system developed by the National Department of Health also excludes some FASDs [32]. This surveillance system mainly considers birth defects that can be clinically diagnosed at birth or few days after birth, which can only be identified during post-natal hospitalisation. The exclusion of some FASDs in the birth defects surveillance system is because of the difficulty of diagnosing certain FASDs at birth as most of their features are rarely manifested at birth. In addition, it requires a multidisciplinary team to arrive at a definitive diagnosis of FASDs [32]. The above gaps speak to the need to develop relevant policies and guidelines to identify FASDs and to guide strategic implementation of appropriate interventions to address FASDs in South Africa.

In 2001, the Western Cape provincial executive council acknowledged FASDs as a provincial health priority for the years 2001 and 2002 [33, 34]. This led to the establishment of the Western Cape provincial FAS reference and working group (now called FASD task team). The FASD Task Team of South Africa comprises of members from the Department of Health, the Department of Social Services, the Department of Education, the Medical Research Council, the University of Stellenbosch, the University of Cape Town, and Non-profit organisations (NPOs) [Foundation for Alcohol Related Research (FARR), Dopstop, and Pebbles project]. The task team is headed by the Provincial Maternal, Child and Women's Health Deputy Director [33, 34]. The aims of the FASD task team is to raise awareness on FASDs, create strategies for the prevention of FASDs, and share skills and information [33, 34].

The FASD task team has been successful in developing FASDs training manuals for health care workers, educators, school psychologists, social workers and other professionals working with individuals with FASDs, their families and caregivers. In addition, the FASD task team has designed posters for creating awareness on FASDs, organising special events to improve public awareness on

International FASDs days, organising FASDs training workshops and developing a website and Facebook page on FASD [33, 34].

The above development is an important and commendable step in developing the capacity to support the prevention and management of FASDs at the provincial level. Nevertheless, a coordinated effort to facilitate the prevention and management of FASDs at the national level is required. To this end, we are proposing a national FASDs guideline that will inform policy on coordinated and multi-sectoral response to FASDs in South Africa. In this protocol, we propose a systematic approach toward developing a guideline to inform policy for the prevention and management FASDs in South Africa.

## Research objectives

To develop a guideline for the prevention and management of FASDs in South Africa, we aimed to achieve the following objectives:

- To review policies and their contents on FASDs in South Africa.
- To explore and describe the content of FASDs policies from the perspective of policymakers.
- To provide an update on the interventions on FASDs internationally and in South Africa.
- To explore and describe the perspectives of service providers involved in the implementation of identified FASDs intervention activities.
- To apply the Delphi technique to guide the development of guidelines for an integrated policy on FASDs for the South African context.



## Understanding policy guidelines

According to the World Health Organization, a guideline is a document that contains recommendations for clinical or public health interventions [35, 36]. It is also described as a document that makes evidence-based recommendations for averting and treating certain conditions, improving health, managing medicines, planning of services for the community, development of an intervention for enhancing population health and to deliver social care for people [37]. Thus, guidelines promote individualised and integrated care, help service providers and recipients and other stakeholders to make informed decisions and serve as a response to a condition that needs urgent attention [35–38]. Therefore, a guideline is considered as a set of systematically developed statements, recommendation or best practice to give a framework for policy implementation [38]. As applies to this protocol, we considered a guideline as a document that contains recommendations that will inform the development of integrated policy on FASDs.



## Adopted Approach

In developing the guideline for FASDs, we adopted the WHO's approach (steps) as stipulated in the WHO's Handbook for guideline development [35, 36].

1. We agreed to design a guideline for the prevention and management of FASDs based-on informal discussions with relevant stakeholders on the need for a policy governing the prevention and management efforts of FASDs.
2. We planned on scoping of the literature and conducting a needs assessment.
3. After gathering preliminary information, the team formulated key PICO questions [39]:
  - A. Population – individuals with FASDs.
  - B. Intervention – a guideline to inform policy.
  - C. Comparison – (Not applicable).



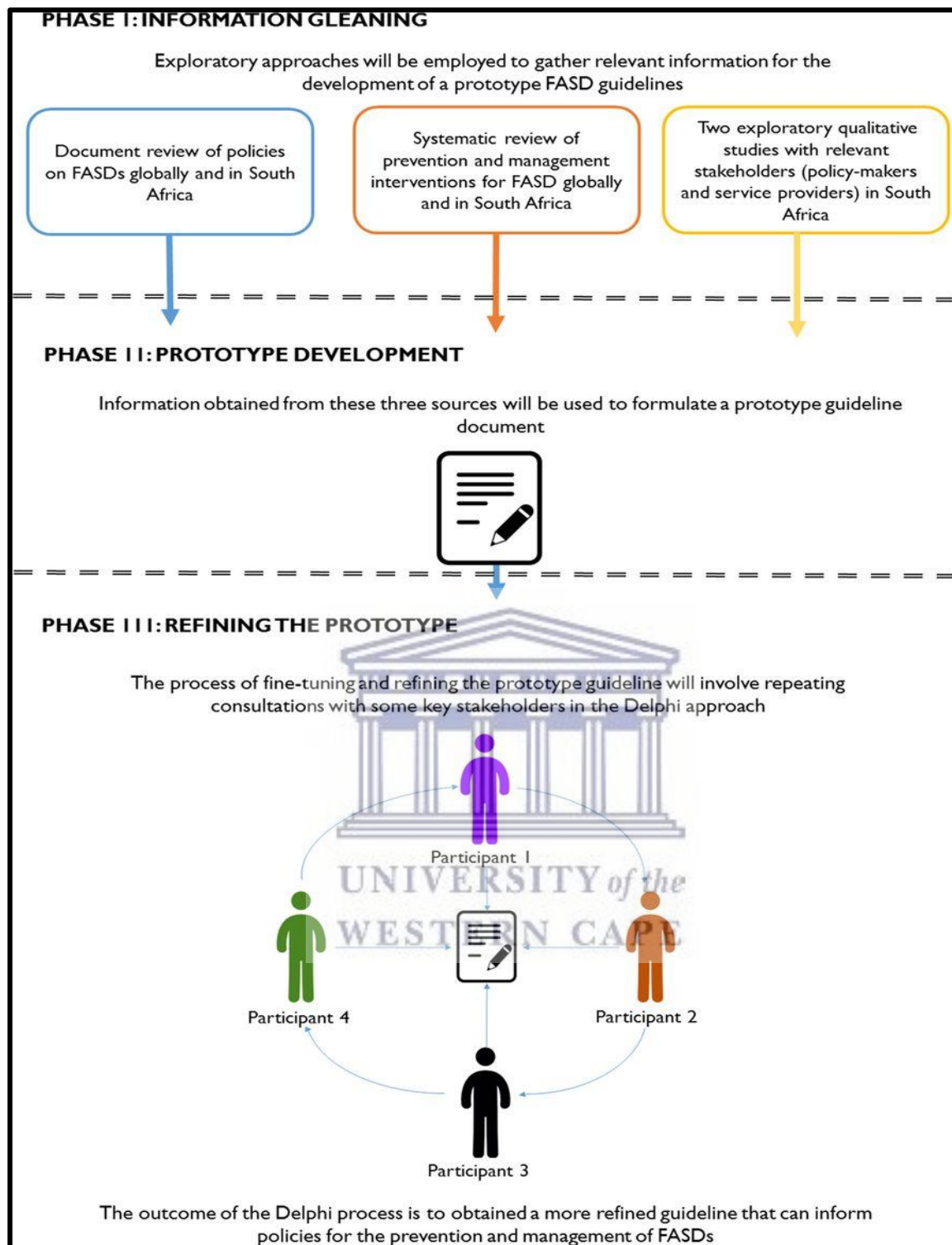
D. Outcomes – a guideline for the prevention and management of FASDs.

4. After agreeing on the need to design the guideline to inform policy on the prevention and management of FASDs, the next step involved designing the project protocol (which is reported in this paper).
5. The team applied for Ethics clearance for the project from the University of the Western Cape – this has been obtained.
6. The next step will entail conducting the various studies and exercises outlined in this protocol.
7. The team will develop and prepare the guideline to inform policy on FASDs based on the findings of the various studies and the outcomes of the various exercises.
8. The team will disseminate the developed guideline through various channels including having feedback meetings with the various stakeholders and sharing our findings, publish the guideline in a peer-reviewed journal, present the findings in journal club meeting organised at the provincial Department of Health and at other national and international conferences [35, 36].

Some of the steps outlined in the WHO's handbook were adapted to our context. The reason for the adaptation is that some parts of the process are not applicable to this study and other parts are beyond the scope of this project.

## **Proposed methodology**

The development of the guideline will follow three phases: (1) Information gleaning, (2) development of prototype and (3) Delphi techniques and developing of guidelines (Figure 1). The importance of involving proven methods, which are both inclusive and participatory, was considered as essential for developing a socially acceptable FASDs guideline for South Africa.



**Figure 1.** A proposed methodological approach for the development of guidelines for fetal alcohol spectrum disorders (FASDs) policy.

## **Phase 1: Information gleaning**

In phase 1, three steps will be undertaken with the purpose of obtaining diverse information to develop a prototype guideline. To this end, we plan to conduct a document review on FASDs policies and a systematic review on FASDs interventions. The document review will consider policies developed South Africa and the systematic review will focus on interventions globally with a focus on South Africa. In addition, we will identify relevant policymakers and service providers from the Departments of Health, Education, and Social Development and engage with them through in-depth interviews and focus group discussions to obtain information on existing policies and interventions on FASDs in South Africa. This information-gleaning phase will be conducted in the following steps.

### **Step 1: Document review of policy on FASD in South Africa**

The researchers will review available relevant documents such as policy documents and guidelines on FASDs. The aim of this review is to explore the availability and content of existing guidelines and policies on FASDs. Websites (government and NPOs) and databases will be searched for these documents. All the policies or guidelines that focused on any aspect of FASDs will be included. A narrative analysis will be used to analyse the relevant documents identified. The information that will be obtained will inform the development of a prototype guideline. Following the document review, a systematic review will be undertaken.

## **STEP 2: Systematic review of interventions for FASDs globally and in South Africa.**

The purpose of the systematic review will be to update the current most recent systematic review on FASDs “Fetal Alcohol Spectrum Disorder Interventions across the life span” [18] to include interventions for prevention. The aim of the systematic review will be to systematically locate, appraise, and synthesise intervention on FASDs. The systematic review will consider the following review question: “What are the prevention and management interventions that are available on FASDs globally and in South Africa?” In conducting this review, the researchers will follow nine steps of a systematic review [40]. These steps include formulating review question, defining search strategy, establishing inclusion criteria and exclusion criteria, choosing a method for the review, conducting methodological quality and critical appraisal, extracting data, analysing and synthesizing data, and writing a report.

What are the interventions that are available on FASDs globally and in South Africa? To answer this question, databases will be searched for articles discussing or evaluating interventions for the prevention and management of FASDs. These databases include, Ebsco Host (Academic Search Complete, ERIC, SoINDEX, Health Source: Nursing/Academic Edition, CINAHL and PsycARTICLES), Science Direct, Springer Links, Wiley Online Library, JSTOR, and SAGE Journals, Pubmed, Cochrane Library, Sabinet, and NEXUS will be searched and retrieved for the period covering 2007 to 2017 using intervention and FASDs as search terms. Furthermore, the references of the retrieved article will be used to search for more articles.

The titles and abstracts of the articles will be screened using inclusion/exclusion criteria and duplicates will be removed. After screening, the articles that meet the inclusion criteria will be read and their methodological quality evaluated. In addition, the included articles will be appraised using a critical appraisal sheet. Narrative synthesis will be used for data analysis. Narrative synthesis can be described as a descriptive written summary of included studies and their findings [41]. The data

extraction tool will consist of four distinct sections namely: the general description, a methodological appraisal, the content intervention, and the analysis of the results. While conducting and reporting the reviews, we will follow the guidelines for systematic reviews.

### **STEP 3: Exploratory qualitative research**

Two exploratory qualitative studies will be conducted. The first qualitative study will explore the availability of guidelines/policies for the prevention and management of FASDs within the South African health system and the need to develop a policy for the prevention and management of FASDs. This study will target the policymakers (administrators involved in policy formulation and programme monitoring on FASDs and related disabilities) from three relevant departments: Department of Education, Department of Health and Department of Social Development.

The second qualitative study will be aimed at identifying existing interventions and guideline/policy statements that are being used by the service providers (individuals involved in providing services and interventions on FASDs and related disabilities) for the prevention and management of FASDs. Relevant service providers include paediatricians, nurses, social workers, and occupational therapist. Policymakers and service providers from the Department of Education, Department of Health and Department of Social Development will be interviewed as part of the processes of developing guidelines that will inform policy on FASDs. These groups of individuals are deemed knowledgeable to provide relevant information toward developing FASDs guidelines.

Purposive sampling will be employed in selecting participants. For the policymakers, we will include those individuals with about five years' experience in policy on FASDs or related disabilities. Similarly, service providers working in primary health care, hospital, schools, social development and NPOs with at least five years of experience in providing interventions and services to individuals with

FASDs will be potential participants. The researchers intend to sample three policymakers from each department and conduct three focus group discussions in each department with an average of 6-8 participants. Data saturation will be used to determine the sample sizes in the two qualitative studies.

In the first qualitative study, data will be collected through in-depth interviews with policymakers using an interview guide. Open-ended questions will be used to start the interviews and follow-up questions will be used to probe for additional explanations when required. The study participants will be asked various questions on available policies on FASDs, the coordination of FASDs interventions and relevant aspects of FASDs to inform the FASDs guidelines. Each interview will last for about 30-60 minutes and each interview will be audio-recorded with the permission from the participants.

Data, in the second qualitative study, will be collected through focus group discussions with selected service providers using a discussion schedule to explore available interventions, services, and policies in practice. Focus groups use unstructured discussion subjects involving small ranges of subjects (6-10). It is cost-effective and time-efficient and participants are allowed to express their viewpoints in detail. Discussants are often motivated to contribute more in the presence of their co-participants [42]. In addition, focus group discussions can give rich information as discussants contribute in moderated discussions. An audio recorder will be used to capture information from the discussants. Notes will also be taken during the interview and the interview recordings will be transcribed for data analysis.

The data will be analysed using thematic content analysis technique [43]. Both inductive – making interpretations of the raw data – and deductive – using a framework – analytic approaches will be used to analyse the data [44]. The framework will be developed from the prevention and management aspects of FASDs. The researchers will use Creswell's data analysis spiral [45]. This process involves reading and memoing, then, describing, classifying and interpreting the data according to themes and

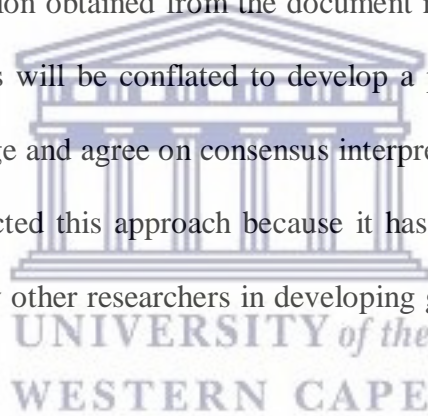


categories and finally visualising and representing the themes and categories. An independent coder will also be used to ensure trustworthiness.

The rigour in the qualitative studies, which is trustworthiness will be established through credibility, transferability, dependability, conformability and reflexivity [46]. In addition, the reporting of the qualitative findings will follow the consolidated criteria for reporting qualitative research (COREQ) [47].

## **Phase 2: Development of prototype**

In the second phase, information obtained from the document review, systematic review and in-depth and focus group interviews will be conflated to develop a prototype guideline for a FASDs policy. The researchers will engage and agree on consensus interpretations of the findings to develop the prototype guideline. We selected this approach because it has been successfully applied in the guideline development process by other researchers in developing guidelines for various issues [48–50].



## **Phase 3: Delphi techniques and developing of guidelines**

In the third phase, we will apply the Delphi approach to refine the developed prototype. The use of the Delphi approach is recommended by the World Health Organization (WHO) Handbook for guideline development [35, 36]. The Delphi technique is a structured communication technique initially developed as a systematic, interactive forecasting method, which relies on a panel of experts [51]. It is common for experts to answer questionnaires in two or more rounds [52]. The researcher gives an anonymous summary of the experts' predictions from the previous round, and the reasons

they provided for their judgments. Experts are encouraged to revise their earlier responses in the light of the replies of other members in the forum. This process narrows the wide range of answers and converges the group answers towards an agreed answer [53]. The process is stopped after a predefined stop criterion and the mean or median scores of the final rounds determine the results [51].

There is no agreement on the sample size of participants in the Delphi discussion forum. We will identify relevant policymakers, health service providers and health policy advocates to participate in a Delphi contribution forum to refine the prototype. Some of the Delphi participants will include those who participated in any of the two qualitative studies. This is because experts on FASDs issues are few and it may be challenging to get a complete set of different participants.

We will start by identifying the experts and contacting them to explain the research. We will then purposefully select 30 experts using the following criteria: Top management decision-makers; policymakers; FASDs service providers and FASDs researchers with about five years of experience relevant to FASDs policies, services and intervention or research [54]. These experts will be contacted via email and telephone for their contributions.

The developed prototype will be used to engage in a Delphi technique with experts on FASDs to develop the proposed guidelines. Descriptions of prevention and management interventions identified in phase 1 will be used to design Likert statements to evaluate the perceptions of the experts on prevention modalities, screening components and management methods. We will solicit their opinions on what should be included or excluded in the proposed guidelines for policies. Participants will be asked to rate their agreement with each statement on a 5-point Likert scale, which will range from 'strongly agree' to 'strongly disagree' and a response option of 'no comment' will be provided to enable participants to indicate that a statement was outside their area of expertise [55].

The data generated will be analysed and these will be used to modify the prototype, which will be used as an instrument for the second round. The experts will be asked to review the items summarised



by the researchers based on the information provided in round one and they will be asked to rate or rank - order items to establish priorities among items and to reach consensus. The information generated in the second round will then be analysed to refine the prototype to obtain the guidelines. The process of guideline development is expected to be evolving, thus, we plan to follow a thorough process and procedures as resource and time would permit.

## **Patient and public involvement**

Patient and public will not be involved in the study. The findings of the study will be disseminated to the study participants through emails.



## **Discussion**

The essence of the proposed guideline is to inform policy development on FASDs. While having informal discussions with the head of a non-governmental organisation, a leading organisation in conducting prevalence studies and rolling out prevention programme on FASDs, we understood that focused guidelines and policies to facilitate effective interventions on FASDs are non-existent. The administrators of the departments of Education, Health and Social Development in the Western Cape province also revealed that drinking alcohol remains a major concern and FASDs are among the negative outcomes of irresponsible drinking practices.

These administrators pointed out that various efforts have been made, ranging from awareness programmes to funding of NGOs to response to FASDs, but these efforts are not being coordinated because there are no specific guidelines or policies on FASDs. Service providers consulted also raised similar concerns. Nevertheless, the service providers suggested that generic programmes are in place

to provide health education on alcohol use during pregnancy to pregnant women and that they would sometimes refer suspected cases of FASDs for proper diagnosis. Of course, these practices are not specifically targeting the problem of FASDs or addressing the issues around FASDs in an intended manner. The lack of focused attention accorded to FASDs prompted the conception to develop guidelines that will enhance the prevention and management of FASDs.

The strength of using the approach outlined in this protocol lies in the fact that it has been successfully used to develop various guidelines for interventions to combat diseases and improve services. In addition, the recommendations from the guidelines will be rooted in a comprehensive and objective assessment of the available evidence and a clear pathway on how recommendations are generated. The demerit of this process is that it requires a lot of resources, time and expertise. The limitation of this study might be that the researchers will not include the individuals with FASDs and their families directly in the study. Another limitation is that the study is restricted to the Western Cape region of South Africa, which might affect the generalizability of the study findings.

It has been reported that there are no guidelines for determining consensus, sample size and sampling techniques when using the Delphi approach. This is because these aspects of the Delphi technique require a lot of time and participants' commitment, consequently, dropout is likely to happen, which leads to low response rate and a delay in data analysis between rounds [56, 57]. To mitigate the impact of these potential challenges, the researchers have decided to adapt the sample size to a manageable number to favour the in-depth engagement and discursive approach with fewer experts, rather than having a large sample of experts with less engagement with the guideline development process.

The finalised guideline will be distributed to all the participants in the study and to the departments of Health, Education and Social Development as well as to the relevant NGOs working on FASDs. The guideline will also be published in a peer-review journal to add to the literature on FASDs.

## **Ethics and Dissemination**

The approval for the study was obtained from the research ethics committee of the University of the Western Cape (BM/16/4/4) and further approvals were obtained from the Western Cape Department of Education (20161212-6937), Department of Health (WC\_2016RP29\_862) and Social Development (12/1/2/4). Before the interviews and the FGDs, the study aims and objectives we will explain to the potential participants and they will be provided with an information sheet written in English explaining their roles. The potential participants will be requested to sign a consent form if they agreed to participate in the study. All participants for the interviews and FGDs will be asked to sign a consent form All information obtained during the study will be kept strictly confidential in a computer with a password known only to the researchers in this study.



## **Declarations**

### **Consent for publication**

Not applicable

### **Competing interests**

The authors declare that there is no competing interest

## **Funding**

This work received no funding

## **Authors' contributions**

BOA and AMB conceived and conceptualised the study and the paper. BOA designed and wrote the first draft of the manuscript. FCM redesigned the manuscript, contributed to the development of the paper and provided comments to improve the manuscript. KJO contributed to the development of the paper and provided comments to improve the manuscript. All authors read and approved the final manuscript.

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## References

- [1] Chudley AE, Conry J, Cook JL, et al. Fetal Alcohol Spectrum Disorder: Canadian guidelines for diagnosis. *CMAJ* 2005; 172: S1–S21.
- [2] Jones KL, Smith DW. Recognition of the Fetal Alcohol Syndrome in early infancy. *Lancet* 1973; 302: 999–1001.
- [3] Jones KL, Smith DW, Ulleland CN, et al. Pattern of malformation in offspring of chronic alcoholic mothers. *Lancet (London, England)* 1973; 1: 1267–71.
- [4] Warren KR. A review of the history of attitudes toward drinking in pregnancy. *Alcohol Clin Exp Res* 2015; 39: 1110–1117.
- [5] Ann P. Streissguth, Helen M. Barr, Julia Kogan et al. Understanding the occurrence of secondary disabilities in clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). *Centers for Disease Control and Prevention* 1996; 96–6.
- [6] Riley EP, Mcgee CL. Fetal Alcohol Spectrum Disorders: An overview with emphasis on changes in brain and behavior. *Experimental Biol Med* 2005; 230: 358–365.
- [7] Riley EP, Infante MA, Warren KR. Fetal Alcohol Spectrum Disorders: an overview. *Neuropsychol Rev* 2011; 21: 73–80.
- [8] Clark E, Lutke J, Minnes P, et al. Secondary disabilities among adults with Fetal Alcohol Spectrum Disorder in British Columbia. *J FAS Int* 2004; 2: 1–12.
- [9] Esper LH, Furtado EF. Identifying maternal risk factors associated with Fetal Alcohol Spectrum Disorders: a systematic review. *Eur Child Adolesc Psychiatry* 2014; 23: 877–889.

- [10] Olivier L, Curfs LMG, Viljoen DL. Fetal Alcohol Spectrum Disorders: prevalence rates in South Africa. *South African Med J* 2016; 106: 103.
- [11] Urban M, Chersich MF, Fourie L-A, et al. Fetal Alcohol Syndrome among grade 1 school children in Northern Cape Province: prevalence and risk factors. *S Afr Med J* 2008; 98: 877–82.
- [12] Urban MF, Olivier L, Viljoen D, et al. Prevalence of Fetal Alcohol Syndrome in a South African city with a predominantly black African population. *Alcohol Clin Exp Res* 2015; 39: 1016–1026.
- [13] May PA, Gossage JP, Marais A-S, et al. The epidemiology of fetal alcohol syndrome and partial FAS in a South African community. *Drug Alcohol Depend* 2007; 88: 259–71.
- [14] May PA, Blankenship J, Marais A-S, et al. Approaching the prevalence of the full Spectrum of Fetal Alcohol Spectrum Disorders in a South African population-based study. *Alcohol Clin Exp Res* 2013; 37: 818–30.
- [15] May PA, de Vries MM, Marais A-S, et al. The continuum of Fetal Alcohol Spectrum Disorders in four rural communities in South Africa: prevalence and characteristics. *Drug Alcohol Depend* 2016; 159: 207–218.
- [16] Jones KL, Streissguth AP. Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorders: a brief history. *J Psychiatry Law* 2010; 38: 373–382.
- [17] Peadon E, Rhys-Jones B, Bower C, et al. Systematic review of interventions for children with Fetal Alcohol Spectrum Disorders. *BMC Pediatr* 2009; 9: 35.
- [18] Reid N, Dawe S, Shelton D, et al. Systematic review of Fetal Alcohol Spectrum Disorder interventions across the life span. *Alcohol Clin Exp Res* 2015; 39: 2283–2295.

- [19] Rehm J, Rehn N, Room R, et al. The global distribution of average volume of alcohol consumption and patterns of drinking. *Eur Addict Res* 2003; 9: 147–56.
- [20] Kalichman SC, Simbayi LC, Cain D, et al. Alcohol expectancies and risky drinking among men and women at high-risk for HIV infection in Cape Town South Africa. *Addict Behav* 2007; 32: 2304–2310.
- [21] Kalichman SC, Simbayi LC, Vermaak R, et al. HIV/AIDS risks among men and women who drink at informal alcohol serving establishments (Shebeens) in Cape Town, South Africa. *Prev Sci* 2008; 9: 55–62.
- [22] Kalichman SC, Simbayi LC, Vermaak R, et al. Randomized trial of a community-based alcohol-related HIV risk-reduction intervention for men and women in Cape Town, South Africa. *Ann Behav Med* 2008; 36: 270–279.
- [23] Suliman S, Seedat S, Williams DR, et al. Predictors of transitions across stages of alcohol use and alcohol-use disorders in South Africa. *J Stud Alcohol Drugs* 2010; 71: 695–703.
- [24] Viljoen DL, Gossage JP, Brooke L, et al. Fetal Alcohol Syndrome epidemiology in a South African community: a second study of a very high prevalence area. *J Stud Alcohol* 2005; 66: 593–604.
- [25] Popova S and Chambers C. Fetal Alcohol Spectrum Disorders must be recognized globally as a large public health problem. *IJADR* 2014; 3: 1.
- [26] Cook JL, Green CR, Lilley CM, et al. Fetal Alcohol Spectrum Disorder: a guideline for diagnosis across the lifespan. *CMAJ* 2016; 188: 191–7.
- [27] Edition F. *Diagnostic and statistical manual of mental disorders*. [https://psychiatryonline.org/pb-assets/dsm/update/DSM5Update\\_October2017.pdf](https://psychiatryonline.org/pb-assets/dsm/update/DSM5Update_October2017.pdf) (2013, accessed 28 February 2018).



- [28] National Organisation for Fetal Alcohol Spectrum Disorders. National FASD Action Plan. <http://www.nofasd.org.au/policy-and-advocacy/national-fasd-action-plan> (2014, accessed 8 January 2018).
- [29] Fitzpatrick JP, Latimer J, Carter M, et al. Prevalence of Fetal Alcohol Syndrome in a population-based sample of children living in remote Australia: The Lililwan project. *J Paediatr Child Health* 2015; 51: 450–457.
- [30] Fitzpatrick JP, Latimer J, Olson HC, et al. Prevalence and profile of neurodevelopment and Fetal Alcohol Spectrum Disorder (FASD) amongst Australian Aboriginal children living in remote communities. *Res Dev Disabil* 2017; 65: 114–126.
- [31] Adnams CM. Fetal Alcohol Spectrum Disorder in Africa. *Curr Opin Psychiatry* 2017; 30: 108–112.
- [32] Rendall-Mkosi K, London L, Adnams C, et al. Fetal Alcohol Spectrum Disorder in South Africa: situational and gap analysis. *UNICEF, Pretoria.* [https://www.unicef.org/southafrica/SAF\\_resources\\_fetalalcohol.pdf](https://www.unicef.org/southafrica/SAF_resources_fetalalcohol.pdf) (2008, accessed 14 September 2017).
- [33] FASDSA - The Task Team. <http://www.fasdsa.org/team.html> (accessed 10 June 2017).
- [34] Marais S, Jordaan E, Olivier L, et al. Fetal Alcohol Spectrum Disorders. In: A. Van Niekerk, S. Suffla, & M. Seedat (Eds.), *Crime, Violence and Injury in South Africa: 21st Century Solutions for Child Safety* 2012; pp. 214–228.
- [35] Blas E, Koller T, Magar V, et al. WHO library cataloguing-in-publication data WHO Handbook for guideline development. *Peer Rev Evidence-based Med World Heal Organ* 2014; 1: 179.



- [36] World Health Organisation. *WHO handbook for guideline development*. World Health Organisation. [http://apps.who.int/iris/bitstream/10665/75146/1/9789241548441\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/75146/1/9789241548441_eng.pdf) (2012, accessed 1 March 2018).
- [37] National Institute for Health and Care Excellence. *Developing NICE guidelines: the manual*. <https://www.nice.org.uk/media/default/about/what-we-do/our-programmes/developing-nice-guidelines-the-manual.pdf> (2014, accessed 10 June 2017).
- [38] Information Technology Services Home SLU. Policies, standards, guidelines, procedures/processes: Saint Louis University Information Technology Services: SLU. <http://www.slu.edu/its/policies> (2017, accessed 10 June 2017).
- [39] Methley AM, Campbell S, Chew-Graham C, et al. PICO, PICOS and SPIDER: a comparison study of specificity and sensitivity in three search tools for qualitative systematic reviews. *BMC Health Services Research* 2014; 14: 579.
- [40] Boland A, Cherry G, Dickson R. *Doing a systematic review: A student's guide*. Sage. [https://books.google.co.za/books?hl=en&lr=&id=Zpc3DwAAQBAJ&oi=fnd&pg=PP1&dq=Boland,+A.,+Cherry,+M.+G.+%26+Dickson,+R.+\(Eds.\).+\(2013\).+Doing+a+systematic+review:+A+student%27s+guide.+Sage.&ots=KhE40AKLA8&sig=62dUpp14JZ0f0LNrYmojuszLZCE](https://books.google.co.za/books?hl=en&lr=&id=Zpc3DwAAQBAJ&oi=fnd&pg=PP1&dq=Boland,+A.,+Cherry,+M.+G.+%26+Dickson,+R.+(Eds.).+(2013).+Doing+a+systematic+review:+A+student%27s+guide.+Sage.&ots=KhE40AKLA8&sig=62dUpp14JZ0f0LNrYmojuszLZCE) (2017, accessed 1 March 2018).
- [41] Petticrew M, Roberts H. How to appraise the studies: an introduction to assessing study quality. In: *Systematic Reviews in the Social Sciences*. Oxford, UK: Blackwell Publishing Ltd 2006; pp. 125–163.
- [42] Patton, MQ. *Qualitative evaluation and research methods (2nd ed.)*. Thousand Oaks, CA, US: Sage Publications, 1990.

- [43] Miles M, Huberman A. *Qualitative data analysis: an expanded sourcebook*. Sage. [https://books.google.co.za/books?hl=en&lr=&id=U4IU\\_-wJ5QEC&oi=fnd&pg=PR12&dq=Qualitative+data+analysis:+An+expanded+sourcebook.&ots=kETi6LOSUR&sig=myBC5ImkUmJHO1z2hizEOBwQzD4](https://books.google.co.za/books?hl=en&lr=&id=U4IU_-wJ5QEC&oi=fnd&pg=PR12&dq=Qualitative+data+analysis:+An+expanded+sourcebook.&ots=kETi6LOSUR&sig=myBC5ImkUmJHO1z2hizEOBwQzD4) (1994, accessed 1 March 2018).
- [44] Burnard P, Gill P, Stewart K, et al. Analysing and presenting qualitative data. *Br Dent J* 2008; 204: 429–432.
- [45] Creswell JW, Poth CN. *Qualitative inquiry and research design: choosing among five approaches*. SAGE, 2016.
- [46] De Vos AS, Delpont C, Fouche C, et al. *Research at grass roots: for the social sciences and human services professions*. Van Schaik, 2011.
- [47] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Heal Care* 2007; 19: 349–357.
- [48] Govender B. The development of guidelines for social workers involved in early childhood development within the Department of Social Development. <http://etd.uwc.ac.za/handle/11394/4972> (2016, accessed 24 August 2017).
- [49] Pharaoh H, Frantz J, Smith M. Development, implementation and evaluation of youth development programmes to address health risk behaviour among grade 8 to grade 10 learners in selected schools in the Paarl area. [http://etd.uwc.ac.za/bitstream/handle/11394/4297/pharaoh\\_h\\_phd\\_chs\\_2014.pdf?sequence=1&isAllowed=y](http://etd.uwc.ac.za/bitstream/handle/11394/4297/pharaoh_h_phd_chs_2014.pdf?sequence=1&isAllowed=y) (2014, accessed 24 August 2017).



- [50] Guidelines in designing a warm up program for the prevention of playing related musculoskeletal disorder among instrumentalists Adedayo Tunde Ajidahun 3102086. [http://etd.uwc.ac.za/bitstream/handle/11394/3035/Ajidahun\\_MSC\\_2011.pdf?sequence=1&isAllowed=y](http://etd.uwc.ac.za/bitstream/handle/11394/3035/Ajidahun_MSC_2011.pdf?sequence=1&isAllowed=y) (2011, accessed 24 August 2017).
- [51] Rowe G, Wright G. The Delphi technique as a forecasting tool: issues and analysis. *Int J Forecast* 1999; 15: 353–375.
- [52] Hsu C-C. The Delphi technique: making sense of consensus. *Pract assessment, Res Eval* 2007; 12: 1–8.
- [53] Keeney S, Hasson F, McKenna H. Consulting the oracle: ten lessons from using the Delphi technique in nursing research. *J Adv Nurs* 2006; 53: 205–212.
- [54] Linstone H, Turoff M. *The delphi method* <https://pdfs.semanticscholar.org/8634/72a67f5bdc67e4782306efd883fca23e3a3d.pdf> (1975, accessed 1 March 2018).
- [55] Watkins RE, Elliott EJ, Halliday J, et al. A modified Delphi study of screening for Fetal Alcohol Spectrum Disorders in Australia. *BMC Pediatr* 2013; 13: 13.
- [56] Donohoe H, Stellefson M, Tennant B. Advantages and limitations of the e-Delphi technique. *Am J Heal Educ* 2012; 43: 38–46.
- [57] Keeney S, Hasson F, McKenna HP. A critical review of the Delphi technique as a research methodology for nursing. *Int J Nurs Stud* 2001; 38: 195–200.

# SECTION II

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## INFORMATION GLEANING

### OVERVIEW

Information gleaning is the first phase of the process for the development of a guideline to inform policy on FASD. To develop a guideline, various methods of enquiry and data collection techniques were employed to gather information. The information gathered in this section was used to develop a prototype guideline. The information-gleaning phase was conducted in the following steps.

In the first step (**Chapter 2**), an exploratory qualitative study was conducted. Service providers from the Department of Education, Health and Social Development were purposively selected for focus group discussions. Questions were asked about current practices and policy requirements for FASD. This chapter has been published in BMC Public Health in 2018.

In the second step (**Chapter 3**), a second exploratory qualitative study was conducted with the policymakers. Policymakers were purposively selected from the Department of Education, Health and Social Development for in-depth interviews. This chapter has been published in the International Journal of Environmental Research and Public Health in 2019.

In step 3 (**Chapter 4**), we conducted a review of related policy documents in South Africa to identify the clauses that are directly or indirectly addressing FASD. This chapter has been published in BMC Health Research Policy and Systems in 2019.

In step 4 (**Chapter 5**), we conducted a scoping review of intervention for the prevention and management of FASD globally. This is under review in the International Journal of Environmental Research and Public Health.



## CHAPTER TWO

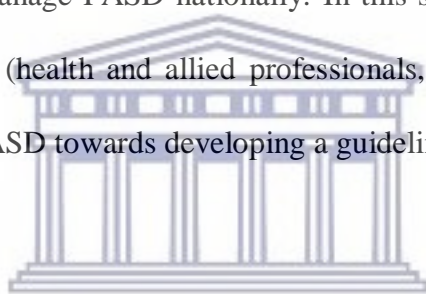
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Exploring service providers' perspectives on the prevention and management of fetal alcohol spectrum disorders in South Africa: A qualitative study. BMC Public Health. 2018; 18:1238. doi: 10.1186/s12889-018-6126-x

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### Abstract

**Background:** Fetal alcohol spectrum disorder (FASD) is among the leading causes of developmental and intellectual disabilities in individuals. Although efforts are being made toward the prevention and management of FASD in South Africa, the prevalence remains high. The sustained high prevalence could be attributed to several factors, including the lack of policy for a coordinated effort to prevent, diagnose and manage FASD nationally. In this study, our aim was to explore the perspectives of service providers (health and allied professionals, teachers, social workers) on the prevention and management of FASD towards developing a guideline to inform policy.



**Method:** Guided by the exploratory qualitative research design, we purposively sampled relevant service providers in the field of FASD prevention and management for focus group discussions. Nine of these discussions were conducted with an average of eight participants per discussion session. The discussants were asked various questions on the current and required interventions and practices for the prevention and management of FASD. Following the Framework Method, data were transcribed verbatim and analysed using the thematic content analysis approach.

**Results:** Our findings show that aspects of the prevention and management of alcohol-related conditions are present in various policies. However, there is no clear focus on coordinated, multi-sectoral efforts for a more comprehensive approach to the prevention and management of FASD. The

participants recognized the need for specific requirements on broad-based preventive awareness programs, training and support for parents and caregivers, inclusive education in mainstream schools and training of relevant professionals.

**Conclusion:** Comprehensive and coordinated prevention and management programs guided by a specific policy could improve the prevention and management of FASD. Policy formulation demonstrates commitment from the government, highlights the importance of the condition, and elaborates on context-specific prevention and management protocols.



## Background

Although generic programs and interventions exist for the prevention and management of fetal alcohol spectrum disorder (FASD), the prevalence in South Africa continues to rise. FASD is a group of conditions used to describe a range of developmental disabilities resulting from prenatal alcohol exposure [1–3]. Individuals with FASD may have abnormal facial features, low body weight, poor coordination, learning disabilities, difficulty with attention, poor reasoning and judgment skills, speech and language delays, hyperactive behavior, and intellectual difficulties or a low IQ (intellectual quotient) [4].

The global prevalence of FASD has been estimated at 8 per 1,000 children and youth in the general population [5]. Zelner and Koren [6] estimated the prevalence of FASD at 9 per 1,000 live births in Canada. In Italy, the prevalence of FASD was reported to be 23 to 47 per 1,000 in first-grade pupils [7], while in Croatia, it was estimated to be 40 per 1,000 in elementary school children [8]. In four communities of USA, the prevalence was estimated to be 11 to 50 per 1,000 children [9], and in a secluded Indigenous population in Australia, the reported prevalence was 194.4 per 1,000 children [10].

In South Africa, FASD prevalence has been estimated to be between 29 to 290 per 1,000 live births [11]. In the Western Cape Province, studies conducted on the prevalence of FASD among primary school pupils showed a persistent increase over the years. In 2007, the prevalence of FASD was estimated at 89.2 per 1,000 [12], and by 2013, it had doubled (135.1 to 207.5 per 1,000) [13]. In 2016, the prevalence of FASD showed a persistent increase (170 to 233 per 1,000) [14], and in 2017 yet another increase among the same group (196 to 276 per 1,000) was recorded [15]. Owing to the excessive alcohol use, the Northern and Western Cape Provinces carry the brunt of FASD in South Africa [16, 17]. The persistent rise in the FASD prevalence in these two Provinces highlights the need



for a coordinated effort – context-specific preventive interventions, early identification, diagnosis, and management – in dealing with FASD.

FASD is recognized as a public health concern in most countries around the world [18–20]. Public health practitioners have advocated for specialized services to address FASD [18, 21]. Services such as context-specific prevention programs, well-resourced mental health facilities for the management of FASD-related mental health problems, specialized schools to manage learning disabilities, and alcohol rehabilitation services for people with substance abuse problems have been identified as pivotal to the prevention and management of FASD [18]. In addition, community-based programs to support pregnant women and sustainable commitment from government and service providers are required to address the high FASD prevalence [18, 21]. Furthermore, Poole et al. [22] identified a four-level comprehensive approach to the prevention and management of FASD, with level two focusing on women of reproductive age and their partners. This comprehensive approach is a step closer to a social determinant approach, which seeks to understand the social, historical, political, and economic underlying causes of disease.

Policy development for FASD aligns with goal three and four of the Sustainable Development Goals [23]. For interventions and programs to be effective and sustainable, they should be embedded in guidelines that may facilitate the development of a FASD policy [24, 25]. Policy development is a step towards designing legislations, which would allow practitioners to make informed decisions, take prompt treatment and management actions, and plan, develop and implement comprehensive community-based interventions [24, 26]. While developing a policy may not be a panacea to achieving the effectiveness and sustainability of interventions for FASD, it may create a framework for the implementation and support for individualized and integrated care [25, 27]. Countries like Canada and Australia with FASD problems similar to South Africa have acknowledged the importance of policies for addressing FASD [28–30]. In South Africa, however, there are no specific FASD policies [31].

Despite the absence of a specific FASD policy [20, 32], other health-related policies contain clauses that could be attributed to the prevention and management of FASD in South Africa. These policies include the Prevention and Treatment of Drug Dependency Act, South Africa Social Security Act, Children's Act 38 of 2005, National Programme of Action for Children, Human Genetics Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities. Other documents include the National Guidelines for the Management and Prevention of Drug Use and Abuse, National Drug Master Plan 2006-2011, Guidelines for Maternity Care in South Africa, Education White Paper 5 on Early Childhood Development and Education White Paper 6 on Inclusive Education [31]. In addition, an American-based practical clinical approach to the diagnosis of fetal alcohol spectrum disorders based on the institute of medicine criteria developed by USA researchers has been used to diagnose FASD in South Africa [33].

Rendall-Mkosi et al. [31] suggested a comprehensive FASD prevention and management approach to be adopted by various government departments (Table 1). Some of the services identified in their approach to the prevention and management of FASD were also mentioned in the Australian action plan on FASD [30] and the Canadian framework for action on FASD [34]. In the Australian action plan, the proposed principles for action were the population health framework, a whole government approach, a human rights-based approach, and women-centered practice. The Canadian framework for action on FASD also highlighted that a comprehensive approach to prevention and management of FASD requires individual and collaborative actions, all sectors, and all government levels (national, provincial and community). In addition, efforts need to focus on prevention, meeting current needs of people with FASD, and strengthening and expanding the support systems, services, and resources.

**Table 1:** Relevant government departments' responsibilities towards the prevention and management of FASD

Relevant government departments	Responsibilities towards the prevention of FASD	Responsibilities towards the management of FASD
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Department of Health	<ul style="list-style-type: none"> <li>- Estimate the prevalence of FAS and FASD</li> <li>- Determine the surveillance strategy for Alcohol-exposed pregnancy (AEP)</li> <li>- Screen for women at high risk for an AEP: binge drinking without using contraceptives</li> <li>- Implement strategies to prevent AEP in high-risk settings e.g. brief interventions at primary level</li> <li>- Create and disseminate educational materials on medical issues for FASD to the public and service providers</li> <li>- Training of service providers on medical issues for FASD</li> </ul>	<ul style="list-style-type: none"> <li>- Developmental screening and referral at birth and infancy.</li> <li>- Diagnosis, feeding support and parenting support in early childhood.</li> <li>- Contraception services for individuals with FASD</li> <li>- Mental health services for individuals with FASD</li> </ul>
Department of Education	<ul style="list-style-type: none"> <li>- Provide secondary and tertiary level education for adolescents and young women</li> <li>- Life skills training in secondary education</li> <li>- Create and disseminate educational materials on educational issues for FASDs to the public and service providers</li> <li>- Training of service providers on educational issues for FASD</li> </ul>	<ul style="list-style-type: none"> <li>- Provide crèches and pre-schools for individuals with FASD</li> <li>- Teacher and parent training on how to manage learning, language, and attention problems in individuals with FASD</li> <li>- Supportive educational environment for individuals with FASD</li> <li>- Classroom support for teachers</li> <li>- Development of specific learning interventions</li> <li>- Life skills training for individuals with FASD</li> </ul>
Department of Social Development	<ul style="list-style-type: none"> <li>- Support for women at high alcohol risk and their families.</li> <li>- Recreational activities to promote healthy lifestyles</li> <li>- Access to specialised alcohol rehabilitation services</li> <li>- Create and disseminate educational materials on social issues for FASD to the public and service providers</li> <li>- Training of service providers on social issues for FASD</li> </ul>	<ul style="list-style-type: none"> <li>- Access to social grants.</li> <li>- Family support against stigma and assistance with child management in the family.</li> <li>- Developing a supportive home environment for women and individuals with FASD</li> <li>- Supportive community for individuals with FASD</li> <li>- Promoting independent among individuals with FASD</li> </ul>
Department of Justice, Safety, and Security	<ul style="list-style-type: none"> <li>- Enforcing liquor laws</li> <li>- Regulation of the liquor industry</li> <li>- Legal protection for women and individuals with FASD</li> <li>- Create and disseminate educational materials on legal issues for FASD to the public and service providers</li> <li>- Training of service providers on legal issues for FASD</li> </ul>	<ul style="list-style-type: none"> <li>- Vulnerable to physical and sexual abuse and domestic violence</li> <li>- Better awareness by the police of FASD vulnerability e.g. recognition of disability in the legal process</li> </ul>
Department of Labour	<ul style="list-style-type: none"> <li>- Work-related skills training for Individuals with FASD</li> <li>- Employment opportunities for women</li> <li>- Create and disseminate public and provider educational materials on labour</li> </ul>	<ul style="list-style-type: none"> <li>- Maternity leave for women to ensure early proper management for individuals with FASD</li> <li>- Efficient unemployment insurance fund (UIF) process</li> </ul>

	issue for FASD to the public and service providers Training of service providers on labour issues for FASD	<ul style="list-style-type: none"> <li>- Alternative skills training for individuals with FASD</li> <li>- Meaningful employment opportunities for individual with FASD (sheltered/mental work)</li> </ul>
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To incorporate the above-mentioned approach and principles and address the lack of a coordinated and holistic plan to tackle FASD in South Africa, we propose the development of a guideline to inform a multi-sectoral and interdepartmental policy [35]. In this paper, we report on a step toward developing a guideline for policy on FASD – exploring the perspectives of service providers (teachers, social workers, occupational therapists, nurses, pediatricians, doctors, and psychologists) on the prevention and management of FASD in South Africa.

## Methods

### Study setting

The study was conducted in the Western Cape Province of South Africa. The Western Cape Province is the fourth largest and the third most populated Province in South Africa with an estimated 6.5 million residents [36].

In the Western Cape Province, alcohol-related business activities ranked second in the most common category of business in the township economy [37]. Most of these businesses are run by women to complement their family income. There are about 25,000 illegal liquor stores (known as shebeens - home-based taverns) in the province, making alcohol accessible to people of all ages [37]. This province is also known for its historical ‘Dop’ system whereby farmworkers’ partial wages were paid in the form of alcohol [38]. The legacy of the ‘Dop’ system reflects a distinctive drinking culture deep-rooted in the social matrix of farmworkers as well as informal settlements where employers paid

their laborers with cheap wine [38]. Alcohol abuse is, therefore, rife in the Western Cape Province owing to its cultural context [39].

According to Statistics South Africa [40], in the Western Cape, 38.1% of women reported consuming alcohol at least once during their lifetime and 27.3% reported drinking alcohol in the past 12 months. In addition, 18.0% reported drinking alcohol in the past seven days and 9.0% reported consuming five or more drinks on at least one occasion in the past 30 days. Furthermore, according to Petersen Williams et al. [41], 36.9% of women in the Western Cape Province consumed alcohol during pregnancy or in the last three months before they were aware of their pregnancy. The uncontrolled sale and drinking patterns displayed by the community, including women who are pregnant, reveal the endemic nature of the risk factors for FASD in the Western Cape [42] and could be the reason behind the increasing prevalence of FASD [14].



## **Study design**

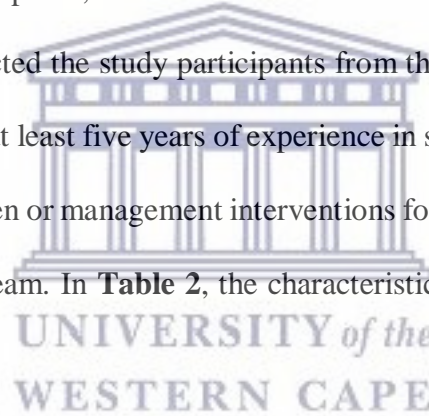
We employed an exploratory qualitative study design to investigate the perspectives of the service providers. According to Glenton, Lewin, Norris and Norris [43], evidence from qualitative research enriches the development and implementation of guidelines as it permits a comprehensive exploration of the perspectives and considerations of relevant stakeholders.

## **Sampling procedure**

For FASD to be effectively prevented, identified, diagnosed, and managed, a wide range of professionals is required. These professionals should consist of nurses, social workers, physicians, psychologist, occupational therapist, speech-language pathologist, and primary healthcare providers (who provide antenatal care and counselling for pregnant women and preventive services for community members) [42]. The professionals may also include addiction counsellors, childcare

workers, cultural interpreters, mental health workers, parents or caregivers, probation officers, psychiatrists, teachers, vocational counsellors, geneticists or dysmorphologists, neuropsychologists, and family therapists [2, 28, 29].

A two-step purposive sampling approach was employed to select the relevant institutions (healthcare facilities, schools, and [non-profit organizations] NPOs) and service providers (allied health, medical, nurse, teacher, and other professionals). In the first step, after permission was obtained from the study host University, we approached each department (Education, Health, and Social Development) for permission. Thereafter, we purposively selected 13 institutions because they render prevention or/and management services on FASD in the Western Cape to participate in the study. However, only ten facilities participated, which included four healthcare facilities, three schools, and three NPOs. In step two, we selected the study participants from the selected institutions. We sought to include service providers with at least five years of experience in service delivery and implementing prevention interventions for women or management interventions for individuals with FASD that were members of a multidisciplinary team. In **Table 2**, the characteristics of the 65 participants that were included in the study are shown.



**Table 2: Characteristics of the study participants**

<b>Characteristics</b>	<b>Participants (N = 65)</b>
Types of institutions	
Schools	3
Healthcare facilities	4
NPOs	2
Gender	
Male	5
Female	60
Profession	
Allied health	20
Medical	10
Nurse	6
Teacher	26



Others	3
Working experience (years)	
1-10	33
11-20	19
21-30	10
31-40	3

## Data collection

Focus group discussions (FGDs) were conducted in English between September 2016 and September 2017. The discussions were guided by a discussion schedule (**Additional file 1**). Open-ended questions were used to start the discussions and we used follow-up questions to probe for additional explanations from the participants when necessary. The study participants were asked various questions on policies that guide the FASD interventions and services, and relevant aspects of FASD to inform the FASD policy. Each discussion lasted about 30–60 minutes and was audio-recorded with permission from the participants. Nine FGDs were conducted with six to eight participants in each group. While conducting the FGDs multiple participants were asked questions, and their responses were noted [44]. Our data collection process was guided by data saturation [44, 45]. We reached data saturation when new information was not elicited with subsequent discussions, and we judged that there were enough data to answer the research questions [46, 47].

## Data analysis

The Framework Method was used to analyze the data [48]. Framework Method is part of the thematic analysis family [49]. Using the Framework Method, one author (BOA) transcribed the discussions, and two of the authors (BOA, FCM) read these thoroughly for familiarization. Notes and memos were made from the transcripts to inductively generate the initial codes, and these codes were re-organized to obtain refined codes. Using the initial codes, two of the authors (BOA, FCM) developed a coding guide (**Appendix A**) and discussed this with the research team (BOA, FCM, LGC, AMB). Codes with similar ideas were clustered to form sub-themes and sub-themes with identical

concepts were further grouped to form the final themes. The coding guide developed was used by ascribing relevant aspects of the texts in the subsequent transcripts to existing categories, themes, and sub-themes. Finally, we charted the data into the framework matrix as illustrated in **Additional files 2 and 3**.

## **Trustworthiness and rigor of the study**

In this study, rigor and trustworthiness were established through explicit measures to ensure credibility, transferability, dependability, conformability, and through a reflexive approach to the inquiry and analysis [50]. To ensure credibility, during the data collection, we ensured that the discussants were allowed to express themselves freely during the discussions. At the end of each FGD, we revisited the main points that came out of the discussions to confirm agreements, disagreements, additions, and corrections from the participants. We also kept a reflective journal during the study, which documented the discussions, deliberations, and decisions of the research team. To ensure the credibility of the study findings, we provided a comprehensive description of the study methodology, and the findings are supported by verbatim responses from the participants. In reporting this study, we followed the relevant aspects of the consolidated criteria for reporting qualitative research (COREQ) [51] (**Appendix B**). The discussion schedule was designed based on FASD literature and in consultation with the research team to ensure dependability. We also ensured the use of the same discussion schedule to guide all the discussions. Furthermore, one member of the research team (BOA) under the guidance of another member (FCM) coded the transcriptions and met afterward to discuss the findings.



## Data management

To maintain anonymity and easy identification of the information sources, we coded service providers (health professionals, teachers, and NPO workers) in the various departments (Education, Health, and Social Development) as DOE<sub>x</sub>, DOH<sub>x</sub>, and DSD<sub>x</sub>. The <sub>x</sub> denotes an arbitrary number from 1–12. The information will be kept for ten years.

## Results

Following the coding guide (**Appendix A**) the findings are presented under the categories, availability of guidelines/policies on FASD, development of guideline/policy document, current practices and available interventions, and identified policy requirements for FASD.

### Category 1: No available guidelines/policies on FASD

All the selected relevant service providers (health professionals, teachers, and NPO workers) acknowledged the absence of policies/guidelines to coordinate efforts toward addressing the issues around FASD.

There is no policy that I am aware of, either in the hospital or at the [Western Cape] province as far as FASD are concerned. (**DOH<sub>2</sub> Health professional<sub>8</sub>**)

There is no guideline to guide us on how to do things, how to deliver our services better than what we are doing now. I think the research [on FASD] is not sufficient to guide the policymakers at the moment [to develop policy on FASD]. (**DSD<sub>2</sub> NPO worker<sub>3</sub>**)

There is no clear policy or guideline for us that guides the intervention. Our NPO is under the Department of Social Development (DSD) and with our intervention programs, we have just started prioritizing [FASD] and I think that it is why your study is so important to see what [FASD] policies that can be put in place. (**DSD<sub>1</sub> NPO worker<sub>3</sub>**)

Some of the participants, however, indicated that various clauses exist in different policies, which could be used for the prevention and management of FASD.

No, we do not [have a policy for FASD], they have mentioned [FASD clauses] in health [policies], but there is no clear [FASD] policy. **(DSD<sub>1</sub> NPO worker<sub>1</sub>)**

I think the government has it [FASD-related management] on add-on basis [in other policies]. [For example], the Department of Education has a policy on inclusive education that will govern the education of all children with special needs, including children with FASD. The Department of Health recognized these [FASD] as a mental health issue and they [FASD] are mentioned in Western Cape Government policy like first 1,000 days. I do not think there is a specific document called FASD policy in Western Cape, but you can find an overview of FASD in different policies. **(DSD<sub>1</sub> NPO worker<sub>2</sub>)**

## **Category 2: The need for developing a guideline/policy document**

Some participants expressed the need for a separate guideline/policy to encourage a holistic and robust approach to address FASD issues. The participants expressed the need for a document that will specify clearly the needs of individuals with FASD.

Our non-profit organization is under the DSD and with our intervention programs, we have just started prioritizing [FASD] and I think that it is why your study is so important to see what [FASD] policies that can be put in place. **(DSD<sub>1</sub> NPO worker<sub>3</sub>)**

We need a document that will state these are the needs of the children with [FASD]. There must be a clear plan, for example, if a child [with an FASD] enters into a system, what are the needs of that child [with an FASD]. This must be in a document. [This is] because from this document, the NPOs can start creating services that are necessary. **(DSD<sub>1</sub> NPO worker<sub>3</sub>)**

The policy should include an urgent referral to a health team when a child is diagnosed with [an FASD]. Early intervention from an allied health perspective; the better the diagnosis and the better the outcome for the child with [an FASD]. So, I would definitely want that in the policy. **(DOH<sub>3</sub> Health professional<sub>6</sub>)**

However, other participants said there are many other policies that can address the issues experienced by individuals with FASD. They argued that the most important issue is the lack of proper implementation of existing policies because of limited resources.

I am adding to what participant eleven has said, there are lots of policies already [though] not specific to FASD but offered services for the children in general. The big concern is not the needs of the child [with an FASD] but lack of funding for the workforce (**DOH<sub>4</sub> Health professional<sub>10</sub>**)

### **Category 3: Current practices and available interventions**

This category presents current practices and interventions for the prevention and management of FASD as reported by the service providers. The participants reported prevention and management interventions currently applied in their various organizations based on the clauses of FASD policies that exist in other South Africa policy documents. A list of the current practices and interventions for the prevention and management of FASD identified by the study participants are presented in **Additional file 2.**

The participants shared that they conduct educational programs in schools aimed at creating awareness for children on FASD. These programs usually focus on prevention, which the service providers do through experiential learning; making the children aware of the danger of drinking alcohol during pregnancy.

We have awareness programs in primary and high schools; focused on the prevention and early interventions. So, we have different programs in schools ... (**DSD<sub>2</sub> NPO workers<sub>1</sub>**)

We have a program, which is called “Care for Babies.” It is of experiential learning to the primary learners’ (grade 6 and 7); experiential learning of foetal alcohol syndrome. We introduced fetal alcohol syndrome [FASD] at their levels. We do activities like

playing games and symbolic talking message for children to understand what is fetal alcohol syndrome, the dangers and disabilities if a mom [mother] drinks alcohol during pregnancy. **(DSD<sub>2</sub> NPO worker<sub>2</sub>)**

A participant reported on an intervention targeting adults (especially pregnant women) in the community. The intervention focuses on the effects of drinking alcohol during pregnancy.

We work in the community with the adult pregnant women; educate, inform, and support them. We share with them the effects of drinking alcohol during pregnancy. So, we have training sessions each month focusing on fetal alcohol syndrome, drugs, and pregnancy itself. We have individual sessions, motivational intervention talk, family sessions, group sessions, and pregnant women sessions. **(DSD<sub>2</sub> NPO workers<sub>1</sub>)**

The participants discussed various interventions targeting pregnant women as they are considered the primary target for prevention.

We have two community workers working in two different areas. We will recruit 40 mentors and 120 pregnant women and divide them into two groups. We have 60 pregnant women and 20 mentors in one area and 60 pregnant women and 20 mentors in the other area. So, each mentor has to mentor three pregnant women and each community worker has to work with 20 mentors. **(DSD<sub>2</sub> NPO workers<sub>1</sub>)**

We have a prevention program, where we work with pregnant women. We will recruit them before twenty weeks of the pregnancy and work with them through the pregnancy period. **(DSD<sub>1</sub> NPO worker<sub>4</sub>)**

The participants mentioned other interventions that cover various segments of the community such as the substance abuse program, which aims to raise awareness on FASD. Also, training of volunteers in the community to disseminate information on FASD to the community.

The Department of Social Development (DSD) has a program, which is called substance abuse program and part of the substance abuse program is awareness intervention. However, they [DSD] do not deliver these services directly they use a service provider in NPOs to provide such services. **(DSD<sub>2</sub> NPO worker<sub>3</sub>)**

We have a program called, Train the Trainer; we train social workers and volunteers (facilitators) in the community on fetal alcohol syndrome, alcohol, and drug abuse. So that they can now present fetal alcohol syndrome to the community and we give them visual presentation material that can be used to develop the community capacity on FASD information. **(DSD<sub>2</sub> NPO workers<sub>2&3</sub>)**

Another participant shared services that focused on parents – counseling and educating on the effects of alcohol on the baby.

Our services focus on the parents, we counsel and educate about the impacts and effects of alcohol on the baby. **(DOH<sub>2</sub> Health professional<sub>4</sub>)**

Some participants reported the existence of referral systems for pregnant women drinking during their pregnancy and high-risk mothers. They mentioned the involvement of families and the provision of education, assistance, and referral aiming at helping the women to stop drinking.

When we see these pregnant patients [consuming alcohol], with dignity we take them to support groups to get assistance and we will involve their family where possible. We help high-risk mums, we get them help with delivery, and we will get involved during birth and post-delivery of the child. **(DOH<sub>2</sub> Health professionals<sub>5</sub>)**

When a mother has been identified consuming alcohol during pregnancy, then they [pregnancy women] will be referred to us. And we will do the education then refer [them] to the community, South African National Council on Alcoholism and Drug Dependence (SANCA), and all other organizations that are within the community that can assist the mother to stop drinking alcohol. **(DOH<sub>2</sub> Health professional<sub>1</sub>)**

In addition to preventive approaches and interventions, the participants identified various management interventions that are currently applied in their organizations based on the FASD policy clauses existing in the different policies used for their organizational operation.

Some participants identified blanket interventions for every child that also encompassed FASD. Every child is screened for developmental delays including delays resulting from prenatal alcohol exposure.

Our service is part of [a] general intervention, as participants one and two have explained. We check every child for developmental delay, and if we identify the need for screening we will screen, and we will then follow through with the management as suggested by the result of the screening. **(DOH<sub>2</sub> Health professional<sub>8</sub>)**

Some of the participants also reported allied health interventions for the comprehensive management of children with FASD.

We treat the FASD patients like any other patient, just like a child that is not speaking because the child has a language delay. We use the same strategies and techniques. **(DOH<sub>2</sub> health professional<sub>7</sub>)**

We just do hearing screening for all children identified with maybe language delays to see if the delay is caused by hearing loss. **(DOH<sub>2</sub> Health professional<sub>8</sub>)**

Some of the participants reported that proper diagnosis made at a tertiary hospital.

We refer them [the children] to be diagnosed at tertiary [hospital], and if required of us to follow up with the patient from a developmental perspective, we do [so] from when they [the children] are born to ages of six. **(DOH<sub>2</sub> Health professional<sub>4</sub>)**

In the clinic, we make a diagnosis, but from a genetic point of view, diagnosis requires [a] medical geneticist and further development follow-up is done at tertiary [hospital]. We will follow up with the patients as a team of allied health professional with the development of the patient. **(DOH<sub>2</sub> Health professional<sub>4</sub>)**

Some of the participants indicated that a collaborative intervention involving the Department of Education's office, the parents, and the schools towards assisting a child with learning disabilities (including FASD) should be established and coordinated.

We have psychologists and therapists working at the Department [of Education] so, a child can be referred there. For instance, if a child is in the mainstream and the child is struggling, they [psychologists and therapists] will assess and then refer [the child] to a school like us [special school]. **(DOE<sub>3</sub> Teacher<sub>5</sub>)**

We have a very good relationship and partnership with the parents and we try to bring those [parents] on board to let them [parents] know what we do at all times. To let [parents] understand their children and for us to know what is going with the parents. We discovered these children



have other social and family problems and that a lot of them are living in foster homes. (DOE<sub>3</sub> Teacher<sub>4</sub>)

The participants shared interventions focused on educating children with FASD to the best of his/her ability. They indicated the provision of specialized and individualized education.

We give them [the children] an education that is our main purpose; they come here to be educated. This is a departmental school and according to white paper 6, every child has a right to be educated according to his/her ability. We educate them [the children] according to their ability – that is the intervention. We also do a sort of curriculum adaptation and extra curriculum activities such as sport and other things; that it is the service that we provide as a school. (DOE<sub>3</sub> Teacher<sub>5</sub>)

We are dealing with SID (severe intellectual disabilities) and FASD is among them. When they [the children] are starting from preschool, we have an individualized educational plan [IEP], which is for each child in our classes. At the beginning of the year, occupational therapists and physiotherapist come in to do an assessment from which an IEP will be developed for each child and this will be followed for the year. (DOE<sub>3</sub> Teacher<sub>1</sub>)

Some participants reported on schools available for educating children with FASD.

We are rendering residential care for children; specifically, children with FASD. We have Schools that accommodate the children that are affected with the FASD. (DSD<sub>1</sub> NPO worker<sub>3</sub>)

Our school is a special school; all our children have a particular special need. So, each child is treated according to these special needs and the FASD children are not different in that sense. So, they have access to our education system. (DOE<sub>3</sub> Teacher<sub>6</sub>)

A participant reported an adaption of the curriculum to make it functional for children with FASD.

Our curriculum is very much functional academic based. We take Curriculum and Assessment Policy Statements (CAPS) and make it more functional for our children. This is because if they are in our school they need to learn in a more practical way. (DOE<sub>3</sub> Teacher<sub>4</sub>)

Some participants also reported that there were interventions that provided skills to individuals with FASD. They also identified a school that is providing skills to individuals with FASD between ages 14 to 18 years.

We provide social skills for them [individuals with FASD] so that they are socially developed in our society. We are teaching the children what they should be doing and how they should behave in society. **(DOE<sub>3</sub> Teacher<sub>4</sub>)**

There are schools of skills, but they take children only from 14 to 18 and those are children who are usually stronger than the children in this type of school. So, some of them have FAS, I taught one of them [an individual with FASD] for some time in the Northern part of the country and she is doing very nicely. **(DOE<sub>3</sub> Teacher<sub>9</sub>)**

Another participant described how individuals with FASD are provided with life skills.

We interact with the community in a sense; all the children are placed in a workshop environment or a work environment so that when they leave, they are equipped with lots of life skills. **(DOE<sub>3</sub> Teacher<sub>6</sub>)**

Participants re-counted various support structures for children, families, pregnant women, and individuals affected by FASD such as the school health system, which caters to children health needs when they are in school.

The school health system connects with the hospital, and social service[s] are involved right from the start as soon as there are concerns about alcohol use in pregnancy. **(DOH<sub>2</sub> Health professional<sub>4</sub>)**

From the age of six, they [children] go to the school health clinic concerning health problems, so they [children] are followed up by the school health clinic as they are in school. And so, the adolescent is meant to be followed up by the school health system. **(DOH<sub>2</sub> Health professional<sub>4</sub>)**

Some of the participants reported training of professionals such as teachers, social workers, psychologists, and other professionals as current programs in place.

We do professional training, where we speak with different professionals such as social workers, nurses to inform them about the services we offer. **(DSD<sub>1</sub> NPO worker<sub>3</sub>)**

We also train teachers who work with the children, so that those teachers can look after/help the children in the class. So that the children do not fall too behind. We also work with the school



psychologist in the areas, so that if the child is not coping with the mainstream school, they [psychologists] can refer the child to the special need schools. (DSD<sub>1</sub> NPO workers<sub>4</sub>)

#### **Category 4: Identified policy requirements for FASD**

This category presents the suggestions made by the participants on what they thought should be included in the FASD guideline. A table identifying all the interventions and programs that were suggested by the participants is submitted as **Additional file 3**.

Participants suggested that preventive awareness programs should be a continuous program and should target people of all ages.

If they [government] would have better prevention awareness programs running, people would be aware of the secondary disability and its impact. (DSD<sub>1</sub> NPO workers<sub>1</sub>)

So, I think prevention should not actually start when they are already pregnant. I think that prevention should be aimed at the adolescent, to teach them good social drinking behaviours. (DOH<sub>3</sub> Health Professional<sub>8</sub>)

Some participants suggested the need to include programs in the policy that target adolescents. The participants stated that adolescent should be well informed of the dangers of drinking alcohol during pregnancy.

We need to target the adolescent population, this is not like a health problem; it is a social/education problem. Once a mother is drinking during pregnancy, there is nothing you can do to change... (DOH<sub>3</sub> Health professional<sub>4</sub>)

These days, teenagers begin to have sex and drinking alcohol at the age of 13 years. So, I think even from primary school, children should be made aware of the negative effects of everything. (DOH<sub>3</sub> Health professional<sub>8</sub>)

Participants also strongly emphasized the need for on-going social marketing by relevant mass media operators regarding sending messages to encourage pregnant women to refrain from drinking during pregnancy. The participants suggested the use of community leaders for social marketing.

Social development can put posters in the community for the community to connect with the media, adverts on TV, and radios. There is a lot of stuff that social development can do as a department. **(DSD<sub>1</sub> NPO worker<sub>3</sub>)**

There is a need for awareness, where this campaign is going out there and say do not drink when you are pregnant. They might use community leaders; they could be trained just in the basic information that drinking is not allowed for pregnant women. **(DSD<sub>1</sub> NPO worker<sub>1</sub>)**

Participants proposed the need for awareness through social media including posters, awareness campaigns, and advertisements.

There is a need to be marketing material; we need to use media that is impactful in the community. We should have a TV media program in the community. **(DSD<sub>1</sub> NPO worker<sub>1</sub>)**

On FASD awareness day (9 September), promoting public awareness is very important in schools, in health services, and in social work services. The government should have policies in place so that they can actively promote public awareness. **(DOE<sub>3</sub> Teacher<sub>6</sub>)**

Participants suggested that there should be awareness at schools (primary and high) and University that no amount of alcohol is safe during pregnancy.

Prevention needs to be happening in the schools, teaching primary and high schools; bring intervention to them, then the Department of Health has Community Health Centres (CHC) to give posters and videos. **(DOH<sub>3</sub> Health professionals<sub>5</sub>)**

Going to the mainstream schools, high schools and telling people about FASD, training and letting them know about drinking during pregnancy. This is because many young people think that one or two drinks are fine to drink when you are pregnant, but they are not always aware of the dangers of drinking. Training young girls at university and letting them be aware. **(DOE<sub>3</sub> SP<sub>4</sub>)**

A participant proposed the need for robust referral pathways for prevention to be included in the policy.

They [drinking women] need to be referred to medical professionals because once you took one child away from drinking women; the women need to be monitored. So, if these women become

pregnant again, they must be urgently referred to an organization that already has a successful program running, so that intervention can take place. **(DSD<sub>1</sub> NPO worker<sub>1</sub>)**

The participants proposed that the problems associated with FASD could not be resolved by one department. Thereby the participants suggested that the policy should facilitate collaboration for preventive efforts among departments.

We need to start providing early intervention from the beginning. There must be a multidisciplinary group in place immediately around the child. So, the policy should be or need to state what will happen with the child. **(DSD<sub>1</sub> NPO worker<sub>3</sub>)**

It is not one specific department, which is supposed to be in charge of this [prevention]. We need to start with the young children so that we can prevent it from happening again in the future. **(DOH<sub>3</sub> Health Professionals)**

Some participants suggested that the policy should facilitate training and support for parents and caregivers of children with FASD to understand the challenges faced by children and learn skills to help them better manage.

A support system may be for the parents; they [parent] should be involved in workshops on how to treat and raise children with FASD. This is because I am sure that they [parent] come from the streets and a lot [of] them do not understand what is wrong with their child. **(DSD<sub>2</sub> NPO worker<sub>1</sub>)**

They [professionals] need to train these parents on the primary and secondary disabilities [related to FASD]. There is a need for social workers to go to these houses to provide emotional support for the parents and make sure that the children are in caring homes. **(DSD<sub>1</sub> NPO worker<sub>3</sub>)**

Some participants identified the need for a separate school and revitalisation of special classes in the mainstream school for children with FASD. The reason the participants provided was that children with FASD might feel inferior to other children because of their intellectual abilities.

They [children with FASD] need to be separated from normal children, so I think we need to build the schools for FASD children. But, we take the same school curriculum and adapted it to

suit their needs and ability. They [children with FASD] might feel inferior to other children because they cannot do what other children can do. **(DSD<sub>2</sub> NPO worker<sub>2</sub>)**

We need more [special] schools like this, maybe smaller ones in each smaller community but the school that will cater for the needs of these children at different levels. Also, they [government] should bring back those special classes to the mainstream schools. **(DOE<sub>3</sub> Teacher<sub>9</sub>)**

Some of the participants advocated that policy should acknowledge that FASD is a multi-professional and interdepartmental issue and the departments should collaborate in addressing the gaps around FASD services.

I think the policy should encourage corporation between [Departments of] Education, Health, and Social Development; they should work together. It should be put into the policy that health services should support education and social services. **(DOE<sub>3</sub> Teacher<sub>6</sub>)**

One department cannot do this in isolation, there should be a fundamental process of diagnosis. When a child with an FASD is diagnosed by the Department of Health, then the Department of Social Development should be informed so that they can follow up with the child. **(DSD<sub>1</sub> NPO worker<sub>2</sub>)**

A participant proposed the need for a referral pathway for management to be included in the policy so that better outcomes can be achieved for individuals with FASD.

The policy should also include urgent referral to a health team when a child is diagnosed. The earlier the intervention from allied health professionals, the better the prognosis and the outcome for the child. So, I would definitely want that in policy, the children should be referred early. **(DOH<sub>3</sub> Health Professional<sub>6</sub>)**

Some participants want courses and training on how to manage FASD to be included in medical training as this is currently absent. Participants were of the opinion that policy could facilitate this.

You never get the training or given skill on how to manage these [FASD]. You were just given information about FASD. So, you were not given the skill after the training that can be used to manage these kinds of cases (FASD) **(DOH<sub>3</sub> Health Professional<sub>1</sub>)**

We do not receive a specific course on FASD, we would just manage the patients based on the symptoms they present. We will manage FASD children like any other child with developmental delay. **(DOH<sub>3</sub> Health Professional<sub>6</sub>)**

A participant proposed training of professionals such as lawyers, teachers, social workers, and nurses to enable a proper understanding of FASD issues.

There should be training for the professionals, lawyers, teachers, social workers, and nursing staff; so that they could start to recognize what is actually happening with individuals with FASD. **(DSD<sub>1</sub> NPO worker<sub>1</sub>)**

The participants reported that they were given generalized training on disabilities as a special need for teachers, and reported a lack of specific training on FASD. The participants thus suggested that policy could facilitate specialized training on FASD; especially training on how to identify affected children and how to counsel the parents of these children.

We are all trained as special needs teachers but there is no specific training for FASD. We are special needs teachers, we cover every diagnosis [disability] that children may have. They [trainer] are not saying there is special training for FASD. **(DOE<sub>3</sub> Teacher<sub>1</sub>)**

The Department [of Education] organises many workshops but we do not have workshops specifically on FASD. So, the Department must provide a way for us on how to identify children and on-going training on screening potential children. Also, training on how to counsel the parent because parents are the reason why the children are [suffering from] FASD as they [the parent] abused alcohol during pregnancy. **(DOE<sub>3</sub> Teacher<sub>6</sub>)**

## Discussion

This study is part of a project aimed at designing a guideline to inform policies on FASD [35]. In this study, we explored the perspectives of different service providers, regarding various existing and required preventive and management approaches for FASD. Additionally, those strategies that could facilitate a multidisciplinary, multi-sectoral, and holistic approach to FASD.

The manifestations of FASD can involve primary and secondary disabilities [52]. These disabilities usually include educational, medical, and social issues. At present, each department in a generic manner addresses the issues related to FASD based on the clauses that exist in their current policies and guidelines. For example, the Department of Education mostly focuses on addressing educational issues (learning disabilities). These are not particularly related to, but may include FASD, and are not particularly focused on the broader medical and social issues. Similarly, the Departments of Health and Social Development, follow policies that address general health issues and social problems, respectively.

With each department delivering care for individuals with FASD working ‘in silos’ and following a nonspecific approach from their own perspective, the prevention and management of FASD remain uncoordinated and ineffective. This approach is contrary to the multidisciplinary, multisectoral and holistic approach required for the proper management of FASD [53], as FASD-related issues are multifaceted with intrinsic and extrinsic factors responsible for the outcomes. Clauses relevant to the prevention and management of FASD that exist in other policies have not been able to effectively address the issues of FASD, which could be facilitated by the creation of a specific FASD policy [11, 54].

Despite that there are various current preventive interventions reported, the prevalence of FASD in South Africa, especially in the Western Cape Province continues to be high [15]. Therefore, researchers and public health specialists advocate the need for preventive interventions that are sensitive, responsive, and appropriate to the context [11, 54]. In South Africa, this is an indication that the current preventive interventions have not been effective in reducing the prevalence of FASD.

The reasons for the persistently high prevalence of FASD could include the generic nature of interventions for FASD prevention and management. Not only that, but it could also be the current lack of specific prevention interventions for women of reproductive age and their partners or families.



Of which the latter is level-two of four levels of prevention for FASD as proposed by Poole et al. [22]. The reason being that alcohol exposure is likely to occur before women know they are pregnant and therefore before they present for prenatal care. Therefore, prevention needs to be targeted more broadly and require proper understanding of alcohol and contraceptive use and norms of reproductive age [31].

Furthermore, the current prevention approaches are focused on educating people about the risks of drinking during pregnancy without taking into account the wider societal problems with alcohol use in the community. These approaches are assuming that the community just needs to be provided with expert information about the risks of alcohol consumption and they will be able to change their behavior. However, research from other drugs/alcohol areas shows that education doesn't necessarily change behavior [55, 56]. Therefore, the policy needs to address the fact that the prevention of alcohol use during pregnancy is much more complicated than just providing information about the risks of drinking during pregnancy. Also, policy needs to address factors that influence women's drinking such as having partners or family members who drink and experiencing domestic violence, as research has shown women experiencing domestic violence are more likely to abuse alcohol [57].

In addition to the above reasons, the high prevalence of FASD in South Africa could be attributed to a lack of re-contextualization and decolonization of current policy discourse and failure to reframe the problem of FASD. Thus, the solution to the FASD problem could be realized by addressing the structural, social and historical processes such as urbanization, racialization, and colonialism that are responsible for women's health and social inequities [58]. Moreover, most of the current interventions are not evidence-based as there is a paucity of local research in South Africa [59]. Therefore, there is a need for specialized and targeted preventive services and the need to address gaps in current policies and policy implementation to facilitate effective intervention [20, 32].

In a broader perspective, the reason for ineffective interventions could also be related to the characteristics of the communities [14], which are marginalized environments where the pre-requisites

of health (peace, food, shelter, sustainable income/livelihood, and stable ecosystem) are not met. Therefore, there is a need to address the above social determinants of health that pre-conditioned the health of these individuals. For this reason, we are developing guidelines to facilitate a holistic policy for FASD, which entails the participation of all in the prevention and management of FASD.

The ineffectiveness of the current preventive interventions could also be a result of the barriers identified previously in Canada [22]. These include the conflicting messages in the media about the amount of alcohol that can be consumed during pregnancy and lack of skills by service providers to discuss alcohol with women and their inability to connect women to the appropriate services. Women also fear losing custody of their children if they access services and existing barriers to accessing support systems such as lack of affordable housing and transportation [22]. Therefore, in addressing these barriers to effective interventions, a policy is needed.

We noted that there are available management services, however only a few specifically target FASD [31]. We also discovered that there are only a few management services targeting adults with FASD [60]. Our study highlights the need for a specialized intervention, which will enable children with FASD to receive early intervention and follow-up to adulthood [61, 62]. Early interventions show promising outcomes and have the ability to prevent secondary disabilities. Therefore, to facilitate appropriate interventions at every age policy is needed, as the effective management of primary and secondary disabilities require sustainable commitment from government and service providers [18, 21].

We found various suggestions on what could be included in a guideline/policy for the prevention and management of FASD in South Africa. Some of our findings were supported by other studies that had examined the policy and intervention requirements for the prevention and management of FASD, locally [31, 63] and internationally [30, 64, 65]. These findings include support for individuals with FASD and their families, public education and awareness, specialized support for pregnant women,



training for relevant professionals and community awareness of FASD to prevent prenatal exposure to alcohol. Therefore, local and international research could assist in informing policy development in South Africa.

Locally, Rendall-Mkosi et al. [31] identified service coordination and consensus building, surveillance and detection of alcohol-exposed pregnancy (AEP) and FASD, monitoring alcohol use in women of childbearing age, the detection of and intervention with women at risk of AEP, public education and awareness, and intervention and support for individuals with FASD. The above interventions were seen as efforts that could facilitate the prevention and management of FASD. In a policy brief in 2008, policy requirements considered to address FASD issues included surveillance and monitoring, screening and brief interventions for women, awareness-raising and education on FASD, liquor control, and research gaps in services and interventions [63].

Internationally, Canadian experts have identified a four-level model for FASD prevention [65]. This includes public awareness and broad health promotion, conversations about alcohol with women of childbearing age and their partners, specialized support for pregnant women and postpartum support for new mothers [65]. The above interventions were similar to our findings on preventive intervention requirements for guideline/policy. George and Hardy [64] analyzed the funding proposals submitted on FASD in Canada and identified the following proposed strategies for the management of FASD:

- (1) Support for individuals with FASD and their families to develop life, social, parenting, and employment skills;
- (2) Access to direct services such as housing and care in schools;
- (3) Intensive training for professionals working with individuals with FASD and the community;
- (4) Provision of libraries and resource rooms, curriculum, program manuals on FASD;
- (5) Access to training designed to raise awareness about FASD;
- (6) Support for individuals with FASD and their families during significant life transitions;

- (7) Peer support for children and youth with FASD and their parents;
- (8) Research on interventions targeting various FASD outcomes; and
- (9) Diagnostic clinics for adults and the creation of networks of professionals and families.

The Australian Action Plan, in which five priority areas for the prevention and management of FASD across the lifespan were identified, resembled those found by George and Hardy [64]. These included increasing community awareness of FASD to prevent prenatal exposure to alcohol and improve the diagnostic capacity of FASD. Furthermore, interventions to assist individuals with FASD to achieve their full potential, improve data collection to understand the extent of FASD, and close the gap on the high prevalence among the certain population were recommended [30].

Findings from this study have significant public health implications. The fact that the current practices have not reduced the prevalence of FASD in South Africa should be seen as a challenge to public health. Given that many women are aware of the dangers of drinking alcohol during pregnancy, the prevalence is still high showing that we need to reconsider how we are approaching the prevention of the problem. Efforts should be made to urgently address the maternal risk factors for FASD [42] and the social determinants that precondition the behavior and health of these women [14]. In addition, we recommend that further research is needed to evaluate current practices and interventions systematically to see the extent they have prevented FASD or benefited individuals with FASD. Also, further research is needed to investigate the barriers and facilitators to reducing the prevalence of FASD in South Africa.

## **Strengths and limitations of the study**

In this study, we used focus groups as a method of inquiry, which allowed the researchers to get a response from multiple participants. Furthermore, it allowed participants to validate each other's

responses. A limitation of this study is that we used available participants in a single setting for most of the focus groups, as it was difficult to combine participants from different settings. This prevented some professionals from participating in the focus group discussions and caused variations in the number of participants per focus group. Furthermore, the participants from the Department of Labour and the Department of Justice who supposedly render services to individuals with FASD were not sampled, while their responses might be valuable in developing an integrated policy.

## Conclusion

Despite various prevention and management strategies being currently implemented, the prevalence of FASD remains high in South Africa, especially in the Western Cape Province. The reason for the persistently high prevalence of FASD could be related to the generic nature of FASD prevention and management approaches, lack of evidence-based approaches and coordinated effort. Therefore, the need for a policy to ensure a coordinated and holistic effort for the prevention and management of FASD is highlighted.



## List of abbreviations

**FASD** - Fetal alcohol spectrum disorders, **NPO** - Non-profit Organisation, **DOH** - Department of Health, **DSD** - Department of Social Development, **DOE** - Department of Education, **COREQ** - Consolidated criteria for reporting qualitative research, **FGD** - Focus group discussions, **SANCA** - South African National Council on Alcoholism and Drug Dependence, **SID** - Severe intellectual disabilities, **CAPS** – Curriculum and assessment policy statements, **IQ** -Intelligence quotient, **USA** – United State of America, **TV** – Television, **CHC** - Community Health Centre, **SAPS** – South Africa police service, **IEP** - Individualized educational plan, **AEP** - Alcohol-exposed pregnancy, **UIF** - Unemployment insurance fund

## **Declarations**

### **Ethics approval and consent to participate**

Ethical approvals for the study were obtained from the Research Ethics Committee of the University of the Western Cape (BM/16/4/4), the Western Cape Department of Education (20161212-6937), and Departments of Health (WC\_2016RP29\_862) and Social Development (12/1/2/4).

Before conducting the discussions, an information sheet written in English, which contained the study aim and objectives, and the roles of the participants, was read to the participants. The participants who agreed to participate in the study were requested to sign a consent form and focus group confidentiality binding form. All the information obtained during the study was kept strictly confidential on a computer with a password known only to the researchers in this study.

### **Consent to publish**

Not applicable.



### **Availability of data and materials**

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

### **Competing interests**

The authors declare no conflict of interest


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## **Authors' contributions**

The paper was conceptualized and the data analyzed by BOA, FCM, LGC and AMB. BOA wrote the first draft of the present manuscript. BOA, FCM, LGC and AMB contributed to the development of the methodology of this study. The work was supervised by AMB. All authors reviewed and provided comments to improve the manuscript. They also read and approved the final manuscript.

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## References

- [1] Burns L, Breen C, Bower C, et al. Counting fetal alcohol spectrum disorder in Australia: the evidence and the challenges. *Drug and Alcohol Review* 2013; 32: 461–467.
- [2] Cook JL, Green CR, Lilley CM, et al. Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *CMAJ* 2016; 188: 191–197.
- [3] Mutch RC, Watkins R, Bower C. Fetal alcohol spectrum disorders: notifications to the Western Australian register of developmental anomalies. *J Paediatr Child Health* 2015; 51: 433–436.
- [4] Centers for Disease Control and Prevention (CDC). Basics about FASDs | FASD | NCBDDD | CDC. <https://www.cdc.gov/ncbddd/fasd/facts.html> (2018, accessed 16 July 2018).
- [5] Lange S, Probst C, Gmel G, et al. Global Prevalence of Fetal Alcohol Spectrum Disorder Among Children and Youth. *JAMA Pediatr* 2017; 171: 948.
- [6] Zelner I, Koren G. Alcohol consumption among women. *J Popul Ther Clin Pharmacol* 2013; 20: e201-6.
- [7] May PA, Fiorentino D, Phillip Gossage J, et al. Epidemiology of FASD in a Province in Italy: prevalence and characteristics of children in a random sample of schools. *Alcohol Clin Exp Res* 2006; 30: 1562–1575.
- [8] Petković G, Barišić I. Prevalence of fetal alcohol syndrome and maternal characteristics in a sample of school children from a rural province of Croatia. *Int J Environ Res Public Health* 2013; 10: 1547–1561.
- [9] May PA, Chambers CD, Kalberg WO, et al. Prevalence of fetal alcohol spectrum disorders in 4 US communities. *JAMA* 2018; 319: 474.

- [10] Wagner B, Fitzpatrick J, Symons M, et al. The development of a culturally appropriate school based intervention for Australian Aboriginal children living in remote communities: A formative evaluation of the Alert Program<sup>®</sup> intervention. *Aust Occup Ther J* 2017; 64: 243–252.
- [11] Olivier L, Curfs LMG, Viljoen DL. Fetal alcohol spectrum disorders: prevalence rates in South Africa. *South African Med J* 2016; 106: 103–106.
- [12] May PA, Gossage JP, Marais A-S, et al. The epidemiology of fetal alcohol syndrome and partial FAS in a South African community. *Drug Alcohol Depend* 2007; 88: 259–271.
- [13] May PA, Blankenship J, Marais A-S, et al. Approaching the prevalence of the full spectrum of fetal alcohol spectrum disorders in a South African population-based study. *Alcohol Clin Exp Res* 2013; 37: 818–830.
- [14] May PA, de Vries MM, Marais A-S, et al. The continuum of fetal alcohol spectrum disorders in four rural communities in South Africa: prevalence and characteristics. *Drug Alcohol Depend* 2016; 159: 207–218.
- [15] May P, De Vries M, Marais A-S, et al. Replication of high fetal alcohol spectrum disorders prevalence rates, child characteristics, and maternal risk factors in a second sample of rural communities in South Africa. *Int J Environ Res Public Health* 2017; 14: 522.
- [16] McKinsty J. Using the past to step forward: fetal alcohol syndrome in the Western Cape province of South Africa. *Am J Public Health* 2005; 95: 1097–1099.
- [17] Cloete L, Ramugondo E. ‘I drink’: mothers’ alcohol consumption as both individualised and imposed occupation. *South African J Occup Ther* 2015; 45: 34–40.
- [18] Fitzpatrick JP, Latimer J, Carter M, et al. Prevalence of fetal alcohol syndrome in a population-



based sample of children living in remote Australia: the Lililwan project. *J Paediatr Child Health* 2015; 51: 450–457.

- [19] Benz J, Rasmussen C, Andrew G. Diagnosing fetal alcohol spectrum disorder: history, challenges, and future directions. *Paediatrics and Child Health* 2009; 14: 231–237.
- [20] Jacobs, L., Steyn, N., & Labadarios D. 'Mind the gap': observations in the absence of guidelines for alcohol abstinence among expectant women in South Africa. <http://repository.hsra.ac.za/bitstream/handle/20.500.11910/3008/7682.pdf?sequence=1> (2013, accessed 12 January 2018).
- [21] Fitzpatrick JP, Latimer J, Olson HC, et al. Prevalence and profile of neurodevelopment and fetal alcohol spectrum disorder (FASD) amongst Australian Aboriginal children living in remote communities. *Res Dev Disabil* 2017; 65: 114–126.
- [22] Poole N, Schmidt RA, Green C, et al. Prevention of fetal alcohol spectrum disorder: current Canadian efforts and analysis of gaps. *Subst Abuse* 2016; 10: 1–11.
- [23] United Nations Development Programme. Sustainable Development Goals | UNDP. <http://www.undp.org/content/undp/en/home/sustainable-development-goals.html> (accessed 8 August 2018).
- [24] Blas E, Koller T, Magar V, et al. WHO library cataloguing-in-publication data WHO Handbook for guideline development. *Peer Rev Evidence-based Med World Heal Organ* 2014; 1: 179.
- [25] World Health Organisation. *WHO Handbook for guideline development*. World Health Organisation. [http://apps.who.int/iris/bitstream/10665/75146/1/9789241548441\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/75146/1/9789241548441_eng.pdf) (2012, accessed 1 March 2018).
- [26] Information Technology Services Home SLU. Policies, standards, guidelines,



procedures/processes : Saint Louis University Information Technology Services : SLU.  
<http://www.slu.edu/its/policies> (2017, accessed 10 June 2017).

- [27] National Institute for Health and Care Excellence. *Developing NICE guidelines: the manual*.  
<https://www.nice.org.uk/media/default/about/what-we-do/our-programmes/developing-nice-guidelines-the-manual.pdf> (2014, accessed 10 June 2017).
- [28] Chudley AE, Conry J, Cook JL, et al. Fetal Alcohol Spectrum Disorder: Canadian guidelines for diagnosis. *CMAJ* 2005; 172: S1–S21.
- [29] Hoyme HE, Kalberg WO, Elliott AJ, et al. Updated clinical guidelines for diagnosing fetal alcohol spectrum disorders. *Pediatrics* 2016; 138: e20154256–e20154256.
- [30] Foundation for Alcohol Education and Research. The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013-2016. <http://fare.org.au/fare-australian-fetal-alcohol-spectrum-disorder-action-plan-2013-2016/> (2013, accessed 5 February 2018).
- [31] Rendall-Mkosi K, London L, Adnams C, et al. Fetal alcohol spectrum disorder in South Africa: situational and gap analysis. *UNICEF, Pretoria*.  
[https://www.unicef.org/southafrica/SAF\\_resources\\_fetalalcohol.pdf](https://www.unicef.org/southafrica/SAF_resources_fetalalcohol.pdf) (2008, accessed 14 September 2017).
- [32] Adnams CM. Fetal alcohol spectrum disorder in Africa. *Curr Opin Psychiatry* 2017; 30: 108–112.
- [33] Hoyme HE, May PA, Kalberg WO, et al. A practical clinical approach to diagnosis of fetal alcohol spectrum disorders: clarification of the 1996 institute of medicine criteria. *Pediatrics* 2005; 115: 39–47.
- [34] Public Health Agency of Canada. Framework: Fetal Alcohol Spectrum Disorder (FASD): A

framework for action - Canada.ca. <https://www.canada.ca/en/public-health/services/reports-publications/fetal-alcohol-spectrum-disorder-fasd-framework-action/fetal-alcohol-spectrum-disorder-fasd-a-framework-action-1.html#d> (accessed 8 June 2018).

- [35] Adebiyi BO, Mukumbang FC, Okop KJ, et al. A modified Delphi study towards developing a guideline to inform policy on fetal alcohol spectrum disorders in South Africa: a study protocol. *BMJ Open* 2018; 8: e019907.
- [36] Statistics South Africa. *Statistical release P0302 Mid-year population estimates*. <http://www.statssa.gov.za/publications/P0302/P03022017.pdf> (2017, accessed 15 March 2018).
- [37] Charman A, Petersen L. *Comment on the Western Cape alcohol-related harms reduction policy green paper charman and petersen, sustainable livelihoods foundation*. <http://livelihoods.org.za/publications/> (2016, accessed 12 January 2018).
- [38] London L. The 'dop' system, alcohol abuse and social control amongst farm workers in South Africa: a public health challenge. *Soc Sci Med* 1999; 48: 1407–1414.
- [39] Ross F. *Raw life, new hope : decency, housing and everyday life in a post-apartheid community*. Claremont: Juta Academic. <https://open.uct.ac.za/handle/11427/7657> (2010, accessed 23 February 2018).
- [40] Statistics South Africa. Media release: South Africa Demographic and Health Survey | Statistics South Africa. *Statistics South Africa*. <http://www.statssa.gov.za/?p=9836> (2016, accessed 12 January 2018).
- [41] Petersen Williams P, Jordaan E, Mathews C, et al. Alcohol and other drug use during pregnancy among women attending midwife obstetric units in the Cape Metropole, South Africa. *Adv Prev Med* 2014; 2014: 1–10.

- [42] Esper LH, Furtado EF. Identifying maternal risk factors associated with Fetal Alcohol Spectrum Disorders: a systematic review. *Eur Child Adolesc Psychiatry* 2014; 23: 877–889.
- [43] Glenton, C., Lewin, S., Norris, S., & Norris S. 15 . Using evidence from qualitative research to develop WHO guidelines. In: *WHO handbook for guideline development*, pp. 183–200.
- [44] Guest G, Bunce A, Johnson L. How many interviews are enough? *Field methods* 2006; 18: 59–82.
- [45] Francis JJ, Johnston M, Robertson C, et al. What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychol Health* 2010; 25: 1229–1245.
- [46] Bowen GA. Naturalistic inquiry and the saturation concept: a research note. *Qual Res* 2008; 8: 137–152.
- [47] Brod M, Tesler LE, Christensen TL. Qualitative research and content validity: developing based on science and experience practices. *Qual Life Res* 2009; 18: 1263–1278.
- [48] Gale NK, Heath G, Cameron E, et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013; 13: 117.
- [49] Miles M, Huberman A. *Qualitative data analysis: an expanded sourcebook*. Sage. [https://books.google.co.za/books?hl=en&lr=&id=U4IU\\_-wJ5QEC&oi=fnd&pg=PR12&dq=Qualitative+data+analysis:+An+expanded+sourcebook.&ots=kETI6LOSUR&sig=myBC5ImkUmJHO1z2hizEOBwQzD4](https://books.google.co.za/books?hl=en&lr=&id=U4IU_-wJ5QEC&oi=fnd&pg=PR12&dq=Qualitative+data+analysis:+An+expanded+sourcebook.&ots=kETI6LOSUR&sig=myBC5ImkUmJHO1z2hizEOBwQzD4) (1994, accessed 1 March 2018).
- [50] Lincoln YS, Guba EG. *Naturalistic inquiry*. Sage Publications. <https://us.sagepub.com/en-us/nam/naturalistic-inquiry/book842> (1985, accessed 12 January 2018).

- [51] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Heal Care* 2007; 19: 349–357.
- [52] Streissguth AP, Bookstein FL, Barr HM, et al. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *J Dev Behav Pediatr* 2004; 25: 228–238.
- [53] Hanlon-Dearman A, Green CR, Andrew G, et al. Anticipatory guidance for children and adolescents with fetal alcohol spectrum disorder (FASD): practice points for primary health care providers. [https://www.researchgate.net/profile/Ana\\_Hanlon-Dearman/publication/271140236\\_Anticipatory\\_Guidance\\_for\\_Children\\_and\\_Adolescents\\_with\\_Fetal\\_Alcohol\\_Spectrum\\_Disorder\\_FASD\\_Practice\\_Points\\_for\\_Primary\\_Health\\_Care\\_Providers/links/5504684b0cf2d60c0e677bc9/Anticipatory\\_Guidance\\_for\\_Children\\_and\\_Adolescents\\_with\\_Fetal\\_Alcohol\\_Spectrum\\_Disorder\\_FASD\\_Practice\\_Points\\_for\\_Primary\\_Health\\_Care\\_Providers/links/5504684b0cf2d60c0e677bc9/Anticipatory\\_Guidance\\_for\\_Children\\_and\\_Adolescents\\_with\\_Fetal\\_Alcohol\\_Spectrum\\_Disorder\\_FASD\\_Practice\\_Points\\_for\\_Primary\\_Health\\_Care\\_Providers.pdf](https://www.researchgate.net/profile/Ana_Hanlon-Dearman/publication/271140236_Anticipatory_Guidance_for_Children_and_Adolescents_with_Fetal_Alcohol_Spectrum_Disorder_FASD_Practice_Points_for_Primary_Health_Care_Providers/links/5504684b0cf2d60c0e677bc9/Anticipatory_Guidance_for_Children_and_Adolescents_with_Fetal_Alcohol_Spectrum_Disorder_FASD_Practice_Points_for_Primary_Health_Care_Providers/links/5504684b0cf2d60c0e677bc9/Anticipatory_Guidance_for_Children_and_Adolescents_with_Fetal_Alcohol_Spectrum_Disorder_FASD_Practice_Points_for_Primary_Health_Care_Providers.pdf) (accessed 7 June 2017).
- [54] Olivier L, Urban M, Chersich M, et al. Burden of Fetal Alcohol Syndrome in a rural West Coast area of South Africa. *South African Med J* 2013; 103: 402–405.
- [55] Larimer ME, Crouse-Cormier JM. Identification, prevention, and treatment revisited: Individual-focused college drinking prevention strategies 1999–2006. *Addict Behav* 2007; 32: 2439–2468.
- [56] Logan DE, Marlatt GA. Harm reduction therapy: a practice-friendly review of research. *J Clin Psychol* 2010; 66: n/a-n/a.
- [57] Zilberman ML, Blume SB. Domestic violence, alcohol and substance abuse. *Rev Bras Psiquiatr* 2005; 27: s51–s55.
- [58] Hunting G, Browne AJ. Decolonizing policy discourse: reframing the ‘Problem’ of fetal alcohol spectrum disorder. *Women’s Heal Urban Life* 2012; 11: 35–53.
- [59] Pienaar K, Savic M. Producing alcohol and other drugs as a policy ‘problem’: a critical analysis of South Africa’s ‘National Drug Master Plan’ (2013–2017). *Int J Drug Policy* 2016; 30: 35–

- [60] Reid N, Dawe S, Shelton D, et al. Systematic review of fetal alcohol spectrum disorder interventions across the life span. *Alcohol Clin Exp Res* 2015; 39: 2283–2295.
- [61] Jirikowic T, Gelo J, Astley S. Children and youth with fetal alcohol spectrum disorders: summary of intervention recommendations after clinical diagnosis. *Intellect Dev Disabil* 2010; 48: 330–344.
- [62] Pei J, Baugh L, Andrew G, et al. Intervention recommendations and subsequent access to services following clinical assessment for fetal alcohol spectrum disorders. *Res Dev Disabil* 2017; 60: 176–186.
- [63] Foetal Alcohol Spectrum Disorder South Africa. Policy brief (emanating from the FASD prevention symposium, 2008). [http://www.fasdsa.org/Policy\\_Brief.pdf](http://www.fasdsa.org/Policy_Brief.pdf) (2008, accessed 5 February 2018).
- [64] George MA, Hardy C. Addressing FASD in British Columbia, Canada: analysis of funding proposals. *J Popul Ther Clin Pharmacol* 2014; 21: 338–345.
- [65] Canada FASD Research Network. *Prevention of Fetal Alcohol Spectrum Disorder (FASD): a multi-level model*. [http://fasd.alberta.ca/documents/CanFASD\\_4\\_levels\\_of\\_prevention\\_brief.pdf](http://fasd.alberta.ca/documents/CanFASD_4_levels_of_prevention_brief.pdf) (2013, accessed 26 February 2018).

## **Additional file 1: Interview guide for focus groups interviews**

### **Introductions and purpose of interview explained and consent form signed.**

- (1) Which services and interventions do you provide to individuals with FASD?
- (2) In what context – as part of the policy or general interventions?

#### **Themes to discuss or probe:**

##### **Department of Health:**

- Diagnosis, follow-up services after diagnosis
- Ages and development (what about adolescents and adults)?
- Mental health and psychiatric conditions
- Use of alcohol/substances
- Sexual behavior
- Preventative services = mother alcohol use, health promotion, maternal, and community education

##### **Department of Education:**

- School experience of individuals with FASD
- Absence from school
- Specific language, cognitive, literacy, social skills or other training? (Child and parents)
- Parental involvement
- Ages and development (what about adolescents)?

##### **Department of Social Development**

- Continuing services to individuals with FASD irrespective of age
- Family services and single parent services
- Living conditions and recreational facilities
- Employment and recreational activities
- Inclusion in communities, schools, etc.
- Financial assistance
- Disability services
- Alcohol and substance abuse
- Sexual behavior
- Conflict with law

Preventative services: alcohol abuse of mothers, communities, alcohol as payment, social skills training, and family coping with FASD

- (3) Describe the services that are currently provided by your department to individuals living with FASD, families and community?
- (4) Can you please describe the type of services you think your department should be provided for individuals living with FASD, families, and community?
- (5) Describe which services/interventions do you think should be included in policy or guidelines for practice in terms of individuals with FASD, families, caregivers, communities, and service providers (training, resources and collaboration between departments)? How can they be included?
- (6) In developing guidelines that will inform policy development express your opinion on those things you think should be included/excluded in the guidelines?
- (7) Describe how adequate are the responses of your department to FASD with regards to existing policies/guidelines and services?



## Additional file 2: Current practices and interventions

<b>Prevention practices and interventions</b>	<b>Clinical</b>	Refer to Non-profit Organisation with service for people with alcohol problems
		Advising pregnant women on alcohol use
		Taking alcohol history during the antenatal booking
		Counselling and referral to the community-based organisations and support group for assistance
		Alcoholic women referred to Social workers
		Family involvement for at-risk mothers
	<b>Educational</b>	Prevention awareness in schools on alcohol
		Community talks on food and alcohol use during pregnancy
		Training of community workers to educate communities on FASD
		Distribution of information pamphlets on alcohol and alcohol abuse
		Health education for women
		Train the trainers programme on FASD
	<b>Social</b>	Support for women in the community to abstain from alcohol during pregnancy.
		Including pregnant women in identifying programmes to prevent FASD
		Raising awareness through theatre, experiential learning, and night sessions in the community and schools
		Educate, inform, mentor, and support pregnant women
		Motivational counselling for pregnant women
<b>Management practices and interventions</b>	<b>Clinical</b>	Screening, diagnostic, assessment, and therapy for children with FASD
		General developmental screening at six weeks for children
		Assisting a child with language and feeding problem
		Referral for a child with developmental delay to appropriate services
		Developmental stimulation for children with FASD with developmental delay
		Mental health service for children with FASD
		General medical support for children with FASD
		Interventions to improve fine and gross motor for children with FASD
		Counselling and educating parents on a child diagnosis and management at home
		Exercise intervention for children with FASD
		General management plan for children with developmental delay
		Referral of children with FASD to children homes
	<b>Educational</b>	Educating children with FASD
		Extracurricular activities for children with FASD
		Language, mathematics, social and life skill development for children with FASD
		Placing children with FASD in a workshop environment.
		Development of IEP and curriculum based on assessment
		Appropriate school referral for children with FASD
		Availability of school of skill for older children

	Parent involvement in the management of children with FASD
	School health clinic assist with the management of children at school
	Occupational services aim to improve learners' outcome
	Storytelling to improve child cognitive
	Exercise activities (finger, drawing, and painting) for children with FASD
	Training of professionals and parents on FASD management
	Special teacher and support teacher to assist the children with FASDs
	Use of picture for the explanation of concepts in the classroom
	Early childhood schools for children with FASD
<b>Social</b>	Residential service for children with FASD
	Interaction with the community toward assisting a child with FASD
	Advocating for the right of individuals with FASD
	Availability of foster care for children with FASD
	Support for parents' with a child with FASD
	Availability of protective workshops for adults with a disability
	Availability of daycare service for children with disability
	Assistance with grants application

### **Additional file 3: Identified policy requirements**

<b>Prevention policy requirement</b>	<b>Clinic setting</b>	Encourage early booking for pregnant women
		Counselling services for women on alcohol abuse
		Holistic approach to FASD prevention
		Refer and support for women with alcohol problems
		On-going counselling on FASD in clinics
		Use of community health forum for FASD prevention
	<b>Educational setting</b>	Education on danger in drinking during pregnancy
		Health education on FASD for all
		Awareness in schools and public places on FASD
		Poster in building on the danger of drinking alcohol during pregnancy
		Use of labelling, posters, adverts, pamphlets, and video on FAS for campaign
		Education on FASD for teenagers and in schools
		Prevention programme on the effect of alcohol for schools and community
		Use of billboard for messages on maternal drinking
		Use peer education for prevention
		Skill training for women in the community



		Awareness of no amount of alcohol
	<b>Social environment</b>	Working with other sectors like Police service
		Regulation of shebeens/taverns to control alcohol sales especially to pregnant women
		After school activities to promote healthy behaviours
		Use of community-based workers to delivered message on FASD at homes in the community
		Enforcing the law against alcohol abuse
		Community-based approach to FASD prevention
		Use of law to prevent the pregnant mother from buy alcohol
		Use of community work to assist women
<b>Management policy requirements</b>	<b>Clinic setting</b>	Awareness and prevention of FASD in clinics
		Motivational talk and counselling in clinics to reduce drinking
		Integrating the system of identification and coordination of services for children
		Early diagnosis and management of FASD
		Provision of mental health service to individuals with FASD
		Stimulation of child's development
		Create national surveillance for FASD
		Thorough developmental screening for children
		Establishment of a multidisciplinary team for management of FASD
		Clear referral pathway between departments on the management of FASD
		Development of appropriate age interventions for children with FASD
	<b>Educational setting</b>	Interdepartmental involvement (SAPS, churches, DOE, DSD, DOH, and NPOs)
		Training and workshops for teachers on how to counsel and support parents' who have children with FASD
		Educate parents and support groups on FASD management
		Provision of specialised schools for children with FASD
		Refer children with FASD who are struggling in the main school to special schools
		Comprehensive learners' bio-data for children with FASD
		Involvement of the parents in the management of children with FASD children

	Assist learners with schools closer to their home
	Increase government involvement in schools
	Modification of CAPS and use of IEP for children with FASD
	Advert on TV, radios, and posters on FASD in the community
	Support for children with FASD in the mainstream
	Building more special school
	Training of social worker, health professionals, and teachers on FASD
	Provide individuals with FASDs with various skills
	Assist teachers with classroom management
	Appropriate placement for learner ship for individuals with FASD
<b>Social environment</b>	Support system for individuals with FASD and family in the community and in schools
	Provision of social grant for individuals with FASD
	Support programmes for individuals with FASD in foster care
	Development of proper implementation plan for policy on FASD
	Awareness programme on primary and secondary disabilities of FASD in the community
	Promote independent living for individuals with FASD
	Community services aim at integrating individuals with FASD
	Provision of grants in form of food to Individuals with alcohol problems
	Awareness and prevention of FASD in the community
	Protection for individuals with FASD
	Build residential and daycare facilities
	Ban alcohol advertisement in media

## Appendix A – Coding guide

Categories	Themes	Sub-themes
<b>Availability (lack) of policies/ guidelines on FASD</b>	No specific guideline/policy document on FASD	
	Clauses in other guidelines/policy documents	

<b>Development of guideline/policy document</b>	There is a need to develop a separate guideline/policy document	
	There is no need to develop separate guideline/policy document	
<b>Current practices and available interventions</b>	Prevention-related interventions	Clinical prevention interventions
		Educational prevention interventions
		Social prevention interventions
	Management-related interventions	Clinical management interventions
		Educational management interventions
		Social management Interventions
<b>Identified policy requirements for FASD</b>	Prevention-related interventions	Clinical prevention policy requirements
		Educational prevention policy requirements
		Social prevention policy requirements
	Management-related interventions	Clinical management policy requirements
		Educational management policy requirements
		Social management policy requirements



## CHAPTER THREE

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Policymakers' perspectives towards developing a guideline to inform policy on Fetal Alcohol Spectrum Disorders: A qualitative study. *International journal of environmental research and public health*. 2019 Jan; 16(6):945.

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### **Abstract**

Fetal alcohol spectrum disorder (FASD) has a high prevalence in South Africa, especially among the poor socioeconomic communities. However, there is no specific policy to address FASD. Using a qualitative study design, we explored the perspectives of policymakers on guidelines/policies for FASD, current practices and interventions, and what practices and interventions could be included in a policy for FASD. The data analysis was done using the Framework Method. Applying a working analytical framework to the data, we found that there is no specific policy for FASD in South Africa, however, clauses of FASD policy exist in other policy documents. Preventive services for women and screening, identification, assessment, and support for children are some of the current practices. Nevertheless, a multi-sectoral collaboration and streamlined program for the prevention and management of FASD are aspects that should be included in the policy. While there are generic clauses in existing relevant policy documents, which could be attributed to the prevention and management of FASD, these clauses have not been effective in preventing and managing the disorder. Therefore, a specific policy to foster a holistic and coordinated approach to prevent and manage FASD needs to be developed.

## Introduction

Alcohol is identified as the primary cause of preventable birth defects and developmental disorders [1]. Fetal alcohol spectrum disorder (FASD) is an umbrella term for the four categorical diagnoses in one diagnostic schema and a diagnostic entity for the adverse effects of prenatal alcohol exposure in another. The four categorical diagnoses of FASD include fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD) [2].

South Africa has the highest alcohol consumption rate (11 liters per capita) in Africa and among the highest in the world [3]. The lifetime consumption of alcohol for men and women is 49% and 22%, respectively [4]. The consumption rate of women seems low, yet those who consume alcohol do so in excess, and binge drinking is rampant [5–7]. Therefore, it is no surprise that in South Africa the national prevalence of FASD ranges from 29 to 290 per 1000 live births [8]. While the national prevalence is comparatively high, the prevalence of FASD in the Northern and Western Cape Provinces has received particular attention. In the Northern Cape, the prevalence of FASD was 88 per 1 000 in grade one learners in 2008 [9]. In 2015, the prevalence had dropped to 63.9 per 1000 in grade one learners, although still relatively high when compared to the national average [10]. In the Western Cape, the prevalence of FASD in grade one learners was estimated at 89.2 per 1000 in 2007 [11]. By 2013, the prevalence had doubled (135.1 to 207.5 per 1000) [12], whereas it had increased to 170 to 233 per 1000 in grade one learners in 2016 [13]. These estimates indicate a persistent rise in the prevalence of FASD in the Western Cape, indicating the need for context-specific preventive interventions and early intervention. Although these studies were conducted at different sites, these areas had similar characteristics (rural and lower socioeconomic status). FASD is recognized as an important public health problem in South Africa [14].

Consequently, various researchers have advocated for services that target FASD in various forms. Some of these recommendations include context-specific prevention programs, the creation of adequately resourced mental health facilities for supporting the mental health needs of women before and during pregnancy and individuals diagnosed with FASD [15, 16]. However, appropriate prevention and management efforts continue to pose a challenge for policymakers and service providers.

According to Pienaar and Savic [17], there is a paucity of local research for evidence-based interventions proposed by the National Drug Master Plan (2013–2017). Therefore, they suggested that lived experiences of alcohol and other drug (AOD) consumers should inform the development of policy. Interventions such as universal prevention, motivational interviewing and service provider short courses for FASD prevention which have been found effective should also be included [18–20]. However, these interventions have not been routine for FASD prevention or have low coverage because of the inadequate health system [21]. Jacobs et al. [14] acknowledged that efforts were being made to develop relevant policies to address the use of alcoholic beverages by pregnant women in South Africa, but the authors stressed the need to address the gaps related to the conspicuous absence of issues around FASD. Adnams [22] echoed the concerns of Jacobs et al. [14], advocating for partnerships and collaboration to address these gaps.

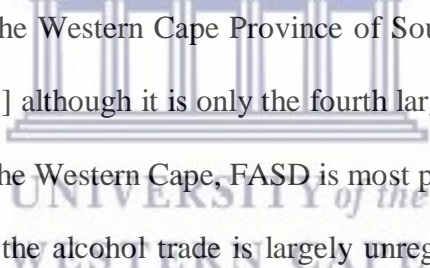
Rendall-Mkosi et al. [23] reviewed the South African National Government policy documents to explore the extent to which FASD is addressed. The authors found that only two documents referred to FAS and another one to women and alcohol consumption during pregnancy. Rendall-Mkosi et al. [23] also found that despite the absence of specific policies on FASD, the Departments of Health, Education, and Social Development were offering services to individuals with FASD. Although, these services are generic to people living with mental diseases and not specifically targeting individuals

with FASD. In light of the absence of a coordinated effort targeting FASD, we identified the need to develop a guideline to inform a multi-sectoral and interdepartmental policy to address FASD.

In this article, we report on a step towards developing a guideline to inform a coordinated approach in the prevention and management of FASD [24]. We explored the perspectives of policymakers on existing guidelines/policies for FASD, current practices and interventions, and what practices and interventions that could be included in a policy for FASD.

## Methodology

### Study setting



This study was conducted in the Western Cape Province of South Africa, which has the highest FASD prevalence in the world [13] although it is only the fourth largest and the third most populated province of South Africa. Within the Western Cape, FASD is most prevalent in the low-income areas, where binge drinking is rife, and the alcohol trade is largely unregulated. The Western Cape has a unique historical drinking culture entrenched in a system known as the ‘dop’ system—whereby the wages of farmworkers are paid using alcohol beverages [25]. Although the system has been abolished, the lingering effects remain. To this end, risk factors for alcohol and substance misuse increase, especially among populations with a low educational level and/or employed in menial jobs. Poor mental health and risky drinking practices, especially among women of childbearing age, are some of the many predisposing factors for FASD and these factors are endemic in this province [26]. The Western Cape has an estimated 6.5 million residents [27] with an infant mortality rate (IMR) of 19.1 per 1000 live births and an under-five mortality rate (U5MR) of 24.1 per 1000 live births [28]. According to Statistics South Africa [4], 38.1% women in the Western Cape reported having drunk



alcohol once in their lifetime, while 27.3% had drunk alcohol in the preceding 12 months. Furthermore, 18% reported having drunk alcohol the preceding seven days, and 9.0% reported having drunk five or more drinks at least on one occasion the preceding 30 days.

According to a study conducted in the Cape Metropole, Western Cape, out of 684 pregnant women sampled, 36.9% confirmed that they had consumed alcohol during their current pregnancy or in the three months before they knew they were pregnant [29]. “In another study conducted in Cape Town with 110 samples (parents or caretakers of 110 children aged 4–12 years), the reported alcohol use six months before pregnancy and during pregnancy was 38% and 15%, respectively [30]. In proxy respondents, alcohol use six months before pregnancy and during pregnancy was 47% and 33%, respectively. The disparity in the percentages recorded is attributable to the stigma and shame associated with drinking during pregnancy [30]. In the Western Cape, women also considered drinking alcohol during pregnancy as a coping strategy for their socio-political realities [31].

In the Western Cape, liquor-related commercial activities are the second most frequent category of business in the township economy [32]. These liquor-related businesses are identified in the form of shebeens/taverns, and an estimated 25,000 of unlicensed/illegal liquor stores are operating in the Western Cape. About 60% of these shebeens/taverns are run by women selling low volumes of alcohol to complement their household income. This trade has made alcohol available to people of all ages.

## **Study design**

We employed an exploratory qualitative design. Information gathered from qualitative research adds value to the development and implementation of guidelines [33] as it allows for an in-depth exploration of the perspectives of relevant stakeholders [34].

## Sampling procedure

A two-step purposive sampling approach was adopted. Step one involved selecting three institutions and step two involved selecting 10 participants who were policymakers on FASD-related service delivery. In step one, the Western Cape Department of Education, and Departments of Health and Social Development were selected as the most relevant stakeholders (policymakers) for the development of policies, interventions, and services for individuals with FASD. In step two, we adopted the following criteria to select the study participants, (1) participants working in any of the above-mentioned Departments; (2) and having at least five years' experience in policymaking or services and implementing interventions for individuals with FASD; (3) or were members of the multidisciplinary team working on FASD. The characteristics of the study participants recruited for the interviews are described in Table 1

**Table 1: Characteristics of study participants**

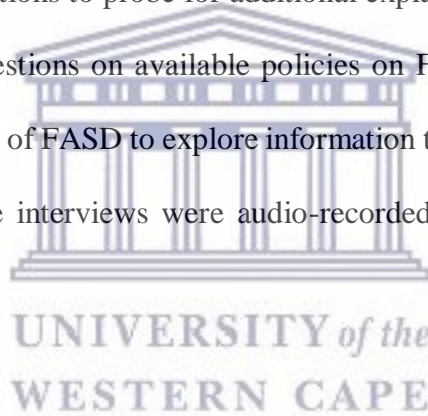
Characteristics	Participants (N = 10)
Number of interviews per department	
Department of Education	4
Department of Health	3
Department of Social Development	3
Gender	
Male	4
Female	6
Profession	
Allied health	5
Others	5
Working Experience (Years)	
5-10	3
11-20	3
21-30	2
31-40	1
41-50	1

Potential participants were directors, assistant directors, heads of programs, policy administrators, policy developers, and policy monitoring and evaluation officers. All the participants had tertiary

qualifications as the lowest qualification. They were recruited via emails, telephone calls, and personal visits. Fifteen potential participants were identified. Twelve agreed to participate in the study, but only 10 were finally interviewed. While conducting the interviews, we reached data saturation with the subsequent responses and discussions, as no ‘new’ information was elicited [35, 36].

## Data collection

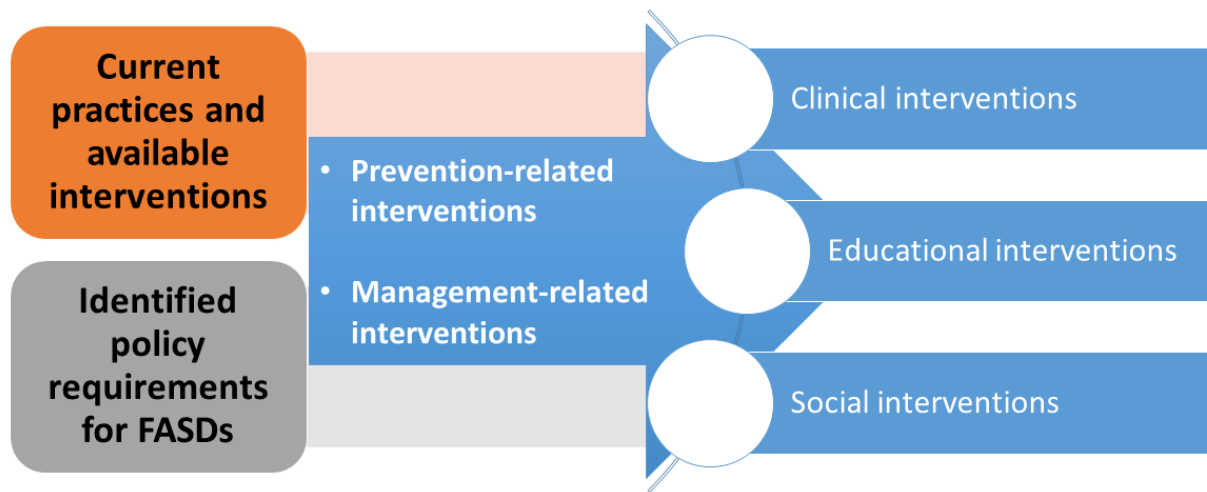
In-depth interviews lasting 30–60 min were conducted in English between September 2016 and 2017, and guided by an interview schedule (**Additional File 1**). We used open-ended questions to start the interviews and follow-up questions to probe for additional explanations when required. We asked the study participants various questions on available policies on FASD, the coordination of FASD interventions, and relevant aspects of FASD to explore information that could inform the development of appropriate guidelines. All the interviews were audio-recorded with permission from the study participants.



## Data analyzes

The data were analyzed using the Framework Method [37], a part of the thematic analysis family [38]. Following the Framework Method, we transcribed the interviews, and read and re-read for familiarization. The transcripts were then coded inductively to generate initial codes and re-organized to obtain refined codes. Using the initial codes, two of the authors (B.O.A. and F.C.M.) and an independent coder developed a working analytic framework (Figure 1). Codes with similar concepts

were grouped to form sub-themes, and those sub-themes, which addressed similar concepts, were further grouped to form the final themes.



**Figure 1: A working analytical framework**

The working analytic framework we developed was applied by attributing relevant aspects of the texts in the subsequent transcripts to existing categories, themes, and sub-themes. Finally, we charted the data into the framework matrix (Tables 2 and 3).

## **Trustworthiness and rigour of the study**

The rigor and trustworthiness were established through credibility, transferability, dependability, conformability, and reflexivity [39]. During data collection, we guarded against leading the respondents and allowed them to express themselves in sharing information. We provided a detailed methodology for the study. Verbatim transcripts of the participants' responses were included to ensure credibility. Furthermore, credibility was enforced through member-checking at the end of each interview—a recap of the salient points that emanated from the interviews. In addition, a reflective journal, which documented the discussions, deliberations, and decisions of the researchers was kept

during the entire study. The reflective journal formed part of the audit trail that was kept for the study. In consultation with the research team and based on the literature on FASD, the interview schedule was developed in a way that allowed the required information to be obtained to ensure dependability. The same interview schedule was used as a guide for all the interviews. Two members of the research team independently coded the transcripts and met afterward to discuss the findings. An agreement was reached by consensus. The research team (a Ph.D. student, an expert on FASD and two supervisors) has no personal relationship with the participants, however, the university that approved the study has a working relationship with the government departments. In reporting this study, all the relevant aspects of the criteria for reporting qualitative research (COREQ) outlined by Tong, Sainsbury, and Craig [40] were followed.

## **Ethical considerations**

The approval for the study was obtained from the research ethics committee of the University of the Western Cape (BM/16/4/4), and further approvals were obtained from the Western Cape Department of Education (20161212-6937), Department of Health (WC\_2016RP29\_862), and Social Development (12/1/2/4). Before conducting the interviews, the study aims and objectives were explained to the potential participants who were provided with an information sheet written in English explaining their roles. The potential participants were requested to sign a consent form as they agreed to participate in the study. Because some of the participants are in prominent administrative positions within their departments, there is a chance that these individuals could be linked to their responses. The researchers warned all the study participants of this potential before they signed the consent forms. All information obtained during the study was kept strictly confidential on a computer with a password known only to the research team.

## Data management

To maintain anonymity and easy identification of the information sources, policymakers in the various departments are coded as DOEX, DOHX, and DSDX. X denotes an arbitrary number from 1–4. DOE represents the Department of Education, DOH denotes the Department of Health, and DSD denotes the Departments of Social Development.

## Results

Presented below are the salient categories, themes, and sub-themes obtained during the data analysis.

### Category 1: Availability (Lack) of guidelines/policies on FASD

All participants from the three selected departments acknowledged the absence of policies/guidelines specifically addressing the issues around FASD.

We (at DOE) do not have any direct policy for FASD but the policy documents I gave you are all part of what we call inclusive education. **(DOE<sub>2</sub>)**

We do not have a guideline per se for FASD. We (at DSD) fund non-profit organizations (NPOs) to render services. In our (DSD) annual performance plans, we (at DSD) have indicators as to what we need to achieve as a department. **(DSD<sub>1</sub>)**

We (at DOH) do not have any guideline or policy specifically for FASD as such in our Department, so there is nothing to guide any intervention or screening anything specifically. **(DOH<sub>2</sub>)**

One of the participants suggested that the absence of a policy on FASD could be related to the fact that other ‘bigger’ issues such as mental health have not yet received the due attention to warrant a separate policy as a coordinated effort to address it.

We [at DOH] do not even have a specific policy for mental health conditions but now it has been combined with clinical conditions, e.g., HIV, AIDS, and mental health are included, that it is [the only] health policy we have for now. We do not have any policy, but we did develop a specific policy last year, but it does not look at FASD condition. It is just into mental illness not into FASD . . . (DOH<sub>2</sub>)

Some participants, nevertheless, indicated that various clauses exist in different policies related to the prevention and management of FASD. The following participants identified aspects of the prevention and management of FASD that were found embedded in policies addressing other issues.

We (at DOE) have a policy document on special education needs in terms of education. It is a very broad policy document but Fetal Alcohol Spectrum Disorder is one of the areas that are titled in the policy document . . . we have the barriers to learning (aspects of the) policies but that includes specific learning barriers, physical barriers (blind, deaf cerebral palsy children). Therefore, FASD is one of the categories . . . (DOE<sub>2</sub>)

I am in women’s health and we (at DOH in our division) deal with maternal health. In maternal health, as part of antenatal care, we follow the National Maternity Care guideline and it speaks to the first antenatal booking. There is history taking that we must do and the part that history taking speaks to alcohol use as well. (DOH<sub>3</sub>)

The FASD is part of a policy (alcohol-related harms reduction policy) but in a certain chapter like health and social services, education awareness and community action group. Therefore, it [FASD policy] is worked into our alcohol-related harms reduction policy, so it (alcohol-related harms reduction policy) is becoming a white paper. It (alcohol-related harm reduction policy) has gone through to the Cabinet and after Cabinet, it (alcohol-related harms reduction policy) could become a white paper—official and then it (white paper) would become policy. (DSD<sub>3</sub>)



## Category 2: Development of guideline/policy document

The participants had different opinions on whether a separate guideline/policy should be developed for FASD. Those who opted for a separate policy argued that FASD is a serious problem, especially in the wine-producing communities of the Western Cape Province.

I would really advocate for a separate policy, separate attention given to FASD due to the severity of the problem. Because it is a severe problem in the Western Cape and if you look at communities, people have a greater need for a specialized service when it comes to FASD (DSD<sub>2</sub>)

Guidelines will definitely be helpful because it will guide appropriate intervention from an early identification point of view. Therefore, if it is identified and properly managed through guidelines, you would probably end up having a more positive result in terms of returning the child to school and not ending up being a dropout. (DOE<sub>2</sub>)

Opponents for having a separate policy on FASD suggested that the implementation of such policies would be resource-intensive, which is impracticable in the context of scarce resources. In addition, these individuals argue that government departments are moving towards policies that are inclusive in nature, rather than having specified policies for various conditions.

I believe everyone or anyone would like a specific policy to be developed for a specific issue. However, the first thing that we look at is if it is practical. Can it be implemented? Can the policy address the issue? In addition, can it serve the purpose that it is being developed for? However, for FASD, as I told you, in the beginning, we have schools for the blind, deaf children, schools for cerebral palsy children; we have schools for learners with slow cognitive thinking. We do not have special schools for FASD, but they will be catered for in the special needs schools. You see, as I told you, if there are funding and resources to develop a specific policy that will address this in education, and then I would advocate it. Then, I would say this could smartly be addressed in the department of health or social development, we (at DOE) are just trying to develop them [individuals affected by prenatal alcohol exposure] for the future. (DOE<sub>4</sub>)

I am not sure if that (separate policy for FASD) is necessary either because in terms of the inclusive policies that child should be identified as having a barrier to learning. Therefore, if you want a policy on that it will cost the management because the teacher needs to know how

to address children with those barriers and that may even be university level. I think maybe there is a need to have a module on how to deal with FASD children because they are going (to) be in the classroom. (DOE<sub>2</sub>)

### **Category 3: Current practices and available FASD interventions**

This category presents current practices and interventions that have been pinpointed for the prevention and management of FASD. The participants identified several prevention programs that are currently run by various departments in the Western Cape.

Regarding FASD, a participant from DSD reported that there are ongoing awareness and prevention programs on alcohol and drug abuse under the special program of the Department of Social Development.

So, it is basically just general awareness and prevention services when it comes to FASD. It's an alcohol and drug abuse awareness program. And alcohol and substance abuse or drug abuse have been identified as a special program under Social Development. (DSD<sub>2</sub>)

Another participant said that in its annual performance plan, DSD has strategies to help mothers with alcohol problems. The participant reported that helping mothers with alcohol problems aims at preventing FASD, which is usually achieved by funding (NPOs).

We (at DSD) have indicators in terms of what we need to achieve with regard to helping and assisting a patient (with an alcohol problem) or a client with FASD. (We assist the) mother first. We as a department (Social Development) fund organizations to do this. (DSD<sub>3</sub>)

The participant from the DSD also reported that there is an ongoing awareness program in various government departments such as the Western Cape Liquor Authority, and the Western Cape Departments of Agriculture, Education, Health, and Social Development.

There is a lot of awareness going on at the clinical level as well as when someone comes to our (Western Cape) local clinics. They (at Western Cape local clinics) do early interventions and try to motivate the client (women) to seek further treatment for the alcohol problem. And then [the Department of Education is running] educational and awareness (programs) at schools, also, the Western Cape Liquor Authority is going to the schools to have roadshows and showing school children the pro(s) and cons of drinking [alcohol]. **(DSD<sub>3</sub>)**

A participant from the DOH indicated that there is a guideline at clinic-level for screening women for any drug use including alcohol.

We (at DOH) have a PACK guideline (practical approach care kit), so this is just to help the clinician in the clinic. So, if you look at the women's health, you screen for any drug [alcohol inclusive] abuse. **(DOH<sub>1</sub>)**

Various FASD-related management interventions that are currently applied in Western Cape departments were also identified by the participants. A participant from the DSD indicated that services are rendered to individuals with FASD which are included in general social work services at the community level.

FASD is more addressed on a local level, at a service delivery level. The actual services that are rendered to the people affected by FASD are included in the generic social work services at grass-root levels in the local offices of the Social Development. **(DSD<sub>2</sub>)**

The participants from the DOE indicated that their department provides educational training and support on FASD for teachers and the support team—psychologists, social workers, and support teachers. The DOE also provides training on how to identify and manage children with FASD in class.

What we (at DOE) have is a commitment to training teachers in the area of the fetal alcohol spectrum disorder. What are the causes? What are their characteristics? In addition, what are the consequences for teaching and learning? Therefore, we have the training sessions across the province for fetal alcohol spectrum disorder. **(DOE<sub>1</sub>)**

We (at DOE) are planning a training workshop for our psychologist and I am busy planning for the training with the NPOs, to train our psychologist on early identification and treatment of FASD children. We have asked that the training must [place] emphasis on early

identifications. Some have to be according to DSM five (Diagnostic and Statistical Manual of Mental Disorders) because they must diagnose correctly. In addition, the emphasis must also be on how to advise the class teacher on how to teach the child in the classroom. **(DOE<sub>2</sub>)**

The following quotes illustrate the availability of referral pathways for the management of a child in schools: one within the Education Department and the other between the DOE and other government departments.

If a child stays out of school for 10 consecutive days without any reason or explanation, we (at DOE) will call for deregistration and the child is taken out of school. However, the child is not lost; the child will be taken to social development to check if the child does not suffer from whatever special needs. After that, the Department of Social Development will be the parent or guardian for the child. **(DOE<sub>4</sub>)**

In schools, teachers are involved in governance. However, when there is a problem and the teacher cannot solve it, the learning support person in the schools or district will help. In addition, if there is a need for (a) psychologist or social worker they will also help. We (at DOE) have outreach teams. They include social workers, psychologist(s), and learning support people; they help an ordinary schoolteacher. Moreover, we have a school-based support team that diagnoses problems in the schools. **(DOE<sub>1</sub>)**

Another participant from the DSD identified an alternative referral pathway through NPOs funded by the DSD. The participant indicated that the NPOs have a role in identifying the child and channeling him/her to the right school.

The child obviously needs to be channeled into the right schools, be identified at home as well at the school . . . We as a department (of Social Development) fund organizations to do this. **(DSD<sub>3</sub>)**

A participant from the DOE indicated that it is the DOE's responsibility to involve parents of a child with special needs, as it is part of the policy (Schools Act).

So, parents' involvement is crucial; if a child transgresses, his parents are always informed. It is part of the policy (School Acts). **(DOE<sub>4</sub>)**

Some participants from the DOE also reported that the Department of Education is currently busy with the screening, early identification, assessment, and support. The Department aims to identify children from the lowest grade possible—such as the reception grade—where they are received into the formal schooling system (grade R).

We as a department (Education) are busy rolling out a process for the identification of the child from grade R level. And it is in two, firstly, there is a learner's profile, which is the biographic details of the learners; some of these details may probably be an indication of FASD. Secondly, there are forms within which the teacher fills in a special needs assessment; form one, two and three. (DOE<sub>2</sub>)

So, the screening, identification, assessment, and support (SIAS) program is to try to bring the identification down, the education spectrum possible. So, if we (at DOE) can try and pick this up as early as grade R. (DOE<sub>3</sub>)

A participant from the DOH reported general service for the management of FASD.

Services (for individuals with FASD) are integrated. It (service for individuals with FASD) is dealt with like any other child requiring service or mother who has a substance problem and requires a specialized health service. (DOH<sub>1</sub>)

In Table 2, the different practices, interventions, and programs that are currently in place are illustrated according to the participants for the prevention and management of FASD.

**Table 2: Current practices and interventions**

<b>Prevention practices and interventions</b>	<b>Clinical</b>	Use of NPOs to assist pregnant women with a drinking problem
		Referring women with alcohol problems to DSD
		Taking alcohol history during the antenatal booking
		Health promotion on alcohols for women in clinics
		Customised message on the risk of alcohol consumptions
		Multisectoral collaboration for alcohol abuse prevention
		Motivational counselling to stop drinking
		Alcohol screening for high-risk women
	<b>Educational</b>	Prevention awareness in schools on alcohol
	<b>Social</b>	Funding NPOs to carry out FASD prevention programme
		Awareness and prevention of alcohol abuse at the local level
		Motivating women to participate in the alcohol programme
		Awareness schools and clinics on the danger of drinking alcohol

<b>Management practices and interventions</b>	<b>Clinical</b>	Alcohol/drug abuse awareness programme in the community
		General developmental screening for children
		Use of NPOs to carry out diagnosis for children
		Multisectoral collaboration for management
	<b>Educational</b>	Educating children with FASD and preparing them for the future
		Parent involvement in the management of a child with FASD
		Commitment to training teachers and members of the support team on the identification and management of a child with FASD
		Availability of outreach team to support teachers and learners
		Adaptation of curriculum for individuals with FASD
		Screening, identification, assessment, and support for children
		Provision of specialised education for individuals with FASD
		Specialised support for individuals with FASD within the mainstream school
		Availability of policy that addressed curriculum, behaviour, and governance
	<b>Social</b>	Early intervention and aftercare assistance for children
		Availability of protective workshops for adults with a disability
		Availability of daycare service for children with disability
		Availability of residential services for children with disability
		Funding NPOs to provide residential care for children with FASD

#### Category 4: Identified policy requirements for FASD

This category presents the suggestions for FASD policy.

The participants suggested that an FASD-related guideline should facilitate early identification, screening, and diagnosis. They advocated that such a guideline would facilitate proper diagnosis, early intervention, and tailored response. The guideline would also ensure the development of diagnostic services with proper measures for accurate diagnoses by qualified health professionals.

Earlier identification and screening for everybody; not just FASD children, all disabilities. What I am saying is if the Department of Health should pick it up in the early years when they are doing the developmental screening and if there could improve communication between the Department(s) of Health and Education. We will address the FASDs issues better. (DOE<sub>2</sub>)

Yes, early identification . . . not to put the diagnosis in the hands of the teachers . . . I think our biggest problem is that they are not diagnosed. So, the child may be referred to us for



concentration problems but actually, it's [an] FASD problem. This is because they are referred to us for behavior (-related issues) but actually, they have a neurological disorder, which we do not know about yet. **(DOE<sub>3</sub>)**

What we need first, is the tool to screen and identify, if we are to identify and collect data. Then, from there we can use this evidence to put measures in place. **(DOH<sub>1</sub>)**

Another participant from the DSD suggested that the needs of individuals with FASD should be included in all social welfare plans, and the functioning of those with FASD should be looked at within the family system.

So, the whole social service sector should really realize that FASD is the problem and that it should be included in all our [social development] social welfare plan(s) . . . We should look at the whole functioning of the person with FASD in the family [as] very important. So, then we should look at the social, emotional, psychological, educational and inspirational aspects of the person's life and obviously the person with the FASD within his family environment. **(DSD<sub>3</sub>)**

A participant from the DOH suggested that assistance should be given to women or pregnant women and a referral pathway for help should be made available.

Firstly, in pregnancy, they (women) need assistance with a safe house and referral pathway. (For example), if I am a heavy drinker and I realize today that I am pregnant, but I feel the responsibility to have my child protected, what is in place for me now to stop drinking? If I am living in an abusive relationship, where I am drinking with my husband? What is in place for me if I want to stop drinking today and leave this abusive drinking husband? So, that I can safeguard my child. Also, the referral pathways. **(DOH<sub>1</sub>)**

Another participant suggested that the pathway for managing a child with FASD should be included in an FASD-related guideline.

If a child is born and it is determined by the Health Department and Social Development that the child has specific disorders, then the child is going to be referred to a specialized school. This (is) done towards educating the child as far as possible. So that the child can fit into the community or into the work environment if it is possible. **(DOE<sub>4</sub>)**



A participant from the DOH suggested the need for early intervention and the need to adopt relevant aspects from other policies like Western Cape Government First 1000 days.

We need remedial interventions early on. We focus a lot on the first thousand days of the brain development, eating and overall care of the child and if the identifying measures can start early on. This might also assist . . . screening pregnant women and helping other people with intervention. **(DOH<sub>1</sub>)**

The participants suggested that a policy guideline could facilitate collaborations among relevant departments and sectors like the Departments of Community Safety, Health, Education, and Rural and Land Reform, the Western Cape Liquor Authority, the South African Police Services (SAPS), the City of Cape Town and the Municipalities. The guideline should also elucidate the roles and responsibilities of the relevant stakeholders with specified and proper channels for collaborations established. The participants advocated that the guideline should illustrate how FASD services should streamline and connect through the developmental stages of an affected child.

Guidelines will definitely be helpful because it will guide appropriate intervention from an early identification point of view. So, if it is identified and properly managed through guidelines, you would probably end up having a more positive result in terms of returning the child to school and not ending up being a dropout. You may say at present, each department works on its own . . . when you speak about Education, the DSD, and the Health; you need to look at a new guideline [that will make us work together]. (A guideline) that will look at how these three departments will connect in transferring information from one department to another department. This is because it is like, we (at the Department of Education) get the child, and we enroll the child. The child starts in grade R and we have no medical history (of the child). We need to track the multi-development (of the child), we need to track the physical (mental, social and others) development of the child, but now we (at the Department of Education) do not have that. **(DOE<sub>2</sub>)**

I think that [inter-departmental collaboration] is definitively the way to go because there are many issues that each Department is dealing with in their own way. This is because if they (departments) can collaborate more and have a relationship with each other, then, it will be better. So, definitely, there is surely a need for multi-sectoral collaboration. Maybe for Social Development, for example, to look at the social need of a child, (Department of) Education

looks at educational need and so on. So, to have a conversation between all the departments definitely on how services can be streamlined, it will make it easier to connect them all. (DOH<sub>2</sub>)

It will not be of any help if the Department of Social Development develops an FASD policy that only applies to our department. So, it (the guideline/policy) needs to cut across all departments and departments follow the same policy or at least we (Departments) fit in into it [the guideline/policy]. (DSD<sub>2</sub>)

Some participants from the DSD expressed the need for all the Departments and other role players to be involved in addressing the FASD issues. This is because each of them provides a specific service or services that are beneficial to individuals with FASD. The participants echoed that the guideline should be designed in such a way that will bring these services together.

Basically, all departments like Department of Community Safety, Department of Health, Department of Education, Department of Rural and Land Reform, the Western Cape Local Authority, the South African Police Services and other key role players like your Municipalities; for example, Cape Town should be involved. For instance, all of them are involved in the alcohol harms reduction policy. (DSD<sub>2</sub>)

The policy care for people with disabilities . . . you will find childcare and protection, you will find your FASD empowerment program, you will find current prevention program, you will find youth program. All I am saying is that irrespective of the social program, it must remain accessible to all people including the persons who have disabilities . . . we (Social Development) will be guided by the integrated service delivery model. Our service delivery, integrated service delivery is divided into four levels. One is awareness, the second is early intervention, the third is statutory and the fourth is reunification. (DSD<sub>1</sub>)

Some participants from the DOE suggested the need for FASD-related training for parents and teachers.

There is a huge problem related to parental training. It is a massive problem because you would have to train every parent and I am thinking in a lot of cases—individuals with FASDs are coming from lots of areas. (DOE<sub>2</sub>)

I think we need to advocate for parental training, early diagnosis, and preschool identification. If we are looking at school policy again, early identification allows us to put them into the program early; and teacher training, train teachers to deal with these children because they are in the classroom. (DOE<sub>4</sub>)

Participants also suggested the provision of inclusive education and that a separate school for children with FASD may not be necessary as this will be contrary to inclusive education. They advocated for more specialized services and support for children with FASD within the mainstream school.

I think it would be contrary to the inclusive education (to have FASD children in special schools). This is because the inclusive education says that we should try to assist the child in the area in which they live. So, we do not want to unnecessarily remove young children from home and place them in a boarding home. So, the inclusive policy, when you read the full services, [the child should be put in] the normal mainstream school in the community, which has additional support. (DOE<sub>2</sub>)

So, I think the contact of the child for me is so crucial because often we think of just removing the child from one school, placing the child at another but we never discuss it with the child . . . removing a child from one school to another is traumatic. This is because the child loses his friends, he loses his teacher—a teacher comes with teaching styles, with different teaching styles—he loses his peer, he loses his safe space and then you put the child into a different school. I mean we need to accommodate the interest of the child and we need to communicate and discuss it with the child. (DOE<sub>4</sub>)

All the various practices, interventions and programs that the study participants identified which should possibly be included in the policy for the prevention and management of FASD are indicated in Table 3.

**Table 3: Identified policy requirements**

Prevention policy requirements	Clinical	Need for multi-sectoral collaboration for prevention
		Facilitate local initiatives to solve alcohol problems
		Establishment of a working group for policy development
		Emphasis on no alcohol is safe during pregnancy
		Need to screen women for alcohol and drug abuse
		Need for prevention programme for the women, the family, and the community

<b>Management policy requirements</b>	<b>Educational</b>	Put law in place to deter people from abusing alcohol
		Awareness about the danger of drink alcohol
		Targeted intervention in high incidence area
	<b>Social</b>	Advocating for the right of individuals with FASD
		Inclusion of the needs of individuals with FASD in social welfare plan
		Skill-building for individuals with FASD
		Alcohol pricing and tavern regulation
		Create local alcohol action committee
		Consultation with relevant implementation stakeholders
	<b>Clinical</b>	Identification of the needs of individuals with FASD
		Need for a safe house for pregnant women and referral pathways
		Need for Seamless connection with services on FASD problems
		Need for a helpline that people can call for information on FASD
		Need for multi-sectoral collaboration for managing FASD
	<b>Educational</b>	Interdepartmental involvement (SAPS, churches and NGOs)
		Need for specialist care for individuals with FASD
		Need for Structured and dedicated programme for FASD
		Training of teachers, social workers, and psychologist on FASD
		Need for Inclusive education for individuals with FASD
		Classroom management guideline For FASD
		Pharmacological management of FASD
		Parents should create a care mechanism for their children.
		Early diagnosis and preschool identification for children
		Need for early intervention for individuals with FASD
		Need for school curriculum adaptation and functional curriculum for individuals with FASD
		Need for additional support within the mainstream school FASD children
		Need for medical assistant in schools for FASD children
		Early identification and prevention
		Clear roles and responsibilities of the different departments of management of FASD
		Appropriate child placement for FASD children
		Clear channels of communication among departments
		Proper communication to the parent about their children
		Communication with FASD children
	<b>Social</b>	Need for specified and appropriate intervention for different age
		Training of caregivers, social service practitioners, and volunteers
		Promoting independent living
		Build residential facilities and daycare
		Care for Individuals with FASD and their families
		Funding NPOs to provide personalised services for FASD

## Discussion

We aimed to identify relevant FASD preventive and management practices and interventions based on the perspectives of policymakers to inform the designing of a guideline for FASD policy. Our findings indicate that there are no specific or separate national policies/guidelines for the prevention and management of FASD in South Africa. However, there are documents on policies/guidelines indirectly addressing the issue of FASD in a generic way [23]. For instance, the National Drug Master Plan, the National Human Genetics Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects, and Disabilities and the Guidelines for Maternity Care in South Africa all have prevention and management modalities that could be identified as related to FASD. In addition, the Education White Paper 5 on Early Childhood Development, Education White Paper 6 on Inclusive Education, South African Schools Act, Western Cape Provincial Schools Act, and the recently drafted Western Cape alcohol-related harms reduction policy also contain elements of FASD prevention and management.

The policies mentioned have not been systematically evaluated to assess the extent to which they address issues regarding FASD [23]. The National Drug Master Plan (2013–2017) proposed the use of evidence-based interventions, however, there is a paucity of local research that could inform possible interventions [17]. Furthermore, existing interventions that are specific to FASD are not addressed by the above policies. Specific interventions in the different sectors have not been made routine for FASD prevention [18–20], and sometimes the financial aid for these interventions is not sufficient [21].

Moreover, although the mentioned policies/guidelines generically cover aspects relevant to FASD, there is no specific national document (policy or guideline) that exclusively and comprehensively focuses on FASD. The lack of FASD policies has a negative influence on the delivery of FASD specialized services. The absence of a specific or separate policy/guideline for the prevention and

management of FASD has also been reported by Rendall-Mkosi et al. [23]. In our study, we found that developing a specific FASD policy that requires huge capital and an additional workforce could be one of the reasons for not having a specific policy. Another reason could be the inadequate and overburdened health system in South Africa [21].

Although it has been reported that FASD is a serious public health issue, particularly in the Western Cape Province and the wine-producing areas [8, 41], we found divergent opinions on whether or not a separate FASD guideline/policy should be developed. Most of the policymakers agreed to the need for a specific policy for FASD, while a few did not see the need to develop guidelines pertaining exclusively to FASD-related issues. They cited high cost as a barrier to developing and implementing such policies. In one accord with these participants, other authors have expatiated that having a separate policy required additional workforce and implementation cost, thereby increasing the burden on an already overwhelmed health, social and educational system [42–45]. The notions expressed by the policymakers could indicate that the relevant departments should work together collaboratively to do more, which may not necessarily translate to increased costs for developing and implementing an FASD policy [46, 47].

We found that there are general awareness programs/services at the local level (community-oriented programs). These awareness programs are carried out as part of the general social work services rendered to the people in the community. In general, these awareness programs focus on drug and substance use/abuse suggesting that preventive efforts for FASD may not necessarily require specialized programs [48, 49]. However, there are few prevention programs targeting women and pregnant women [15, 16] at clinics with the aim of preventing FASD. We discovered that the DSD usually funds NPOs to provide prevention programs. There are also educational and awareness programs such as roadshows at schools. These are being carried out by the DOE and Western Cape Liquor Authority.



Although there are several current preventive interventions/practices reported, these have not been effective in reducing the prevalence of FASD in South Africa, especially in the Western Cape [50]. The ineffectiveness of these interventions could be attributed to other mitigating factors such as poor living conditions, poor nutrition, poor socioeconomic status, low level of education, low-income, and unemployment [13]. Therefore, there is a need for comprehensive preventive services addressing gaps in current policies and policy implementation to facilitate strategic interventions [14, 22].

Regarding the management of FASD, the findings indicated that services are also rendered to individuals with FASD as well as their families, as part of generic social work services at the local level. The DSD sponsors organizations to render services to individuals with FASD and their families. However, the problem with this is that such services only address the social issues neglecting the medical and educational issues, which are equally important for the holistic management of FASD. Therefore, there is a need to develop a national policy that will facilitate the coordinated management of FASD across the relevant departments. We found that in the DOH, based on available policies, services such as general developmental screening, diagnosis, developmental stimulation, and general medical management are part of integrated services, and there are no specialized services for individuals with FASD and their families. While the integrated services could place less burden on the health system, the effectiveness of these services may be undermined if the social and educational issues are not addressed concurrently.

We discovered that in the DOE, FASD is considered as one of several causes of learning disabilities. Thus, the DOE has policies addressing learning disabilities rather than focusing on FASD. The problem with defining FASD based on one's ability to learn is that individuals with FASD do not only have learning disabilities but also, these learning disabilities could lead to other pertinent concerns regarding their well-being becoming neglected. Therefore, policies focused on addressing the



educational needs of individuals will inherently fail to address the broader social issues of individuals with FASD [51].

In addition, one of the policies relates to screening, identifying, assessing, and supporting people with learning disabilities from grade R [52–54]. These individuals with learning disabilities are supported from when they are very young, as an early intervention has shown promising outcomes [55]. The DOE also provides training on FASD and other learning disabilities (identification, consequences for teaching and learning, and classroom management) for teachers, social workers, psychologists and members of the support team.

In our study, we showed that efforts are being made to use a multi-professional support team for children with special educational needs (including children with FASD) starting from school to the provincial office. When a child is suspected of having FASD-related learning disabilities or any other learning difficulties, he/she is referred to a school-based support team. If the school-based support team is not equipped to resolve the issues, the child will be referred to the district-based support team, and may finally be referred to the provincial-based support team. They will assess the child and determine if he/she should continue in the mainstream or be moved to a special school. The inadequacy of these efforts is that the special education needs of these children are enormous; there are inadequate resources to meet these needs and those of their teachers and the support team [56]. Because of this, teachers may not be adequately trained to handle the emotional, social and other issues faced by individuals with FASD. The DOE also involves parents in the management of individuals with FASD.

Apart from the current practices and programs, we also identified other important aspects regarding the prevention and management of FASD that could be included in a guideline/policy in our study. The DOH and DSD should provide preventive services to women, pregnant women, and the community [23]. A child should be screened and diagnosed at an early stage by the DOH; this should be communicated to the DOE towards educating the child as far as possible. The DOE should

communicate to the Department of Labor towards providing appropriate employment or augmenting the child's education with necessary skills concerning employment or entrepreneurship. Consultations with the DSD should be done to assess the suitability of the child for social grants or any other social welfare packages. The guideline/policy should also facilitate the provision of inclusive education in line with the inclusive education policy [23].

Some of the suggestions made on what should be included in the policy were aligned with the four-part framework by pan-Canadian prevention experts proposed by Poole et al. [57]. This four-part framework consists of four levels of prevention for FASD. Level 1 involves comprehensive awareness building and health promotion efforts. Level 2 relates to discussions on alcohol use and related risks with all women of childbearing years and their support networks. Level 3 suggests specialized, holistic support of pregnant women with alcohol and other health/social problems. Finally, level 4 encompasses postpartum support for new mothers and support for child assessment and development.

We discovered that some of the current practices and available interventions suggested by the policymakers were similar to those identified by FASD service providers in another study [58]. These interventions and policy requirements included training and support for parents, caregivers, and teachers, multi-sectoral/inter-departmental collaboration, and general awareness in the community and schools. Not only that, screening, early identification and diagnosis and providing assistance for women with alcohol use problems were also part of the interventions and policy requirements mentioned. These interventions and policy requirements were also aligned with the policy developed to tackle FASD in Canada and Australia. These policies include the Canadian Framework for Action on FASD and Australian National FASD Strategy for Action Plan 2018–2028 [59, 60].

Most of the approaches identified in our study are classified as downstream and midstream approaches to addressing FASD. Arguments have been made that addressing FASD-related issues at the level of social determinants of health can improve health and reduce disparity [61]. Consequently,

calls have been made for the use of an upstream approach (referred to as the second approach) for the prevention of FASD [62]. Therefore, for an FASD policy to be comprehensive and holistic, upstream prevention approaches should also be considered.

## **Strengths and limitations of the study**

In this study, the researcher interviewed policymakers from the three major departments (Education, Health, and Social Development) that are responsible for the implementation of policies and the provision of services to individuals with FASD. A limitation of the study that was expected to inform policy on FASD nationally was that it was only conducted in one of nine provinces in South Africa. We also did not interview policymakers from the Department of Labor and the Department of Justice, who may have had additional information to improve the guideline. Furthermore, we used purposeful sampling in the study, which may have prompted biased opinions. Moreover, since the focus of this study was on policymakers, we did not include women who drank during pregnancy, women with children who have FASD, women who went through pregnancy and did not drink, individuals with FASD or women with prenatal alcohol use who quit drinking upon hearing they were pregnant.

## **Conclusion**

There is a consensus among relevant policymakers that there is no specific guideline/policy document on FASD. Many of the participants agreed that a national guideline/policy should also be developed for the holistic prevention and management of FASD. However, some of the participants suggested that developing a national policy that is exclusive to FASD and comprehensive to address all relevant aspects will be costly. In the study, we identified some aspects for the prevention and

management of FASD that are being applied at various health system levels including those that could be added to build a guideline to inform policy about FASD.

## Supplementary Materials

The following are available online at <http://www.mdpi.com/1660-4601/16/6/945/s1>,  
Additional file 1: Interview schedule.

## Author Contributions

Conceptualization, B.O.A., F.C.M., L.G.C. and A.-M.B.; Data curation, B.O.A.; Formal analysis, B.O.A., F.C.M. and L.G.C.; Funding acquisition, B.O.A. and F.C.M.; Investigation, B.O.A., F.C.M., L.G.C. and A.-M.B.; Methodology, B.O.A., F.C.M., L.G.C. and A.-M.B.; Project administration, B.O.A.; Resources, B.O.A. and F.C.M.; Software, B.O.A. and F.C.M.; Supervision, F.C.M., L.G.C. and A.M.B.; Validation, B.O.A., F.C.M., L.G.C. and A.-M.B.; Visualization, B.O.A. and F.C.M.; Writing—original draft, B.O.A.; Writing—review & editing, B.O.A., F.C.M., L.G.C. and A.M.B.

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## Conflicts of Interest

The authors declare that there is no conflict of interest.

# Additional file 1

## INTERVIEW GUIDE FOR UNSTRUCTURED INTERVIEWS WITH POLICYMAKERS

### Introductions and purpose of interview explained and consent form signed.

1. Do you have policies/guidelines documents specifically for FASD in your department?
2. Describe which aspects of FASD are focused on in these policies/guidelines?

Probe on themes:

#### **Department of Health:**

- Diagnosis, follow-up services after diagnosis
- Ages and development (what about adolescents and adults)?
- Mental health and psychiatric conditions
- Use of alcohol/substances
- Sexual behavior
- Preventative services = mother alcohol use, health promotion maternal and community education

#### **Department of Education:**

- School experience of people with FASD
- Absence from school
- Specific language, cognitive, literacy, social skills or other training? (Child and parents)
- Parental involvement
- Ages and development (what about adolescents)?

#### **Department of Social Development**

- Continuing services to people with FASD irrespective of age
- Family services and single parent services
- Living conditions and recreational facilities
- Employment and recreational activities
- Inclusion in communities, schools, etc.
- Financial assistance
- Disability services
- Alcohol and substance abuse
- Sexual behavior
- Conflict with law

Preventative services: alcohol abuse of mothers, communities, alcohol as payment, social skills training and family coping with FASD

3. Describe how the policies/guidelines are being implemented? Who are involved in services? Which regions?
4. If the policy/guideline needs to be improved or new policy/guideline needs to be developed, what should be included/excluded?

## Reference

1. Bailey, B.A.; Sokolo, R.J. Pregnancy and alcohol use: Evidence and recommendations for prenatal care. *Clin. Obstet. Gynecol.* **2008**, *51*, 436–444.
2. Blackburn, C.; Whitehurst, T. Fetal alcohol spectrum disorders (FASD): Raising awareness in early years settings. *Br. J. Spec. Educ.* **2010**, *37*, 122–129.
3. WHO. *Global Status Report on Alcohol and Health*; WHO: Geneva, Switzerland, 2014; pp. 1–100.
4. Statistics South Africa. *Media Release: South Africa Demographic and Health Survey* |Statistics South Africa; Statistics South Africa: Pretoria, South Africa, 2016. Available online: <http://www.statssa.gov.za/?p=9836> (accessed on 12 January 2018).
5. Vellios, N.G.; Van Walbeek, C.P. Self-reported alcohol use and binge drinking in South Africa: Evidence from the National Income Dynamics Study, 2014–2015. *S. Afr. Med. J.* **2017**, *108*, 33–39.
6. Peltzer, K.; Davids, A.; Njuho, P. Alcohol use and problem drinking in South Africa: Findings from a national population-based survey. *Afr. J. Psychiatry* **2011**, *14*, 30–37.
7. Chambers, D. Binge-Drinking Is a Huge Problem in SA—But We Can’t Admit It| UCT News. 2018. Available online: <https://www.news.uct.ac.za/article/-2018-01-04-binge-drinking-is-a-huge-problem-in-sa-but-we-cant-admit-it> (accessed on 1 February 2019).
8. Olivier, L.; Curfs, L.M.G.; Viljoen, D.L. Fetal alcohol spectrum disorders: Prevalence rates in South Africa. *S. Afr. Med. J.* **2016**, *106*, 103–106.
9. Urban, M.; Chersich, M.F.; Fourie, L.-A.; Chetty, C.; Olivier, L.; Viljeon, D. Fetal alcohol syndrome among grade 1 school children in Northern Cape province: Prevalence and risk factors. *S. Afr. Med. J.* **2008**, *98*, 877–882.

10. Urban, M.F.; Olivier, L.; Viljoen, D.; Lombard, C.; Louw, J.G.; Drotsky, L.M.; Temmerman, M.; Chersich, M.F. Prevalence of fetal alcohol syndrome in a South African city with a predominantly black African population. *Alcohol Clin. Exp. Res.* **2015**, *39*, 1016–1026.
11. May, P.A.; Gossage, J.P.; Marais, A.-S.; Adnams, C.M.; Hoyme, H.E.; Jones, K.L.; Robinson, L.K.; Khaole, N.C.; Snell, C.; Kalberg, W.O.; et al. The epidemiology of fetal alcohol syndrome and partial FAS in a South African community. *Drug Alcohol Depend.* **2007**, *88*, 259–271.
12. May, P.A.; Blankenship, J.; Marais, A.-S.; Gossage, J.P.; Kalberg, W.O.; Barnard, R.; De Vries, M.; Robinson, L.K.; Adnams, C.M.; Buckley, D.; et al. Approaching the prevalence of the full spectrum of fetal alcohol spectrum disorders in a South African population-based study. *Alcohol Clin. Exp. Res.* **2013**, *37*, 818–830.
13. May, P.A.; de Vries, M.M.; Marais, A.-S.; Kalberg, W.O.; Adnams, C.M.; Hasken, J.M.; Tabachnick, B.; Robinson, L.K.; Manning, M.A.; Jones, K.L.; et al. The continuum of fetal alcohol spectrum disorders in four rural communities in South Africa: Prevalence and characteristics. *Drug Alcohol Depend.* **2016**, *159*, 207–218.
14. Jacobs, L.; Steyn, N.; Labadarios, D. ‘Mind the Gap’: Observations in the Absence of Guidelines for Alcohol Abstinence among Expectant Women in South Africa. 2013. Available online: <http://repository.hsrb.ac.za/bitstream/handle/20.500.11910/3008/7682.pdf?sequence=1> (accessed on 12 January 2018).
15. Fitzpatrick, J.P.; Latimer, J.; Carter, M.; Oscar, J.; Ferreira, M.L.; Olson, H.C.; Lucas, B.R.; Doney, R.; Salter, C.; Try, J.; et al. Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: The Lililwan project. *J. Paediatr. Child. Health* **2015**, *51*, 450–457.
16. Fitzpatrick, J.P.; Latimer, J.; Olson, H.C.; Carter, M.; Oscar, J.; Lucas, B.R.; Doney, R.; Salter, C.; Try, J.; Hawkes, G.; et al. Prevalence and profile of neurodevelopment and fetal alcohol spectrum

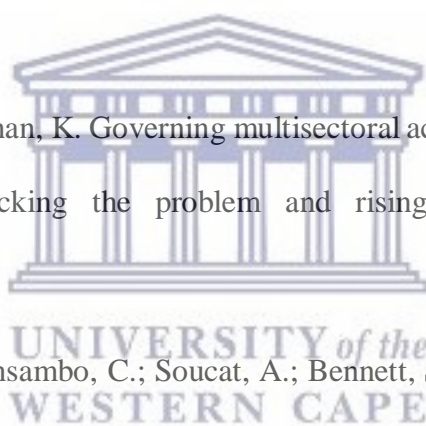


- disorder (FASD) amongst Australian Aboriginal children living in remote communities. *Res. Dev. Disabil.* **2017**, *65*, 114–126.
17. Pienaar, K.; Savic, M. Producing alcohol and other drugs as a policy ‘problem’: A critical analysis of South Africa’s ‘National Drug Master Plan’ (2013–2017). *Int. J. Drug Policy* **2016**, *30*, 35–42.
  18. Mwansa-Kambafwile, J.; Rendall-Mkosi, K.; Jacobs, R.; Nel, E.; London, L. Evaluation of a service provider short course for prevention of fetal alcohol syndrome. *J. Stud. Alcohol Drugs* **2011**, *72*, 530–535.
  19. Chersich, M.F.; Urban, M.; Olivier, L.; Davies, L.A.; Chetty, C.; Viljoen, D. Universal prevention is associated with lower prevalence of fetal alcohol spectrum disorders in Northern Cape, South Africa: A multicentre before-after study. *Alcohol Alcohol.* **2012**, *47*, 67–74.
  20. Rendall-Mkosi, K.; Morojele, N.; London, L.; Moodley, S.; Singh, C.; Girdler-Brown, B. A randomized controlled trial of motivational interviewing to prevent risk for an alcohol-exposed pregnancy in the Western Cape, South Africa. *Addiction* **2013**, *108*, 725–732.
  21. Kirigia, J.M.; Pathe Barry, S. Health challenges in Africa and the way forward. *Int. Arch. Med.* **2008**, *1*, 27.
  22. Adnams, C.M. Fetal alcohol spectrum disorder in Africa. *Curr. Opin. Psychiatry* **2017**, *30*, 108–112.
  23. Rendall-Mkosi, K.; London, L.; Adnams, C.; Morojele, N.; McLoughlin, J.A.; Goldstone, C. *Fetal Alcohol Spectrum Disorder in South Africa: Situational and Gap Analysis*; UNICEF: Pretoria, South Africa, 2008; Available online: [https://www.unicef.org/southafrica/SAF\\_resources\\_fetalalcohol.pdf](https://www.unicef.org/southafrica/SAF_resources_fetalalcohol.pdf) (accessed on 14 September 2017).

24. Adebiyi, B.O.; Mukumbang, F.C.; Okop, K.J.; Beytell, A.M. A modified Delphi study towards developing a guideline to inform policy on fetal alcohol spectrum disorders in South Africa: A study protocol. *BMJ Open* **2018**, *8*, e019907.
25. London, L. The ‘dop’ system, alcohol abuse and social control amongst farm workers in South Africa: A public health challenge. *Soc. Sci. Med.* **1999**, *48*, 1407–1414.
26. Esper, L.H.; Furtado, E.F. Identifying maternal risk factors associated with Fetal Alcohol Spectrum Disorders: A systematic review. *Eur. Child. Adolesc. Psychiatry* **2014**, *23*, 877–889.
27. Statistics South Africa. *Statistical Release*; Statistics South Africa: Pretoria, South Africa, 2017.
28. Medical Research Council (MRC). *Western Cape Mortality Profile 2011*; MRC: London, UK, 2014. Available online: [www.westerncape.gov.za](http://www.westerncape.gov.za) (accessed on 12 January 2018).
29. Petersen Williams, P.; Jordaan, E.; Mathews, C.; Lombard, C.; Parry, C.D. Alcohol and other drug use during pregnancy among women attending midwife obstetric units in the Cape Metropole, South Africa. *Adv. Prev. Med.* **2014**, *2014*, 871427.
30. Katwan, E.; Adnams, C.; London, L. Childhood behavioural and developmental disorders—Association with maternal alcohol consumption in Cape Town, South Africa. *S. Afr. Med. J.* **2011**, *101*, 724–727.
31. Cloete, L.; Ramugondo, E. ‘I drink’: mothers’ alcohol consumption as both individualised and imposed occupation. *S. Afr. J. Occup. Ther.* **2015**, *45*, 34–40.
32. Charman, A.; Petersen, L. Comment on the Western Cape Alcohol-Related Harms Reduction Policy Green Paper Charman and Petersen, Sustainable Livelihoods Foundation. 2016. Available online: <http://livelihoods.org.za/publications/> (accessed on 12 January 2018).

33. Glenton, C.; Lewin, S.; Norris, S.; Norris, S. Chapter 15: Using evidence from qualitative research to develop WHO guidelines. In *WHO Handbook for Guideline Development*; WHO: Geneva, Switzerland, 2014; pp. 183–200.
34. Creswell, J.; Creswell, J. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*; Sage Publications: Thousand Oaks, CA, USA, 2017.
35. Bowen, G.A. Naturalistic inquiry and the saturation concept: A research note. *Qual. Res.* **2008**, *8*, 137–152.
36. Brod, M.; Tesler, L.E.; Christensen, T.L. Qualitative research and content validity: Developing based on science and experience practices. *Qual. Life Res.* **2009**, *18*, 1263–1278.
37. Gale, N.K.; Heath, G.; Cameron, E.; Rashid, S.; Redwood, S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med. Res. Methodol.* **2013**, *13*, 117.
38. Miles, M.; Huberman, A. *Qualitative Data Analysis: An Expanded Sourcebook*; Sage: Thousand Oaks, CA, USA, 1994; Available online: <https://books.google.co.za/books?hl=en&lr=&id=U4IU-wJ5QEC&oi=fnd&pg=PR12&dq=Qualitative+data+analysis:+An+expanded+sourcebook.&ots=kETi6LOSUR&sig=myBC5ImkUmJHO1z2hizEOBwQzD4> (accessed on 1 March 2018).
39. Lincoln, Y.S.; Guba, E.G. *Naturalistic Inquiry*; Sage Publications: Thousand Oaks, CA, USA, 1985; Available online: <https://us.sagepub.com/en-us/nam/naturalistic-inquiry/book842> (accessed on 12 January 2018).
40. Tong, A.; Sainsbury, P.; Craig, J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *Int. J. Qual. Health Care* **2007**, *19*, 349–357.
41. Olivier, L.; Urban, M.; Chersich, M.; Temmerman, M.; Viljoen, D. Burden of Fetal Alcohol Syndrome in a rural West Coast area of South Africa. *S. Afr. Med. J.* **2013**, *103*, 402–405.

42. Crede, S.; Sinanovic, E.; Adnams, C.; London, L. The utilization of health care services by children with fetal alcohol syndrome in the Western Cape, South Africa. *Drug Alcohol Depend.* **2011**, *115*, 175–182.
43. Popova, S.; Lange, S.; Burd, L.; Urbanoski, K.; Rehm, J. Cost of specialized addiction treatment of clients with fetal alcohol spectrum disorder in Canada. *BMC Public Health* **2013**.
44. Popova, S.; Lange, S.; Burd, L.; Rehm, J. Cost attributable to fetal alcohol spectrum disorder in the Canadian correctional system. *Int. J. Law Psychiatry* **2015**, *41*, 76–81.
45. Stade, B.; Ali, A.; Bennett, D.; Campbell, D.; Johnston, M.; Lens, C.; Tran, S.; Koren, G. The burden of prenatal exposure to alcohol: Revised measurement of cost. *Can. J. Clin. Pharmacol.* **2009**, *16*, e91–e102.
46. Bennett, S.; Glandon, D.; Rasanathan, K. Governing multisectoral action for health in low-income and middle-income countries: Unpacking the problem and rising to the challenge. *BMJ Glob. Health* **2018**, *3*, e000880.
47. Rasanathan, K.; Atkins, V.; Mwansambo, C.; Soucat, A.; Bennett, S. Governing multisectoral action for health in low-income and middle-income countries: An agenda for the way forward. *BMJ Glob. Health* **2018**, *3*, e000890.
48. Pei, J.; Baugh, L.; Andrew, G.; Rasmussen, C. Intervention recommendations and subsequent access to services following clinical assessment for fetal alcohol spectrum disorders. *Res. Dev. Disabil.* **2017**, *60*, 176–186.
49. Jirikowic, T.; Gelo, J.; Astley, S. Children and youth with fetal alcohol spectrum disorders: Summary of intervention recommendations after clinical diagnosis. *Intellect. Dev. Disabil.* **2010**, *48*, 330–344.
50. May, P.; De Vries, M.; Marais, A.-S.; Kalberg, W.; Buckley, D.; Adnams, C.; Hasken, J.; Tabachnick, B.; Robinson, L.; Manning, M.; et al. Replication of high fetal alcohol spectrum disorders prevalence



rates, child characteristics, and maternal risk factors in a second sample of rural communities in South Africa. *Int. J. Environ. Res. Public Health* **2017**, *14*, 522.

51. Streissguth, A.P.; Bookstein, F.L.; Barr, H.M.; Sampson, P.D.; O'MALLEY, K.I.E.R.A.N.; Young, J.K. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *J. Dev. Behav. Pediatr.* **2004**, *25*, 228–238.
52. Cook, J.L.; Green, C.R.; Lilley, C.M.; Anderson, S.M.; Baldwin, M.E.; Chudley, A.E.; Conry, J.L.; LeBlanc, N.; Looock, C.A.; Lutke, J.; et al. Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan. *CMAJ* **2016**, *188*, 191–197.
53. Hoyme, H.E.; Kalberg, W.O.; Elliott, A.J.; Blankenship, J.; Buckley, D.; Marais, A.S.; Manning, M.A.; Robinson, L.K.; Adam, M.P.; Abdul-Rahman, O.; et al. Updated clinical guidelines for diagnosing fetal alcohol spectrum disorders. *Pediatrics* **2016**, *138*, e20154256.
54. Watkins, R.E.; Elliott, E.J.; Halliday, J.; O'Leary, C.M.; D'Antoine, H.; Russell, E.; Hayes, L.; Peadon, E.; Wilkins, A.; Jones, H.M.; et al. A modified Delphi study of screening for fetal alcohol spectrum disorders in Australia. *BMC Pediatr.* **2013**, *13*, 13.
55. Reid, N.; Dawe, S.; Shelton, D.; Harnett, P.; Warner, J.; Armstrong, E.; LeGros, K.; O'Callaghan, F. Systematic review of fetal alcohol spectrum disorder interventions across the life span. *Alcohol Clin. Exp. Res.* **2015**, *39*, 2283–2295.
56. Koren, G.I.; Fantus, E.; Nulman, I. Managing fetal alcohol spectrum disorder in the public school system: A needs assessment pilot. *Can. J. Clin. Pharmacol.* **2010**, *17*, e79–e89.
57. Poole, N.; Schmidt, R.A.; Green, C.; Hemsing, N. Prevention of fetal alcohol spectrum disorder: Current Canadian efforts and analysis of gaps. *Subst. Abuse* **2016**, *10*, 1–11.

58. Adebiyi, B.O.; Mukumbang, F.C.; Cloete, L.G.; Beytell, A.M. Exploring service providers' perspectives on the prevention and management of fetal alcohol spectrum disorders in South Africa: A qualitative study. *BMC Public Health* **2018**.
59. Public Health Agency of Canada. *Fetal Alcohol Spectrum Disorder (FASD): A Framework for Action*; Health Canada: Ottawa, ON, Canada, 2003. Available online: <https://www.canada.ca/en/public-health/services/reports-publications/fetal-alcohol-spectrum-disorder-fasd-framework-action.html> (accessed on 8 August 2018).
60. Australian Government. *Title: National Fetal Alcohol Spectrum Disorder Strategic Action Plan*; Australian Government: Canberra, Australia, 2018. Available online: <https://beta.health.gov.au/resources/publications/national-fetal-alcohol-spectrum-disorder-fasd-strategic-action-plan-2018-2028> (accessed on 2 February 2019).
61. Williams, D.R.; Costa, M.V.; Odunlami, A.O.; Mohammed, S.A. Moving upstream: How interventions that address the social determinants of health can improve health and reduce disparities. *J. Public Health Manag. Pract.* **2008**, *14*, S8–S17.
62. Sanders, J.; Currie, C.L. Looking further upstream to prevent fetal alcohol spectrum disorder in Canada. *Can. J. Public Health* **2014**, *105*, e450–e452.



# CHAPTER FOUR

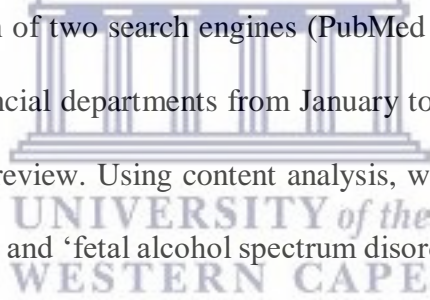
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To what extent is the Fetal alcohol syndrome disorder considered in policy-related documents in South Africa? A document review. Health Research Policy and Systems 2019 17:46.

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## Abstract

**Background:** South Africa is considered to have the highest prevalence of fetal alcohol spectrum disorder (FASD) globally. Nevertheless, the extent to which the South African government has responded to the high FASD prevalence at the policy level is unclear. Herein, we aimed to identify targeted and generic clauses that could be attributed to the prevention and management of FASD in relevant South African policy documents.



**Methods:** We conducted a search of two search engines (PubMed and Google) and the websites of South African national and provincial departments from January to April 2018. A total of 33 policy documents were included in this review. Using content analysis, we sought documents that mention the terms ‘fetal alcohol syndrome’ and ‘fetal alcohol spectrum disorder’. The Framework method was also used to thematically identify specific and generic clauses attributed to the prevention and management of FASD in South Africa.

**Results:** The content analysis indicated that 12 policy documents contained the searched terms. Findings from the thematic analysis showed that targeted and generic clauses for FASD exist in various policy documents. Some of the generic clauses focused on the regulation of liquor outlets, enforcement of liquor laws, and the general management of persons with mental and educational challenges. Specific clauses focused on creating platforms to improve the awareness, screening, identification and support for individuals with FASD.



**Conclusions:** There is a noticeable increase in the number of policy documents that considered elements of FASD enacted in the last decade. Although this study revealed the existence of targeted and generic clauses that could be attributed to the prevention and management of FASD, the sustained high prevalence of FASD in South Africa, as reported in the literature, calls for more holistic and comprehensive approaches to tackle the FASD problem in South Africa.



## INTRODUCTION

Fetal alcohol spectrum disorder (FASD) is a group of physical, behavioural and learning conditions that can occur in persons who were exposed to alcohol during pregnancy [1]. According to reports, no amount of alcohol is safe, and there is no safe time to drink during pregnancy that will not lead FASD [2, 3]. Therefore, any amount of alcohol consumed during pregnancy places the foetus at risk.

Globally, 1 in every 13 prenatal alcohol-exposed pregnancies results in FASD, with a global prevalence of 8 per 1000 children and youth in the general population as reported in 2017 [4]. In South Africa, the national prevalence of FASD ranges from 29 to 290 per 1000 live births [5], representing the highest rate globally. In the Western Cape Province, a recently published study estimated the prevalence to be between 196 and 276 children per 1000 [6], representing the highest prevalence in South African provinces.

The high prevalence of FASD recorded in South Africa has been attributed, in part, to the historical drinking culture driven by a system known as the ‘dop system’, whereby farmworkers’ wages were paid in alcoholic beverages [7, 8]. The high prevalence of FASD could also be ascribed to the lack of a comprehensive and multi-sectoral policy. To this end, incessant calls for a coordinated effort for the prevention and management of FASD have been made [5]. The coordinated effort for the prevention and management of FASD requires a sustainable commitment from the government, which could be facilitated by a multi-sectoral approach to policy development.

South Africa has the highest alcohol consumption rate (11 l per capita) in Africa, and is among the highest in the world [9]. The levels of lifetime consumption of alcohol for men and women are 49% and 22%, respectively [10]. Drinking during pregnancy is common in many countries, including South Africa [11], where women consider drinking as a coping strategy for their socioeconomic and socio-political realities [12]. In a study conducted in the Cape Metropole of the Western Cape Province, 36.9% of women confirmed that they had consumed alcohol during their current pregnancy or in the

3 months before they knew they were pregnant [13]. In another study conducted in the East Metropole, 22% of the pregnant women in the sample reported using alcohol during pregnancy [14]. This high rate of alcohol consumption is facilitated by the vast presence of illegal liquor stores. For example, in a single province (Western Cape), there are approximately 25,000 illegal liquor stores, known as shebeens (home-based taverns), making alcohol readily accessible to people of all ages [15]. The South African government must make a conscious effort to address and tackle this endemic risk factor for FASD [16].

In South Africa, policy-making is in most part the responsibility of the national government, with implementation and monitoring usually occurring at all levels of the government, though mostly at provincial and municipal levels. However, in a few instances, provincial and municipal governments can develop policies to address localised issues. Developing a policy document is an indication of the government's acknowledgment of a dilemma and acts as a response in the form of an action plan or a strategy to address a specific problem. The policy document usually contains stipulations on the allocation of resources, the timeframe for action and the framework for implementation [17, 18, 19, 20, 21]. The development of a National Strategy for HIV, tuberculosis and sexually transmitted infections is a good example of the importance of a policy document in South Africa [22, 23, 24, 25]. Despite its shortcomings on implementation, progress has been made towards reaching the 90–90–90 target, especially in achieving a 90% rate of diagnosis in HIV-positive individuals [24]. Learning from the success recorded on HIV, our consideration is that the South African government can achieve some success in curbing the escalating prevalence of FASD in South Africa by developing a comprehensive multi-sectoral policy.

Countries such as Australia, Canada and the United States of America [5, 26, 27, 28, 29] have not only recognised FASD as a public health issue but have developed specific FASD guidelines/policies to address it. These guidelines/policies include action plans [30], screening tools [31], frameworks for

action [32], diagnosis guidelines [33, 34, 35] and treatment improvement protocols [36]. However, in South Africa, the approach to addressing FASD at all levels of government remains non-specific as demonstrated by the presence of generic policies.

In 2008, Rendall-Nkosi et al. [17] conducted a situational analysis to examine the extent to which FASD has been addressed in various South African policy documents. According to these authors, only two policy documents used the term fetal alcohol syndrome (FAS), namely the National Drug Master Plan 2006–2011, and the National Human Genetics Policy Guidelines for the Management & Prevention of Genetic Disorders, Birth Defects & Disabilities. However, other policy documents, including the Guidelines for Maternity Care in South Africa 2002, Education White Paper 5 on Early Childhood Development 2001, and Education White Paper 6 on Inclusive Education 2001, contained blanket or generic clauses that could be attributed to the prevention and management of FASD. The authors also reported that services for individuals with FASD are fragmented among the essential departments (Education, Health, Labour, and Social Development), which may be because of the absence of a multi-sectoral guideline/policy for FASD [17].

Rendall-Nkosi et al. [17], in their situation analysis in 2008, recommended that a further detailed document review in South Africa should be conducted to examine the extent to which FASD is considered in policy documents. To the best of our knowledge, theirs is the only document review on FASD policy reported in the literature. To this end, we conducted another review to examine the extent to which FASD is considered in policy-related documents. We aimed to examine the targeted and blanket clauses that could be attributed to the prevention and management of FASD. These clauses could form part of a proposed guideline policy for the prevention and management of FASD, which is the aim of the larger study [20].

## Methods

### Study design

We conducted a document review with a qualitative approach to analysis [37]. This approach allows for an in-depth examination and interpretation of data to elicit meaning and gain an understanding of a particular issue [38]. Using a document review approach was informed by our aim to identify clauses that speak to the prevention and management of FASD in various relevant South African policies either specifically or in an inclusive manner.

### Identifying relevant documents

We searched PubMed and Google search engines and the websites of South African national and provincial departments, specifically the departments of Education, Health, Social Development, and Trade and Industry, from January to April 2018. We applied the following standard Boolean phrase during the searches: ['foetal alcohol spectrum disorder' OR 'alcohol-related neurodevelopmental disorder' OR 'foetal alcohol syndrome' AND 'policy' OR 'guideline' OR 'gazette' OR 'action plan' OR 'white paper' OR 'green paper' AND 'South Africa']. Of note, the use of foetal during the search also captured documents using 'fetal'. In addition to the online searches, we contacted the departmental designated contact persons in the Departments of Education, Health, Social Development, and Trade and Industry by email to request other policy documents, which may not be available online. These departments were selected because they have policy documents with clauses that could be attributed to the prevention and management of FASD or regulations of alcohol. We also searched references of the selected relevant policy documents for additional related information.

Herein, we considered a policy document as an action plan or a guideline that contains the intention of a government (national or provincial) concerning a particular issue. The search terms were identified and defined by two of the authors (BOA and FCM). BOA conducted the electronic search following the defined search terms and contacted other stakeholders for relevant documents. BOA and FCM finalised the list of documents that met the inclusion criteria. AMB supervised the work.

## Inclusion

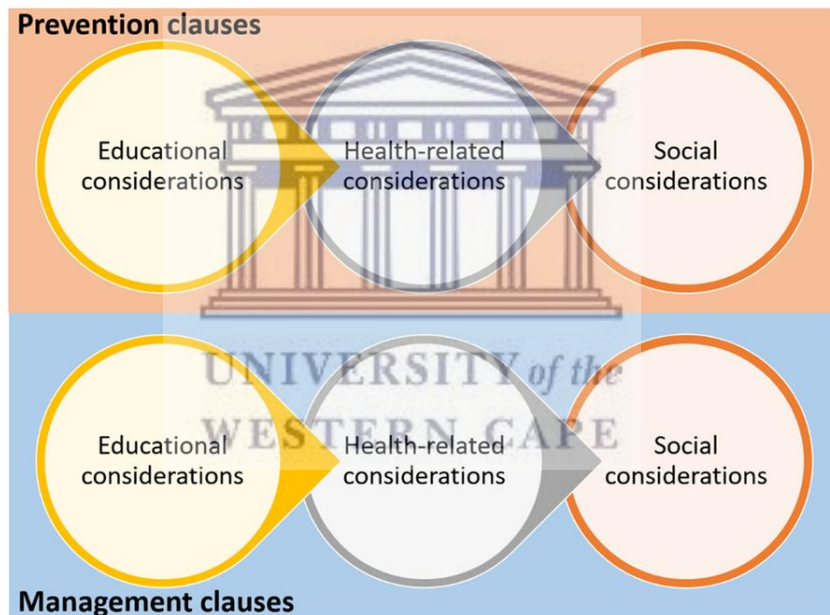
- The document must be about South African policy.
- The document must contain clauses specifically targeting FASD or be attributed to FASD as well as clauses that address alcohol drinking in general.
- If the documents were published in series, the most recent series was considered.

Our initial search yielded 371 articles and documents. Following deduplication, we obtained 152 articles and documents. After screening the titles, executive summaries/abstract and the full texts, we obtained 33 relevant policy documents included for analysis. The list of the documents and their descriptions are presented in **Additional file 1**.

## Data Analysis

The data were analysed using both content analysis [39] and the Framework method [40], a family of thematic analysis [41]. During content analysis, we specifically searched for the terms FAS and FASD. To do this, the first author (BOA) typed each of the terms into the search console of the PDF file of each policy document to identify the occurrence of FAS, FASD or both.

The thematic analysis entailed reading and re-reading the identified policy documents for familiarisation. Coding of relevant clauses was performed inductively to generate initial codes, which were re-organised to obtain refined codes. In the thematic analysis, we read all the selected documents to identify clauses targeted or attributed to FASD. These clauses, usually sentence(s), were then chatted into an analytical framework (**Fig. 1**). The framework revealed a classification of the FASD clauses into the main categories of prevention and management. Each category was further subdivided into education, health and social considerations. In a discursive process, consensus was reached between the authors on the fitting of the various clauses under the appropriate themes and subthemes within the analytical framework.



**Figure 1:** A heuristic framework that guided the document analysis

## Data management

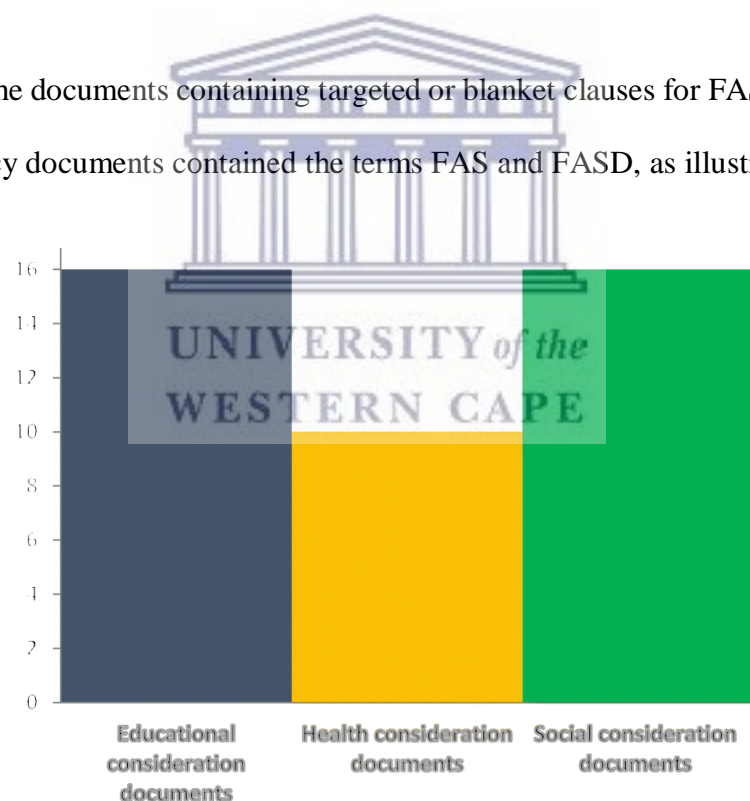
For easy identification, we coded the policy documents as DRX, wherein DR stands for policies, action plans or guidelines, and X denotes an arbitrary number from 1 to 33. Targeted clauses are



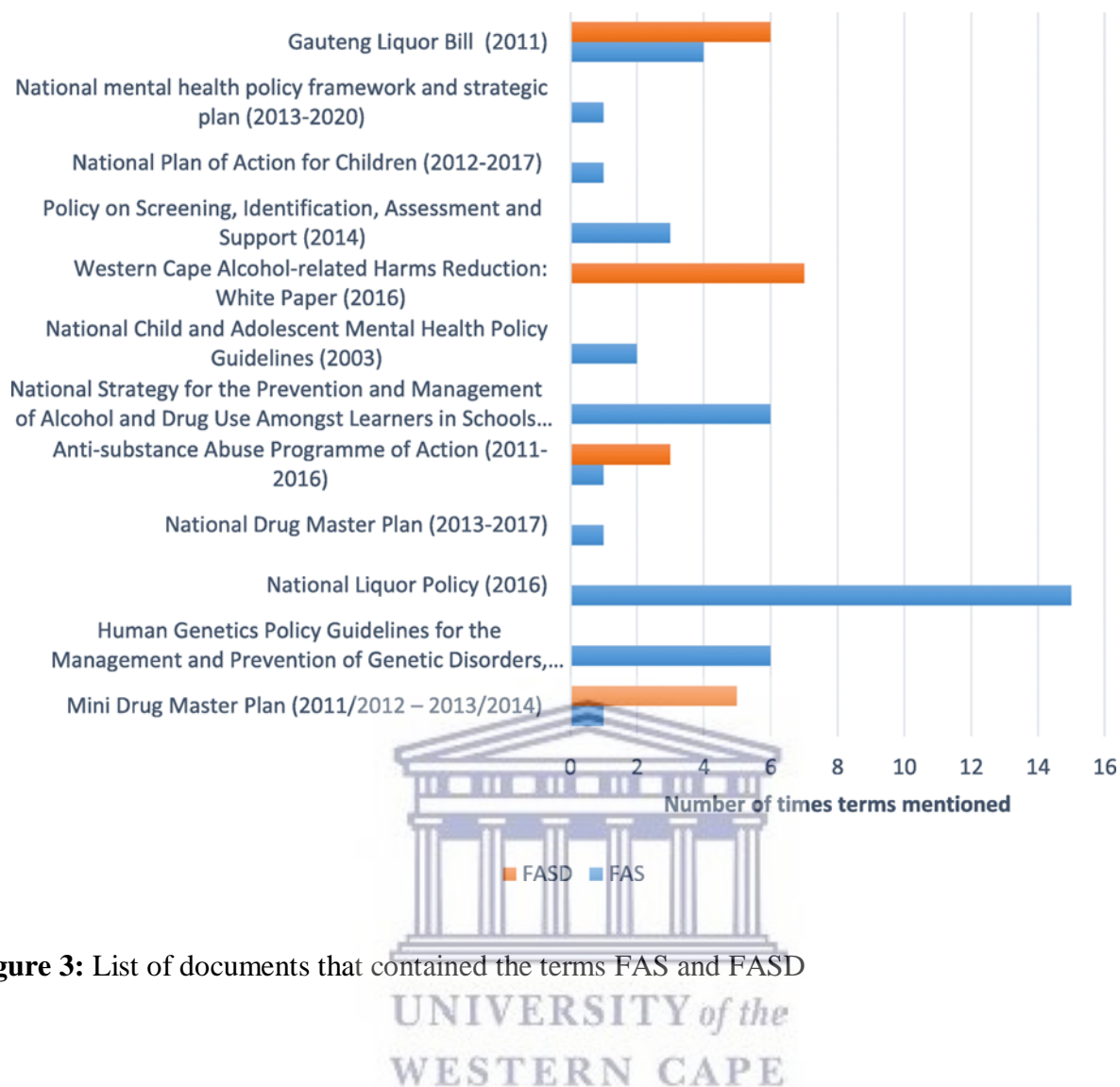
clauses that directly address FASD-related issues in the selected policy documents. Blanket clauses are clauses that could be ascribed to the prevention and management of FASD in the selected policy documents but could be relevant to other conditions. Also described as a generic clause, a blanket clause is considered to be attributed to FASD if it is meant for other conditions, but the clause can also be related to addressing any of the FASD outcomes. While reporting on the specific clauses and blanket clauses attributed to FASD (**Fig. 1**), we selected only some of the clauses to describe in the Results section. The complete set of clauses is presented as **Additional file 2**.

## Results

Figure 2 denotes the documents containing targeted or blanket clauses for FASD. Content analysis indicated that 12 policy documents contained the terms FAS and FASD, as illustrated in **Fig. 3**.



**Figure 2:** Number of documents that contained each aspect of FASD prevention and management



**Figure 3:** List of documents that contained the terms FAS and FASD

## Presentation of targeted and blanket Clauses of FASD

We present the targeted and blanket clauses following our heuristic framework (**Fig. 1**).

### Targeted clauses

#### Prevention targeted clauses

Two policy documents contained educational considerations specifically targeting the prevention of FASD. The documents include (1) the Human Genetics Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities [70], and (2) the Western Cape

Alcohol-related Harms Reduction: White Paper [71]. Focus on education in these documents is captured in the following two clauses.

The continuation of education programmes on FASD. The Western Cape Government (WCG) will continue to focus on education programmes on FASD in collaboration with strategic partners specialising in the field, with the aim of expanding the programme. Current initiatives include screening participants and providing psychosocial therapy and life-skills training. **(DR18: page 62)**

Educate all women regarding the deleterious effects of alcohol on the foetus. Educate all women to avoid alcohol throughout pregnancy. **(DR2: page 18)**

Three policy documents contained health-related clauses specifically addressing the prevention of FASD. These include (1) the Human Genetics Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects, and Disabilities [70]; (2) the Western Cape Alcohol-related Harms Reduction: White Paper [71], and (3) the National Child and Adolescent Mental Health Policy Guidelines [72]. Below, we share clauses selected from some of these documents.

Public efforts to improve health, nutrition, education and self-reliance, particularly of women; avoidance of unintended pregnancies, and proper birth spacing through access to contraception and other methods of family planning; improved access to, and quality of, prenatal care and genetic counselling; avoidance of exposure to teratogens (e.g. alcohol) during pregnancy. **(DR2: page 15)**

Improve the detection rate for alcohol and other drug abuse at antenatal clinics, and provide the appropriate services to reduce the incidence of fetal alcohol syndrome. **(DR11: page 21)**

Clauses of social consideration mainly targeting the prevention of FASD were found in (1) the Mini Drug Master Plan [73], and (2) the Human Genetics Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities [70].

Increase capacity for prevention, identification and development of appropriate interventions for individuals and families affected by FASD. **(DR23: page 16)**

Target all women of reproductive age with the following message of awareness: alcohol, smoking and substance abuse can damage the foetus, so avoid these during pregnancy. Identification of

pregnant women at risk; identification of pregnant women aged 35 years or more; identification of pregnant women exposed to teratogens, e.g. alcohol. **(DR2 page 18)**

### **Management targeted clauses**

Two of the policy documents contained health-related clauses specifically targeting the management of FASD, these were (1) the Human Genetics Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities [70], and (2) the Mini Drug Master Plan [73].

Identification and development of appropriate interventions for individuals and families affected by FASD. **(DR23: page 16)**

Offer early detection of FAS, with appropriate referral of affected individuals and their parents for counselling and care. Rehabilitation of disabilities and psychosocial support of affected individuals and their families. **(DR2: page 18)**

### **Blanket clauses**

These clauses, although of more general nature, were ascribed to the prevention and management of FASD in the selected policy documents.

### **Prevention blanket clauses**

Blanket educational-related clauses that could be attributed to the prevention of FASD were identified in seven policy documents, namely (1) the National Strategy for the Prevention and Management of Alcohol and Drug Use amongst Learners in Schools [74], (2) the City of Cape Town Alcohol Drug Strategy [75], (3) the Western Cape Alcohol-related Harms Reduction: White Paper [71], (4) the National Child and Adolescent Mental Health Policy Guidelines [72], (5) the National

Adolescent and Youth Health Policy [76], (6) the National Drug Master Plan [77], and (7) the Anti-substance Abuse Programme of Action [78]. The following illustrative clauses were taken from two of the documents.

Primary prevention: Implement school-based alcohol and drug use prevention programmes including life skills training as part of life skills/orientation subject. Implement information and awareness campaigns. Implement co-curricular activities and safety interventions such as peer education clubs. Implement drug-free sports programmes. Involve families and communities. **(DR13: page VI and 23)**

Intensified campaigns to educate people about substance abuse. Educational campaigns to inform and educate people, in particular, young people, about the dangers of alcohol and drug abuse. **(DR15: page 86)**

The Guidelines for Maternity Care in South Africa [79], the City of Cape Town Alcohol Drug Strategy [75], the Prevention and Treatment for Substance Abuse Act [80], the Western Cape Alcohol-related Harms Reduction: White Paper [71], and the National Drug Master Plan [77] contained health-related blanket clauses that could be ascribed to the prevention of FASD. The two selected clauses exemplify the nature of these generic prevention intentions.

At first visit, take a full and relevant history including medical conditions, including psychiatric problems, and previous operations; use of alcohol, tobacco and other substances; family and social circumstances. **(DR1: page 35)**

The identification of risky behaviour that is associated with and predisposes people to substance abuse; the detection of conditions such as poverty and other environmental factors that contribute to crime and the abuse of substances. Identification of individuals, families and communities at risk; screening for problematic substance use to facilitate early detection and appropriate interventions; enabling affected persons to recognise the warning signals of substance abuse. Identification of individuals, families and communities at risk; screening for problematic substance use to facilitate early detection and appropriate interventions. **(DR7: page 16)**

Eight policy documents contained clauses attributed to blanket social considerations ascribed to the prevention of FASD. These documents comprised (1) the National Strategy for the Prevention and Management of Alcohol and Drug Use Amongst Learners in Schools [74], (2) the National Drug

Master Plan [77], (3) the Prevention and Treatment for Substance Abuse Act [80], (4) the Western Cape Alcohol-related Harms Reduction: White Paper [71], (5) the National Child and Adolescent Mental Health Policy Guidelines [72], (6) the City of Cape Town Alcohol Drug Strategy [75], (7) the Anti-substance Abuse Programme of Action [78], and (8) the National Liquor Policy [81].

Establishment and provision of community-based services: provide professional and lay support within the home environment; establish recreational, cultural and sports activities to divert young people from substance abuse. **(DR7: page 24)**

Comprehensive prevention programmes: implementation of universal and targeted programmes, such as those covering life skills. Multiple approaches to prevention across different disciplines, e.g. youth development programmes, sport and skills development. **(DR15: page 86)**

### Management blanket clauses

Blanket educational clauses that could be attributed to the management of FASD were contained in 10 of the 33 identified policy documents, namely (1) the National Integrated School Health Policy [82], (2) the Policy on Screening, Identification, Assessment and Support [83], (3) the National Integrated Early Childhood Development Policy [84], (4) the National Development Plan 2030 [85], (5) the Education White Paper 5 on Early Childhood Education [86], (6) the Special Needs Education: Building an Inclusive Education and Training System (Education White Paper 6) [87], (7) the National Child and Adolescent Mental Health Policy Guidelines [72], (8) the Guidelines for Responding to Learner Diversity in the Classroom [88], (9) the Guidelines to Ensure Quality Education and Support in Special Schools and Special School Resource Centres [89], and (10) the National Adolescent and Youth Health Policy [76]. Two of these clauses are represented below.

Five specific support provision areas are identified: Specialist support staff, assistive devices, specialised equipment and teaching and learning support materials, curriculum differentiation to meet the individual needs of learners. **(DR16: page 8)**



Provide a stimulating environment to enhance the development of the child. Provide special classes in normal schools and special schools for intellectual children and adolescents. **(DR11: page 23)**

The Human Genetics Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities [70], the National Integrated Early Childhood Development Policy [84], and the National Development Plan 2030 [85] contained blanket clauses relating to the health management of FASD. The subsequent clauses exemplify this.

Screening and early detection of disability, diagnostic and therapeutic support service, 24-hour service and specialist support. **(DR2 page 22)**

Nutrition intervention for pregnant women and young children. Ensure household food and nutrition security. **(DR30 page 30)**

Social consideration blanket clauses attributed to the management of FASD were found in eight documents, including (1) the National Development Plan 2030, (2) National Disability Policy [90], (3) the National Child and Adolescent Mental Health Policy Guidelines [72], (4) the National Integrated Early Childhood Development Policy [84], (5) the Guidelines to Ensure Quality Education and Support in Special Schools and Special School Resource Centres [89], (6) the National Youth Policy [91], (7) the Special Needs Education: Building an Inclusive Education and Training System (Education white paper 6) [87], and (8) the Human Genetics Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities [70]. Illustrated are two of the clauses from the documents.

Strengthen youth service programmes and introduce new, community-based programmes to offer young people life-skills training, entrepreneurship training and opportunities to participate in community development programmes. Efforts to ensure relevant and accessible skills development programmes for people with disabilities, coupled with equal opportunities for their productive and gainful employment, must be prioritised. **(DR30: page 30)**

Ensure that an intellectually disabled child or adolescent is in the hands of an effective carer; where possible, ensure that the natural parents are the primary caregivers for intellectually disabled children and adolescent; provide ongoing emotional and (if necessary) material and human resource



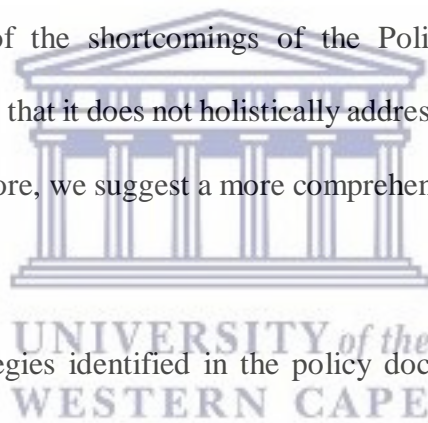
support for the parents and other caregivers; provide a stimulating environment to enhance the development of the child. (DR11: page 23)

## Discussion

Herein, we aimed to identify the targeted and generic clauses that could be attributed to the prevention and management of FASD in various related policy documents in South Africa. The study also serves as an update to the South African FASD policy document review conducted in 2008 [17]. The significance of this review lies in its capacity to shed light on the extent to which FASD issues are considered in existing South African policy documents, as there is no specific policy document currently addressing FASD. Furthermore, the targeted and generic clauses identified could inform the development of a guideline for policy to address FASD in South Africa.

Our findings confirmed that South Africa still does not have a specific policy addressing FASD since the observation was first made by Randall-Nkosi et al. in 2008 [17]. In their review, only two policy documents used the term FAS, with FASD not being reported at all. However, based on our review, there has been an increase in the use of FAS and FASD, with 12 policy documents mentioning these terms since 2008. The increase in the number of policy documents mentioning FAS and FASD could be seen as an indication that more consideration is given to the issue of FASD across various South African government departments. However, we cannot categorically say that this increase in consideration has translated to an improvement in service delivery. Services are still generic in nature with gaps in policy [18, 21, 42], particularly those involving the coordination of services, communication and collaboration among departments, as previously reported [17, 19]. Therefore, we believe that developing a multi-sectoral policy for FASD could improve communication and collaboration among the relevant departments and, consequently, the coordination of FASD-related services.

Most of the policy documents identified in our review contained targeted and blanket or generic clauses that could be attributed to the prevention and management of FASD. We found a distinct improvement on what was reported in 2008, although none of the policy documents provided a comprehensive, holistic and detailed strategy on how FASD could be prevented and managed. For example, the National Liquor Policy (2016) provided an excellent contextualisation and detailed account of the problem of FASD in South Africa but contained only generic approaches for the prevention of FASD. Although the policy on Screening, Identification, Assessment, and Support (2014) does not mention the terms FAS and FASD, the document provided detailed information on screening, identification, assessment and support for learners identified with learning difficulties; this information could benefit individuals with FASD as it is not unusual for them to present learning difficulties [1]. However, one of the shortcomings of the Policy on Screening, Identification, Assessment, and Support (2014) is that it does not holistically address issues (medical and social) other than the educational issue. Therefore, we suggest a more comprehensive approach to the management of FASD.



Some of the prevention strategies identified in the policy documents were efforts proposed to reduce accessibility and availability of alcohol [21]. These exertions include banning alcohol advertisement, increasing the legal drinking age, regulating alcohol trading hours and liquor outlets, and enforcement of liquor laws. These strategies were similar to those identified in previous studies of policy requirements for FASD in South Africa [18, 21, 42]. These strategies have been found to be effective in reducing accessibility and availability of alcohol. In two studies [43, 44], an association between alcohol availability, rates of alcohol consumption and alcohol-related harms were found. Evidence also indicates that increasing the minimum purchase age of alcohol reduces alcohol-related harms [45]. However, enforcing liquor laws remains a prominent problem in South Africa as the government is struggling to balance the economic benefits of liquor against public health hazards [46]. In the Western Cape, for example, there are approximately 25,000 unlicensed/illegal liquor stores

making alcohol available and accessible at a lower price [15]. Therefore, in order to reduce accessibility and availability of alcohol, we recommend that the government should take the enforcement of liquor laws seriously.

Other sections that were identified and could be ascribed to the prevention of FASD were education and creating awareness on the dangers of alcohol to different groups (children, adolescents and adults) and at different levels (schools and communities). Education and awareness formed part of the policy requirements for FASD in previous studies [18, 21, 42]. Education alone does not really modify behaviour as reported in the literature [47, 48]. However, research has also shown that education and awareness have the potential to reduce the prevalence of FASD in areas where they are low [49]. Therefore, we suggest education- and awareness-targeted FASD prevention programmes in areas where education and awareness of FASD are low [49, 50]. In areas where education and awareness on FASD are high, we suggest personalised interventions delivered through innovative approaches such as motivational interviewing and case management [51, 52]. These personalised interventions could be targeted at pregnant women and women of childbearing age.

In our review, we identified proposed clauses to enhance the cessation of drugs and alcohol use, including addressing pregnant women at clinics and in communities. These services include counselling, treatment and rehabilitation services, aftercare and reintegration services, screening, identification, and support and skills development, all of which align with the policy requirements for preventing FASD previously identified [18, 21, 42]. The mentioned services are notable, and if routinely carried out, could assist individuals who are struggling with alcohol, especially pregnant women and those of reproductive age, to minimise or cease drinking during pregnancy. However, research has shown that only 45% of health professionals who care for pregnant women routinely ask about alcohol use and only 25% of them provide information on the consequences of alcohol use in

pregnancy [53]. Therefore, we recommend training of health professionals on how best to assist women with an alcohol problem.

Addressing alcohol consumption during pregnancy to prevent FASD is essential. Therefore, it will require asking about alcohol use and providing information on the consequences of its use during pregnancy with specific reference to FASD. The latter should be made a compulsory routine for health professionals caring for pregnant women. Inadequate access to treatment for substance abusers in South Africa has also been reported [54, 55, 56], particularly in historically disadvantaged communities [55, 56]. Furthermore, barriers such as limited allocation of resources, stigma and negative beliefs about treatment, hamper substance users from seeking treatment [57, 58]. The inadequate access and barriers to treatment have the potential to influence alcohol use before and during pregnancy. Therefore, we propose an increase in access to treatment. In addition, barriers to treatment specifically for alcohol users should be addressed.

We discovered various levels of support and social security systems for individuals with disabilities outlined in some of the policy documents, which have been reported as part of policy requirements for FASD [21]. The support aims at improving learning participation, meeting the learning needs, assisting parents, and providing a supportive learning environment. Though these support programmes were not specifically targeted at individuals with FASD, those living with the disorder could benefit from them if they qualified. The social security system could also be beneficial to individuals with FASD but would depend on whether they qualify based on the types of primary and secondary characteristics they exhibit. If the South African government can recognise FASD as a disability irrespective of the types of primary and secondary characteristics presented, it would be a first step in the right direction. Therefore, we suggest the inclusion of individuals with FASD and their parents/caregivers in social services allowing them to maximise their potential and improve developmental outcomes [59].

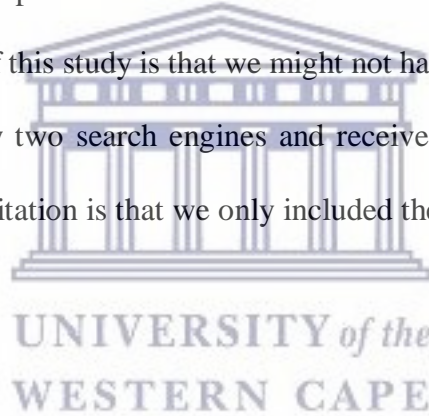
Other strategies we identified in the reviewed policy documents could be ascribed to the management of individuals with FASD, including screening, assessment, identification and support, early childhood development programmes, provision of inclusive education, differentiation and modification of assessment and curriculum, skills development, and training of teachers. These aligned with the policy requirements identified for the management of FASD in South Africa [18, 21, 42]. All these mentioned strategies may be useful if they are directly targeting FASD [59]. Although a screening protocol exists for conditions posing learning barriers, including FASD, there is no national surveillance for FASD in South Africa [17, 18], which means the situation is very similar to what was reported in 2008.

According to the literature, many individuals with FASD only get discovered when they present with other co-morbidities such as intellectual difficulties and conduct disorder, while some of them are misdiagnosed or never diagnosed [60]. Therefore, they are unable to receive the necessary treatment in a timely manner, suggesting the need for national surveillance and specialist diagnostic and support services, as earlier advocated by previous studies [17, 18]. Training all professionals on how to manage FASD should be considered essential, as FASD requires a multidisciplinary team to diagnose and manage [33]. Nevertheless, no specialised training on FASD for health professionals is in place, as reported by the participants in a study published in 2018 [21]. Various studies have indicated the need for training professionals on FASD [53, 61, 62, 63, 64, 65, 66]. We suggest that skills development should also be considered paramount as most of the individuals with FASD may not be able to complete formal education [67, 68].

The continuous rise in the prevalence of FASD in South Africa remains a public health concern as reported in the literature [5, 18]. Therefore, it is pertinent for the South African government to respond to this epidemic in a more coordinated and comprehensive manner by designing a specific policy and targeted interventions aimed at preventing and managing FASD. Reducing the prevalence of FASD

will directly or indirectly contribute to the reduction in crime rate, risky sexual behaviour, learning problems, alcohol-related harms and other secondary FASD disabilities [67, 68]. We advocate that the South African government should also replicate the success recorded in HIV/AIDS for FASD [22, 23, 24]. When developing a policy for FASD, new approaches to policy development on FASD should be considered. We propose that the South African government should learn from the approaches adopted by other governments such as Australia; an example is the Development of Action Australian Plan on FASD (2013–2016), which has led to an increase in government funding, expansion of prevention programmes, and the establishment of specialist FASD diagnostic services [69].

The strength of this study lies in the fact that we accessed several policy documents for FASD-related conditions from multiple departments to show the extent to which FASD has been considered in those policies. The limitation of this study is that we might not have included all the relevant policy documents because we used only two search engines and received only a few responses from the people we contacted. Another limitation is that we only included the latest policy documents of those published in series.



## **Conclusion**

Herein, we revealed the existence of targeted and generic clauses that could be attributed to FASD. There has also been an increase in the number of policy documents mentioning FASD in the last 10 years. However, the sustained high prevalence of FASD in South Africa reported in the literature calls for holistic and comprehensive approaches to tackle this problem.

## List of abbreviations

**FAS:** fetal alcohol syndrome; **FASD:** Fetal alcohol spectrum disorder

## Declarations

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## Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

## Authors' contributions

The paper was conceptualised by BOA, FCM and AMB, and the data were analysed by BOA and FCM. BOA wrote the first draft of the present manuscript. BOA and FCM contributed to the development of the methodology of this study. The work was supervised by AMB. All authors



reviewed and provided comments to improve the manuscript. They also read and approved the final manuscript.

### **Ethics approval and consent to participate**

This is part of a larger study. The Ethical approvals for the larger study were obtained from the Research Ethics Committee of the University of the Western Cape (BM/16/4/4), the Western Cape Department of Education (20161212–6937), and Departments of Health (WC\_2016RP29\_862) and Social Development (12/1/2/4).

### **Consent to publication**

Not applicable.

### **Competing interest**

The authors declare no conflict of interest



## References

1. Centers for Disease Control and Prevention (CDC). Basics about FASD. 2018. [www.cdc.gov/ncbddd/fasd/facts.html](http://www.cdc.gov/ncbddd/fasd/facts.html). Accessed 16 Jul 2018.
2. Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities. Alcohol Use in Pregnancy. 2018. [www.cdc.gov/ncbddd/fasd/alcohol-use.html](http://www.cdc.gov/ncbddd/fasd/alcohol-use.html). Accessed 16 Jul 2018.
3. National Organization on Fetal Alcohol Syndrome. National Organization of Fetal Alcohol Syndrome. 2018. <https://www.nofas.org/>. Accessed 16 Jul 2018.
4. Lange S, Probst C, Gmel G, et al. Global prevalence of fetal alcohol spectrum disorder among children and youth. *JAMA Pediatr.* 2017; 171:948.
5. Olivier L, Curfs LMG, Viljoen DL. Fetal alcohol spectrum disorders: prevalence rates in South Africa. *South African Med J.* 2016; 106:103–6.
6. May P, De Vries M, Marais A-S, et al. Replication of high fetal alcohol spectrum disorders prevalence rates, child characteristics, and maternal risk factors in a second sample of rural communities in South Africa. *Int J Environ Res Public Health.* 2017; 14:522.
7. London L. The ‘dop’ system, alcohol abuse and social control amongst farm workers in South Africa: a public health challenge. *Soc Sci Med.* 1999; 48:1407–14.
8. Williams G. Slaves, workers, and wine: the ‘Dop system’ in the history of the Cape Wine industry, 1658–1894. *J South Afr Stud.* 2016; 42:893–909.
9. World Health Organization. *Global Status Report on Alcohol and Health*. Geneva: WHO; 2014.

10. South African Government. South African Demographic and Health Survey (SADHS). 2016. <https://www.gov.za/documents/south-african-demographic-and-health-survey-sadhs>. Accessed 16 Apr 2019.
11. Popova S, Lange S, Probst C, et al. Prevalence of alcohol consumption during pregnancy and fetal alcohol spectrum disorders among the general and Aboriginal populations in Canada and the United States. *Eur J Med Genet*. 2017; 60:32–48.
12. Cloete L, Ramugondo E. ‘I drink’: mothers’ alcohol consumption as both individualised and imposed occupation. *South African J Occup Ther*. 2015; 45:34–40.
13. Petersen Williams P, Jordaan E, Mathews C, et al. Alcohol and other drug use during pregnancy among women attending midwife obstetric units in the Cape Metropole, South Africa. *Adv Prev Med*. 2014; 2014:1–10.
14. Vythilingum B, Roos A, Faure SC, Geerts L, Stein DJ. Risk factors for substance use in pregnant women in South Africa. *South African Med J*. 2012; 102:792–3.
15. Charman A, Petersen L. Comment on the Western Cape alcohol-related harms reduction policy green paper charman and petersen, sustainable livelihoods foundation. 2016. <http://livelihoods.org.za/publications/> Accessed 12 Jan 2018.
16. Esper LH, Furtado EF. Identifying maternal risk factors associated with Fetal Alcohol Spectrum Disorders: a systematic review. *Eur Child Adolesc Psychiatry*. 2014; 23:877–89.
17. Rendall-Mkosi K, London L, Adnams C, et al. Fetal Alcohol Spectrum Disorder in South Africa: Situational and Gap Analysis. Pretoria: UNICEF. 2008. [www.unicef.org/southafrica/SAF\\_resources\\_fetalalcohol.pdf](http://www.unicef.org/southafrica/SAF_resources_fetalalcohol.pdf). Accessed 14 Sep 2017.

18. Jacobs L, Steyn N, Labadarios D. 'Mind the Gap': Observations in the Absence of Guidelines for Alcohol Abstinence among Expectant Women in South Africa. 2013. <http://repository.hsrb.ac.za/bitstream/handle/20.500.11910/3008/7682.pdf?sequence=1>. Accessed 12 Jan 2018.
19. Adnams CM. Fetal alcohol spectrum disorder in Africa. *Curr Opin Psychiatry*. 2017; 30:108–12.
20. Adebisi BO, Mukumbang FC, Okop KJ, et al. A modified Delphi study towards developing a guideline to inform policy on fetal alcohol spectrum disorders in South Africa: a study protocol. *BMJ Open*. 2018; 8:e019907.
21. Adebisi BO, Mukumbang FC, Cloete LG, et al. Exploring service providers' perspectives on the prevention and management of fetal alcohol spectrum disorders in South Africa: a qualitative study. *BMC Public Health*. 2018; 18:1238. <https://doi.org/10.1186/s12889-018-6126-x>.
22. Wouters E, van Rensburg H, Meulemans H. The National Strategic Plan of South Africa: what are the prospects of success after the repeated failure of previous AIDS policy? *Health Policy Plan*. 2010; 25:171–85.
23. Hopkins KL, Doherty T, Gray GE. Will the current National Strategic Plan enable South Africa to end AIDS, tuberculosis and sexually transmitted infections by 2022? *South Afr J HIV Med*. 2018; 19:6.
24. Johnson LF, Dorrington RE, Moolla H. Progress towards the 2020 targets for HIV diagnosis and antiretroviral treatment in South Africa. *South Afr J HIV Med*. 2017; 18:8.

25. Chibango C. South Africa's HIV and AIDS policy and legislation: an analysis. *Greener J Med Sci.* 2013; 3:240–50.
26. World Health Organization. Fetal Alcohol Syndrome: Dashed Hopes, Damaged Lives. *Bull World Health Organ.* 2011; 89:398–9.
27. Benz J, Rasmussen C, Andrew G. Diagnosing fetal alcohol spectrum disorder: history, challenges, and future directions. *Paediatr Child Health.* 2009; 14:231–7.
28. Fitzpatrick JP, Latimer J, Olson HC, et al. Prevalence and profile of neurodevelopment and fetal alcohol spectrum disorder (FASD) amongst Australian Aboriginal children living in remote communities. *Res Dev Disabil.* 2017; 65:114–26.
29. Calhoun F, Attilia ML, Spagnolo PA, et al. National Institute on Alcohol Abuse and Alcoholism and the study of fetal alcohol spectrum disorders. The International Consortium. *Ann Ist Super Sanita.* 2006; 42:4–7.
30. Foundation for Alcohol Education and Research. The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013-2016. 2013. <http://fare.org.au/fare-australian-fetal-alcohol-spectrum-disorder-action-plan-2013-2016/> Accessed 5 Feb 2019.
31. Watkins RE, Elliott EJ, Halliday J, et al. A modified Delphi study of screening for fetal alcohol spectrum disorders in Australia. *BMC Pediatr.* 2013; 13:13.
32. Public Health Agency of Canada. Framework: Fetal Alcohol Spectrum Disorder (FASD): A Framework for Action - Canada.ca. [www.canada.ca/en/public-health/services/reports-publications/fetal-alcohol-spectrum-disorder-fasd-framework-action/fetal-alcohol-spectrum-disorder-fasd-a-framework-action-1.html#d](http://www.canada.ca/en/public-health/services/reports-publications/fetal-alcohol-spectrum-disorder-fasd-framework-action/fetal-alcohol-spectrum-disorder-fasd-a-framework-action-1.html#d). Accessed 8 Jun 2018.

33. Cook JL, Green CR, Lilley CM, et al. Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *CMAJ*. 2016; 188:191–7.
34. Bower C, Elliott EJ, Zimmet M, Doorey J, Wilkins A, Russell V, et al. Australian guide to the diagnosis of foetal alcohol spectrum disorder: A summary. *J Paediatr Child Health*. 2017; 53(10):1021–3.
35. Bertrand J, Floyd LL, Weber MK, Fetal Alcohol Syndrome Prevention Team, Division of Birth Defects and Developmental Disabilities, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC). Guidelines for identifying and referring persons with fetal alcohol syndrome. *MMWR Recomm Rep*. 2005;54(RR-11):1–14. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/16251866>.
36. Substance Abuse and Mental Health Services Administration (SAMHSA). SAMHSA's New Treatment Improvement Protocol focuses on FASD. SAMHSA - Substance Abuse and Mental Health Services Administration. 2018. <https://www.samhsa.gov/fetal-alcohol-spectrum-disorders-fasd-center>. Accessed 16 Jul 2018.
37. Bowen GA. Document analysis as a qualitative research method. *Qual Res J*. 2009; 9(3):27–40.
38. Corbin J, Strauss A. Basics of Qualitative Research (3rd ed.): Techniques and Procedures for Developing Grounded Theory. Thousand Oaks: SAGE Publications, Inc; 2008. <https://doi.org/10.4135/9781452230153>.
39. Erlingsson C, Brysiewicz P. A hands-on guide to doing content analysis. *African J Emerg Med*. 2017; 7:93–9.

40. Gale NK, Heath G, Cameron E, et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol.* 2013; 13:117.
41. Miles M, Huberman A. *Qualitative Data Analysis: An Expanded Sourcebook.* Thousand Oaks: Sage; 1994.
42. Adebisi BO, Mukumbang FC, Cloete LG, et al. Policymakers' perspectives towards developing a guideline to inform policy on fetal alcohol spectrum disorder: a qualitative study. *Int J Environ Res Public Health.* 2019; 16:945.
43. Bowers Y, Rendall-Mkosi K, Davids A, et al. Liquor outlet density, deprivation and implications for foetal alcohol syndrome prevention in the Bergriver municipality in the Western Cape, South Africa. *South African Geogr J.* 2014; 96:153–65.
44. Donnelly N, Poynton S, Weatherburn D, et al. Liquor outlet concentrations and alcohol-related neighbourhood problems. *BOCSAR NSW Alcohol Studies Bulletins* (2006): 15.
45. Wagenaar AC, Toomey TL. Effects of minimum drinking age laws: review and analyses of the literature from 1960 to 2000. *J Stud Alcohol Suppl.* 2002; 14:206–25.
46. Parry CDH. Alcohol policy in South Africa: a review of policy development processes between 1994 and 2009. *Addiction.* 2010; 105:1340–5.
47. Larimer ME, Counce JM. Identification, prevention, and treatment revisited: individual-focused college drinking prevention strategies 1999–2006. *Addict Behav.* 2007; 32:2439–68.
48. Logan DE, Marlatt GA. Harm reduction therapy: a practice-friendly review of research. *J Clin Psychol.* 2010; 66:201–14.



49. Chersich MF, Urban M, Olivier L, et al. Universal prevention is associated with lower prevalence of fetal alcohol spectrum disorders in Northern Cape, South Africa: a multicentre before-after study. *Alcohol Alcohol*. 2012; 47:67–74.
50. Parry CDH, Gossage JP, Marais A-S, et al. Comparison of baseline drinking practices, knowledge, and attitudes of adults residing in communities taking part in the FAS prevention study in South Africa. *Afr J Drug Alcohol Stud*. 2012; 11:65–76.
51. de Vries M, Joubert B, Cloete M, et al. Indicated prevention of fetal alcohol spectrum disorders in South Africa: effectiveness of case management. *Int J Environ Res Public Health*. 2015; 13:76.
52. Hanson JD, Miller AL, Winberg A, et al. Prevention of alcohol-exposed pregnancies among nonpregnant American Indian women. *Am J Health Promot*. 2013; 27:S66–73.
53. Payne J, Elliott E, D'Antoine H, et al. Health professionals' knowledge, practice and opinions about fetal alcohol syndrome and alcohol consumption in pregnancy. *Aust N Z J Public Health*. 2005; 29:558–64.
54. Lutchman S. Insufficient access to substance abuse treatment centres for illicit drug users and its potential effect on a foetus: a breach of the right to access health care services. *Law Democracy Dev*. 2015; 19:65.
55. Myers B, Parry CD. Access to substance abuse treatment services for black South Africans: findings from audits of specialist treatment facilities in Cape Town and Gauteng: original article. *Afr J Psychiatry*. 2005; 8:15–9.
56. Myers BJ, Louw J, Pasche SC. Inequitable access to substance abuse treatment services in Cape Town, South Africa. *Subst Abuse Treat Prev Policy*. 2010; 5:28.

57. Myers B, Louw J, Fakier N. Alcohol and drug abuse: removing structural barriers to treatment for historically disadvantaged communities in Cape Town. *Int J Soc Welf*. 2008; 17:156–65.
58. Myers B, Fakier N, Louw J. Stigma, treatment beliefs, and substance abuse treatment use in historically disadvantaged communities. *Afr J Psychiatry*. 2009; 12 (3):218–22.
59. Reid N, Dawe S, Shelton D, et al. Systematic review of fetal alcohol spectrum disorder interventions across the life span. *Alcohol Clin Exp Res*. 2015; 39:2283–95.
60. Popova S, Lange S, Shield K, et al. Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis. *Lancet*. 2016; 387:978–87.
61. Mukherjee R, Wray E, Curfs L, et al. Knowledge and opinions of professional groups concerning FASD in the UK. *Adopt Foster*. 2015; 39:212–24.
62. Flannigan K, Pei J, Stewart M, et al. Fetal alcohol spectrum disorder and the criminal justice system: a systematic literature review. *Int J Law Psychiatry*. 2018; 57:42–52.
63. Cox LV, Clairmont D, Cox S. Knowledge and attitudes of criminal justice professionals in relation to fetal alcohol spectrum disorder. *Can J Clin Pharmacol*. 2008; 15:e306–13.
64. Van Schalkwyk I, Marais S. Educators' relational experiences with learners identified with fetal alcohol spectrum disorder. *South African J Educ*. 2017; 37:1–9.
65. Scheepers P. Educators' knowledge of and attitudes toward fetal alcohol spectrum disorder. 2009. <http://scholar.sun.ac.za/handle/10019.1/2079>. Accessed 21 Aug 2018.
66. Passmore HM, Mutch RC, Burns S, et al. Fetal alcohol spectrum disorder (FASD): Knowledge, attitudes, experiences and practices of the Western Australian youth custodial workforce. *Int J Law Psychiatry*. 2018; 59:44–52.

67. Clark E, Lutke J, Minnes P, et al. Secondary disabilities among adults with fetal alcohol spectrum disorder in British Columbia. *J FAS Int.* 2004; 2:1–12.
68. Streissguth AP, Barr HM, Kogan J, Bookstein FL. Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome and Fetal Alcohol Effects. 1996. p. 1–72.
69. Reid N. Fetal alcohol spectrum disorder in Australia: what is the current state of affairs? *Drug Alcohol Rev.* 2018; 37(7):827–30.
70. Human Genetics Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities. 2001. <https://www.westerncape.gov.za/text/2003/humangenetics.pdf>. Accessed 15 Apr 2019.
71. The Western Cape Alcohol-related Harms Reduction: White Paper. 2017. [https://www.westerncape.gov.za/text/2017/September/white\\_paper\\_alcohol-related\\_harms\\_reduction.pdf](https://www.westerncape.gov.za/text/2017/September/white_paper_alcohol-related_harms_reduction.pdf). Accessed 15 Apr 2019.
72. The National Child and Adolescent Mental Health Policy Guidelines. 2003. [https://www.health-e.org.za/wp-content/uploads/2013/11/child\\_mental\\_health.pdf](https://www.health-e.org.za/wp-content/uploads/2013/11/child_mental_health.pdf). Accessed 15 Apr 2019.
73. Mini Drug Master Plan. <http://policyresearch.limpopo.gov.za/handle/123456789/889>. Accessed 24 Aug 2018.
74. National Department of Basic Education. National Strategy for the Prevention and Management of Alcohol and Drug Use Amongst Learners in Schools. 2013. [http://www.kzneducation.gov.za/Portals/0/snes/NationalStrategy\\_UNICEF\\_PRINT\\_READY.pdf](http://www.kzneducation.gov.za/Portals/0/snes/NationalStrategy_UNICEF_PRINT_READY.pdf). Accessed 15 Apr 2019.

75. City of Cape Town. The City of Cape Town Alcohol Drug Strategy.  
2014. <https://libguides.lib.uct.ac.za/c.php?g=182363&p=1581389>. Accessed 16 Apr 2019.
76. National Department of Health. National Adolescent & Youth Health Policy.  
2017. <https://www.saferspaces.org.za/resources/entry/national-adolescent-youth-health-policy-2017>. Accessed 16 Apr 2019.
77. South Africa Government. National Drug Master Plan 2013-2017.  
2013. <https://www.gov.za/documents/national-drug-master-plan-2013-2017>. Accessed 16 Apr 2019.
78. Anti-Substance Abuse Programme of Action.  
2011. [https://www.thedti.gov.za/business\\_regulation/docs/nla/Anti\\_Substance\\_Abuse.pdf](https://www.thedti.gov.za/business_regulation/docs/nla/Anti_Substance_Abuse.pdf).  
Accessed 24 Aug 2018.
79. National Department of Health. The Guidelines for Maternity Care in South Africa.  
2015. <https://www.google.com/search?client=firefox-b-d&q=The+Guidelines+for+Maternity+Care+in+South+Africa>. Accessed 16 Apr 2019.
80. South African Government. Prevention of and Treatment for Substance Abuse Act.  
2009. <https://www.gov.za/documents/prevention-and-treatment-substance-abuse-act>.  
Accessed 16 Apr 2019.
81. South Africa Government. Liquor Act: National Liquor Policy.  
2016 <https://www.gov.za/documents/liquor-act-national-liquor-policy-30-sep-2016-0000>.  
Accessed 16 Apr 2019.

82. National Department of Basic Education. The National Integrated School Health Policy. 2012. <https://serve.mg.co.za/content/documents/2017/06/14/integratedschoolhealthpolicydbeanddoh.pdf>. Accessed 16 Apr 2019.
83. National Department of Basic Education. The Policy on Screening, Identification, Assessment and Support. 2014. <https://wcedonline.westerncape.gov.za/Specialised-ed/documents/SIAS-2014.pdf>. Accessed 16 Apr 2019.
84. The National Integrated Early Childhood Development Policy. 2015. <http://www.gauteng.gov.za/government/departments/education/Policies/2015/NationalintergratedEarlyChildhooddevelopmentPolicy2015.pdf>. Accessed 16 Apr 2019.
85. National Development Plan 2030. 2013. <https://www.gov.za/documents/national-development-plan-2030-our-future-make-it-work>. Accessed 16 Apr 2019.
86. South Africa Government. Education White Paper 5 on Early Childhood Education. 2001. <https://www.gov.za/documents/education-white-paper-5-early-childhood-education>. Accessed 16 Apr 2019.
87. South Africa Government. Special Needs Education: Education White Paper 6. 2001. <https://www.gov.za/documents/special-needs-education-education-white-paper-6>. Accessed 16 Apr 2019.
88. National Department of Basic Education. The Guidelines for Responding to Learner Diversity in the Classroom. 2011. [https://www.education.gov.za/Portals/0/Documents/Publications/GUIDELINESFORRESPONDINGTOLEARNERDIVERSITYTHROUGHCAPS\(FINAL\).pdf?ver=2016-02-24-110910-340](https://www.education.gov.za/Portals/0/Documents/Publications/GUIDELINESFORRESPONDINGTOLEARNERDIVERSITYTHROUGHCAPS(FINAL).pdf?ver=2016-02-24-110910-340). Accessed 16 Apr 2019.

89. National Department of Basic Education. The Guidelines to Ensure Quality Education and Support in Special Schools and Special School Resource Centres. 2008. <https://wcedonline.westerncape.gov.za/Specialised-ed/documents/Guidelines-to-ensure-QualityEducationandSupport.pdf>. Accessed 16 Apr 2019.
90. National Disability Policy. [https://www.westerncape.gov.za/assets/departments/social-development/national\\_disability\\_policy.pdf](https://www.westerncape.gov.za/assets/departments/social-development/national_disability_policy.pdf). Accessed 16 Apr 2019.
91. South African Government. National Youth Policy. 2015. <https://www.gov.za/documents/national-youth-policy-2015-2020-8-jun-2015-0000>. Accessed 16 Apr 2019.



**Additional file 1:** List of documents containing clauses for FASD

	<b>Title</b>	<b>Author/year</b>	<b>Description</b>
DR1	Guidelines for Maternity Care in South Africa (GFMC)	National Department of Health, South Africa (2015).	This document describes maternity care in South Africa. It consists of seventeen chapters. Chapter one provides an overview of the current situation and data on maternal care in South Africa. Chapter four contains subsections on preconception care (ask about the use of tobacco, alcohol and other recreational drugs) and first antenatal visit (take a full and relevant history including, use of alcohol, tobacco, and other substances)
DR2	Human Genetics Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects, and Disabilities (HGPB)	National Department of Health, South Africa (2001).	This document describes the prevention and management of genetic disorders, birth defects and disabilities in South Africa. Chapter one detailed situational analysis of genetic disorders and birth defects in South Africa. It comprises of fourteen chapters. Chapter four consists of strategies for prevention of the genetic disorder. Fetal alcohol syndrome was list one of the priority disorders.
DR3	Special Needs Education: Building an Inclusive Education and Training System (Education white paper 6) (SNEB)	National Department of Education, South Africa (2001).	This document describes an inclusive education and training system in South Africa. It contains four chapters. Chapter one provides context to inclusive education in South Africa. The document detailed how every learner can be assisted in an inclusive manner with exclusion, either in the mainstream schools or special schools
DR4	National Liquor Policy (NALP)	Department of Trade and	This document outlines the policy recommendations intended to amend the Liquor Act, 59 of 2003 ("the Act"). This document consists of five sections. Section three (purpose and problem statement) outlines the socio-economic impact of liquor and other costs of alcohol abuse.



		Industry, South Africa (2016)	
DR5	City of Cape Town Alcohol Drug Strategy 2014 -2017 CCTA)	City of Cape Town (2014 - 2017)	This document outlines the strategy to reduce the health, economic and social burden caused by alcohol and other drugs (AOD) abuse in Cape Town. It consists of six sections.
DR6	Gauteng Liquor Bill (GALB)	Gauteng Government (2011)	The purpose of this document is to: (1) facilitate responsible attitudes towards the production, distribution, promotion, marketing, advertising, sale and consumption of liquor; (2) ensure that appropriate measures are in place to reduce the harm caused by the consumption of alcohol including reducing the per capita consumption of alcohol; and (3) facilitate the entry and empowerment of new entrants in the liquor industry in Gauteng province. It consists of nine sections
DR7	Prevention and Treatment for Substance Abuse Act (PTSA)	South Africa Government (2008)	This document consists of eleven chapters. It provide: (1) a comprehensive national response for the combating of substance abuse; (2) mechanisms aimed at demand and harm reduction in relation to substance abuse through prevention, early intervention, treatment and reintegration programmes; (3) for the registration and establishment of treatments centres and halfway houses; (4) for the committal of persons to and from treatment centres and for their treatment, rehabilitation and skills development in such a treatment centres; (5) for the establishment of the central drug authority; and (6) for matters connected therewith
DR8	South African Children Act (SACA)	South Africa Government (2005)	This document consists of twenty-two chapters. It was developed: (1) to give effect to certain rights of children as contained in the Constitution; (2) to set out principles relating to the care and protection of children; to define parental responsibilities and rights; (3) to make further provision regarding children's courts; (4) to provide for the issuing of contribution orders; (5) to make new provision for the adoption of children; (6) to provide for inter-country adoption; (7) to give effect to the Hague Convention on Inter-country Adoption; (8) to prohibit child abduction and to give effect to the Hague Convention on International Child Abduction; (9) to provide for surrogate motherhood; to create certain new offences relating to children; and (10) to provide for matters connected therewith.

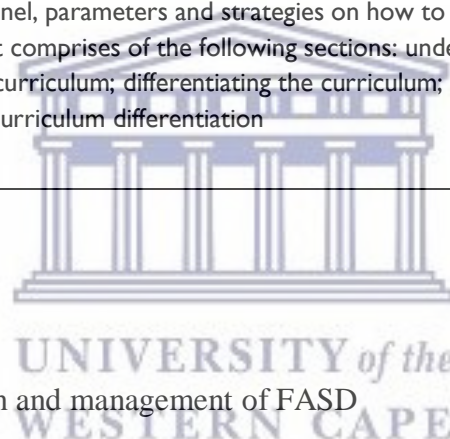
DR9	Anti-substance Abuse Programme of Action (AAPA)	South Africa Government (2011-2016)	The programme of Action was developed based on resolutions taken during the 2nd Biennial Anti Substance Summit held from the 15th to the 17th March 2011 at the International Convention Centre in KwaZulu Natal Province.
DR10	National Liquor Act (NALA)	South Africa Government (2003)	This Act was developed to establish national norms and standards in order to maintain economic unity within the liquor industry; to provide for essential national standards and minimum standards required for the rendering of services; to provide for measures to promote co-operative government in the area of liquor regulation, and to provide for matters connected therewith. It consists of eight chapters. Chapter one comprises of definitions, interpretation, objects, and application of the Act.
DR11	National Child and Adolescent Mental Health Policy Guidelines (NCAM)	National Department of Health, South Africa (2003)	This document serves as a framework for establishing mental health services for children and adolescents at national, provincial and local levels of health care within the Primary Health Care approach using an inter-sectoral approach. They have been developed in relation to other South African policies, legislation, and treaties that address themselves to the enhancement of survival as well the protection and development of children and adolescents. The document adopts a holistic approach in addressing the various risk and protective factors that can affect the mental health of children and adolescents. These causal factors can exist in the physical, emotional and social domains of the human being.
DR12	National Adolescent and Youth Health Policy (NAYH)	National Department of Health, South Africa (2017)	This document was formulated: (1) to promote the mental health and wellbeing of adolescents and youth in schools, families, and communities; (2) to reduce substance abuse and violence; (3) to provide comprehensive, integrated sexual and reproductive health services; (4) to test and treat for HIV/AIDS and TB and keep people within the health system; (5) to support nutrition and healthier diet; (6) to strengthen health systems to respond to the needs of adolescents and youth.
DR13	National Strategy for the Prevention and Management of Alcohol and Drug Use Amongst Learners in Schools (NSPM)	National Department of Basic Education (2103)	This document was developed in order to provide an integrated and comprehensive strategy that can guide the Department of Basic Education (DBE) and the provinces in a coordinated effort to address alcohol and drug use in schools. It comprises of five chapters.

DR14	Education White Paper 5 on Early Childhood Education (EWPE)	National Department of Basic Education (2001)	This document consists of six sections. It focuses on expanding early childhood development (ECD) provision, correcting the imbalances in the provision, ensuring equitable access and improving the quality and delivery of ECD programmes.
DR15	National Drug Master Plan (NDMP)	National Department of Social Development (2013 - 2017)	This document complements the work of the Inter-Ministerial Committee on Alcohol and Drug Abuse by guiding and monitoring the actions of the government departments to reduce the demand for and supply of drugs and the harm associated with their use and abuse. It comprises of ten chapters
DR16	Policy on Screening, Identification, Assessment, and Support (PSIA)	National Department of Basic Education (2014)	This document was created to provide a policy framework for the standardization of the procedures to identify, assess and provide programmes for all learners who require additional support to enhance their participation and inclusion in school. It contains seven chapters
DR17	Western Cape Liquor Act (WCLA)	Western Cape Government (2008)	This act was developed to provide for the licensing for the retail sale and the micro-manufacture of liquor in the Western Cape Province, and to provide for incidental matters. It consists of thirteen chapters.
DR18	Western Cape Alcohol-related Harms Reduction: White Paper (WCAH)	Western Cape Government (2016)	This document was developed to provide interventions to contribute to the reduction of alcohol-related harms in the Western Cape. A further purpose is to provide for ancillary matters to increase the efficiency and effectiveness of supplementary supporting structures that are related to alcohol-related harms reduction.
DR19	South African Schools Act (SASA)	National Department of Basic Education (1996)	This document was created: (1) to provide for a uniform system for the organization, governance, and funding of schools; (2) to amend and repeal certain laws relating to schools; and (3) to provide for matters connected therewith. It comprises of seven chapters.

DR20	South Africa Mental Health Act (SAMH)	South Africa Government (2002)	This document was developed; (1) to provide for the care, treatment and rehabilitation of persons who are mentally ill; (2) to set out different procedures to be followed in the admission of such persons; (3) to establish Review Boards in respect of every health establishment; (4) to determine their powers and functions; (5) to provide for the care and administration of the property of mentally ill persons; (6) to repeal certain laws; and (7) to provide for matters connected therewith.
DR21	South African Social Security Agency Act, (SASS)	South Africa Government (2004)	This document was formulated: (1) to provide for the establishment of the South African Social Security Agency as an agent for the administration and payment of social assistance; (2) to provide for the prospective administration and payment of social security by the Agency and the provision of services related thereto; and (3) to provide for matters connected therewith. It consists of six chapters.
DR22	National Integrated School Health Policy (NISH)	National Department [Basic Education and Health] (2012)	This document describes how to the improvement of the general health of school-going children as well as the environmental conditions in schools and address health barriers to learning in order to improve education outcomes of access to school, retention within school and achievement at school.
DR23	Mini Drug Master Plan (MDMP)	National Department of Health (2011/2012 – 2013/2014)	This document was developed to reduce the health, economic and social burden caused by substance abuse in South Africa, through the provision of targeted demand and harm reduction interventions provided by the National Department of Health, thereby supporting the implementation of the National Drug Master Plan.
DR24	National mental health policy framework and strategic plan (NMHP)	National Department of Health (2013-2020)	This document was formulated to enable the mental health and well-being of all South Africans from infancy to old age, through the provision of evidence-based, affordable and effective promotion, prevention, and treatment and rehabilitation interventions. In partnerships between providers, users, carers and communities, the human rights of people with mental illness will be upheld; they will be provided with care and support, and they will be integrated into normal community life.
DR25	National Integrated Early Childhood Development Policy (NIEC)	National Department of Social Development (2015)	This document comprises of twelve chapters. The purpose of this Policy is: (1) to provide an overarching multi-sectoral enabling framework of early childhood development services, inclusive of national, provincial and local spheres of government; (2) to define a national comprehensive early childhood development programme and support, with identified essential components; (3) to identify the relevant role players and their roles and responsibilities for

			the provision of the various components of early childhood development services; and (4) to establish national integrated early childhood development leadership and coordinating structure.
DR26	National Youth Policy (NAYP)	South Africa Government (2015 – 2020)	This document describes the intention of government toward youth in South Africa. It is comprised of background, introduction, rationale, context, and legislation, defining and profiling South Africa's youth, situation analyses and challenges, policy proposals, and conclusion.
DR27	White Paper on the Rights of Persons with Disabilities (WPRP)	National Department of Social Development (2015)	This document is intended to accelerate transformation and redress with regard to full inclusion, integration, and equality for persons with disabilities. It consists of seven parts
DR28	National Plan of Action for Children (NPAC)	National Department of Women, children and with Disabilities (2012-2017)	This document was developed to promote the realization of children's rights to survival, development, protection, participation and to mobilize resources on all levels.
DR29	Western Cape School Act (WCSA)	Western Cape Government (1997)	This document was formulated to provide for a uniform education system for the organization, governance, and funding of all schools; consequentially to repeal certain laws relating to schools, and to make provision for the specific educational needs of the Western Cape province
DR30	National Development Plan 2030 (NDPL)	South Africa National Government (2013)	This document consists of fifteen chapters. Each chapter in this plan contains a range of targets and proposals. Some of these are general statements of policy intent. Others are policy proposals actions and processes that need to occur. The plan is to change the life chances of millions of people in South Africa.
DR31	National Disability Policy (NADP)	National Department of Social Development	This document outlines the: context, background, aim, purpose, scope, policy and legislative mandates, key principles, roles, responsibilities, approach, structures for Implementation, resource allocations and monitoring and evaluation. It aims to facilitate the provision of integrated social services to people with disabilities
DR32	Guidelines to Ensure Quality	National Department of	This document was developed to ensure quality education and support in special schools outlines some of the requirements for a functional special school. The information in this guideline is organized under the following

	Education and Support in Special Schools and Special School Resource Centres (GEQE)	Basic Education (2014)	headings: legislative and policy framework; curriculum management and implementation; personnel supply and qualifications; and Infrastructure and hostel accommodation
DR33	Guidelines for Responding to Learner Diversity in the Classroom (GRLD)	National Department of Basic Education (2011)	This document is intended to provide teachers, principals, subject advisors, administrators, school governors, and other personnel, parameters and strategies on how to respond to learner diversity in the classrooms through the curriculum. It comprises of the following sections: understanding diversity in the classroom; responding to diversity through the curriculum; differentiating the curriculum; analyzing, recording and reporting on assessment; and accessing support for curriculum differentiation



**Additional file 2.1:** Targeted clauses for the prevention and management of FASD

Themes	Sub-themes	Codes from various sources
Prevention	Education	<p>The continuation of education programmes on FASD. The Western Cape Government (WCG) will continue to focus on education programmes on FASD in collaboration with strategic partners specialising in the field, with the aim of expanding the programme. Current initiatives include screening participants and providing psychosocial therapy and life-skills training. (DR18: page 62)</p> <p>Educate all women regarding the deleterious effects of alcohol on the foetus. Educate all women to avoid alcohol throughout pregnancy. (DR2: page 18)</p>



		Education of women of child-bearing age who are not on birth control of the risks alcohol consumption poses to foetal development (through life-skills education in schools and broader education campaigns). (DR18: page 51)
	Health	<p>Public efforts to improve health, nutrition, education and self-reliance, particularly of women; avoidance of unintended pregnancies, and proper birth spacing through access to contraception and other methods of family planning; improved access to, and quality of, pre-natal care and genetic counselling; avoidance of exposure to teratogens (e.g. alcohol) during pregnancy. (DR2: page 15)</p> <p>Improve the detection rate for alcohol and other drug abuse at antenatal clinics, and provide the appropriate services to reduce the incidence of foetal alcohol syndrome. (DR11: page 21)</p> <p>Provide interventions at antenatal clinics to reduce the likelihood of alcohol-exposed pregnancies. Included in the measures are: (ii) encouraging earlier uptake of antenatal services for pregnant women and expecting fathers, and ongoing screening of alcohol use for women attending antenatal clinics, and (iii) active case management of mothers who attend antenatal clinics who are at higher risk of an alcohol-exposed pregnancy. The latter has been found to help women at risk to either stop drinking or cut down on drinking during pregnancy, leading to a reduced risk of FASD. (DR18: page 51)</p>
	Social	<p>Identification and development of appropriate interventions for individuals and families affected by FASD. (DR23: page 16)</p> <p>Target all women of reproductive age with the following message of awareness: alcohol, smoking and substance abuse can damage the foetus, so avoid these during pregnancy. Identification of pregnant women at risk; identification of pregnant women aged 35 years or more; identification of pregnant women exposed to teratogens, e.g. alcohol. (DR2: page 18)</p>
Management	Education	
	Health	<p>Identification and development of appropriate interventions for individuals and families affected by FASD. (DR23: page 16)</p> <p>Offer early detection of FAS, with appropriate referral of affected individuals and their parents for counselling and care. Rehabilitation of disabilities and psycho-social support of affected individuals and their families. (DR2: page 18)</p>
	Social	

**Additional file 2.2:** Blanket clauses that can be attributed to the prevention of FASD

Themes	Sub-themes	Codes from various sources
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Prevention	Education	<p>Early Detection: Partake in early warning systems. Train educators &amp; parents to identify warning signs. Train educators &amp; district officials to conduct drug testing. Implement drug testing in schools where there is reasonable suspicion that learners are using drugs. Set up systems to ensure continuation of education during treatment (DR13: page VI and 24)</p> <p>Primary Prevention: Implement school-based alcohol and drug use prevention programmes including life skills training as part of life skills/orientation subject. Implement information &amp; awareness campaigns. Implement co-curricular activities and safety interventions such as peer education clubs. Implement drug free sport programmes. Involve families &amp; communities. (DR13: 24)</p> <p>Implement school-based alcohol and drug use prevention programmes including life skills training as part of life skills / orientation subject. (DR13: page 23)</p> <p>Early intervention: training of social workers; brief intervention. (DR5: page 8)</p> <p>Train all enforcement officials in all aspects of liquor legislation, liquor control and liquor enforcement. Develop a guide and make it available to prosecutors and other state officials. (DR18: page 40)</p> <p>Train primary health care practitioners and educators in basic counselling skills and trauma support. Ensure that children and adolescents who suffer from post-traumatic stress disorder receive, in addition to other treatment approaches, counselling from a professional who has the appropriate training and experience. Improve the substance-related component in the training of people who are already counselling children and adolescents. Improve training of health personnel (especially nursing staff) in the detection, diagnosis, and management of patients suffering from substance abuse, both in their specialised professional training and their continuing professional development. (DR11: pages 21 and 22)</p> <p>The curriculum must include accessible and practical information about HIV/AIDS and TB, mental health, sexual and reproductive health, nutrition and healthy weight, substance abuse and violence prevention. (DR12: page 8)</p> <p>Prioritise the Provincial substance abuse forum (PSAF) and Local drug action committees (LDACs) as platforms for integration, referral pathways and reciprocal communication. Continue and strengthen the Western Cape Education Department (WCED) education and awareness interventions. Develop norms and standards for school-based prevention programmes. Leverage the after-school space for education and awareness targeted at youth and the provision of, or referral to interventions. Support education and awareness at the post-school education level. Promote a clean fun campaign. Mainstream education and awareness in all WCG departments. Promote and</p>
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		<p>strengthen education and awareness programmes with stakeholders Improve the reach and ease of access to education and awareness material. Expand and strategically direct addiction care education courses. (DR18: pages 58-62)</p> <p>Intensified campaigns to educate people about substance abuse. Educational campaigns to inform and educate people, in particular young people, about the dangers of alcohol and drug abuse. (DR15: page 86, DR9 page 12)</p> <p>Implement information &amp; awareness campaigns. (DR13: page VI)</p> <p>Educate parents, teacher and other adults close to children and adolescents of the importance of not explicitly or implicitly condoning cigarette smoking, inappropriate alcohol use and illicit drugs. (DR11: page 20)</p>
	Health	<p>The following information should be provided to all women of childbearing age before conception: the risks to the foetus when the mother takes teratogenic medications during pregnancy. Certain essential information must be provided to all pregnant women, verbally and (where possible) in the form of written or illustrated cards or pamphlets. This includes: abuse of alcohol, tobacco and recreational drugs. (DR1: pages 34 and 38)</p> <p>At first visit, take a full and relevant history including: medical conditions, including psychiatric problems, and previous operations; use of alcohol, tobacco and other substances; family and social circumstances. (DR1: page 35)</p> <p>Women at risk for having a child with a birth defect or genetic disorder; refer as early as possible in the pregnancy for counselling regarding management and the performance of prenatal tests. Check list of risk factors requiring referral or hospital delivery: known substance abuse including alcohol. (DR1: pages 34 and 43)</p> <p>Screening: high risk individual, pregnant women, street people, mental health and testing people in high risk work. (DR5: page 8)</p> <p>The identification of risky behaviour that is associated with and predisposes people to substance abuse; the detection of conditions such as poverty and other environmental factors that contribute to crime and the abuse of substances. Identification of individuals, families and communities at risk; screening for problematic substance use to facilitate early detection and appropriate interventions; enabling affected persons to recognise the warning signals of substance abuse. Identification of individuals, families and communities at risk; screening for problematic substance use to facilitate early detection and appropriate interventions. (DR7: page 16)</p>

	<p>Provide programmes for screening, provision of information, brief motivational interventions and appropriate treatment services for hazardous and harmful drinking in primary health care settings, including antenatal clinics, and in emergency units. Provide interventions at antenatal clinics to reduce the likelihood of alcohol-exposed pregnancies. Strengthen the to-be-developed early screening and referral services at schools and other institutions of learning, targeting high-risk areas in the province. Specialised services for treatment and brief interventions for youth to be expanded and included at child- and youth-care centres and appropriate health facilities. (DR18: page 50-51)</p> <p>Developing and implementing multi-disciplinary and multi-modal protocols and practices for integrated diagnosis, treatment and funding of co-occurring disorders for adults, youths and children, e.g. providing for prevention, early detection, treatment and aftercare services, and integrating requisite changes through policy, legislation, protocols and practices. (DR15: page 98)</p>
Social	<p>Treatment, Care and Support: Establish strong referral systems to access treatment, care &amp; support Create awareness of treatment and counselling services. Address barriers that limit access to treatment amongst learners (e.g. transport, cost and stigma). (DR13: page VI)</p> <p>Implement co-curricular activities and safety interventions such as peer education clubs. Implement drug free sport programmes. (DR13: page VI)</p> <p>Ensure equal access to resources, especially for civil society and organisations in rural areas, e.g. recreational facilities, sport facilities, diversion programmes, intellectual development programmes, skills development. (DR15: page 89)</p> <p>Establishment and provision of community-based services: provide professional and lay support within the home environment; establish recreational, cultural and sports activities to divert young people from substance abuse. (DR7: page 24)</p> <p>The Department of Social Development (DSD), in collaboration with the Department of Health (DOH) and other stakeholders, will strengthen evidence-based prevention, early intervention, detoxification, treatment and aftercare interventions. (DR18: page 49)</p> <p>Justice and Constitutional Development; engage in effective co-operation and practical action in addressing the world drug problem on the basis of common and shared responsibility for: increasing international co-operation and following an integrated, multi-disciplinary, mutually reinforcing and balanced approach in demand and supply reduction strategies; strengthening mechanisms for cooperation and co-ordination; and developing methods to facilitate the exchange of experiences and good practice. (DR15: page 105)</p> <p>Coordination: facilitate collaborations; facilitate referral; involve ward committees. Sector Coordination: facilitate collaborations and support Non-governmental organisation (NGOs) and Community-based organisation (CBO). Sphere Coordination: facilitate inter-government collaborations. (DR5: page 8)</p>

	<p>Support the work done by faith based organisations, NGO's and CBO's in educating children and adolescents about substance abuse. (DR11: page 20)</p> <p>Ensure that the social skills that are particularly relevant for substance use are included in existing life skills programmes. (DR11: page 20)</p> <p>Measures aimed at skills development for individuals, families and communities to enable them to enjoy a better quality of life. (DR7: page 16)</p> <p>Comprehensive prevention programmes: implementation of universal and targeted programmes, such as those covering life skills. Multiple approaches to prevention across different disciplines, e.g. youth development programmes, sport and skills development. (DR15: page 86)</p> <p>After-school programmes, youth development and skills and capacity building. (DR5: page 8)</p> <p>Establish an effective referral system to services provided by the DOH, DSD, other departments and Non-profit organisations (NPOs) to provide long-term treatment, prevention and diversion activities Outpatient care for clients on treatment and rehabilitation services, as well as active outreach into communities, to be strengthened to improve treatment outcomes. (DR18: page 52)</p> <p>Utilise the Child-to-Child approach and strategies to encourage peer support for behavioural change and support seeking by children and adolescents. Create local group-based support for parental, societal and economic empowerment opportunities for women with children. Support self-help groups and families of children and adolescents with substance use problems. (DR11: page 22)</p> <p>Provide for support groups for service users and those affected by substance abuse. (DR7: page 24)</p> <p>Strengthening aftercare services, e.g. providing for prevention, early detection, treatment and aftercare services; integrating requisite changes through policy, legislation, protocols and practices, with emphasis on children, young people and learners. Increasing the provision of rehabilitation and aftercare, e.g. through providing for prevention, early detection, treatment and aftercare services, and integration of requisite changes through policy, legislation, protocols and practices, with special provision for access by all communities. (DR15: page 98)</p> <p>Aftercare and reintegration that provide for — the integration of people who have undergone the formal treatment episode into their families and communities. (DR7: page 18)</p>
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	<p>Medical interventions that address the physiological and psychiatric needs of the service user; psycho-social programmes that address the relationships, emotions, feelings, attitudes, beliefs, thoughts and behaviour patterns of service users. (DR7: page 16)</p> <p>Improve availability of substance-related counselling services at key sites (e.g. schools, health facilities, prison, streets. (DR11: page 20)</p> <p>The community-based model for substance abuse treatment and rehabilitation is expanded. (DR18: page 53)</p> <p>Increasing the provision of rehabilitation and after care and ensuring that all communities have access to these services. (DR9: page 13)</p> <p>Progressively increase the coverage of alcohol-related harms interventions at all public-health and social-service facilities in the Western Cape as well as for community action engagement interventions. (DR18: page 28)</p> <p>Lobby for a national ban on alcohol advertising that is visible to any person under the age of 18 and for restrictions on sports advertising and promotion that links alcohol to aspirational achievement. (DR18: page 25)</p> <p>The national minimum legal age at which alcohol can be purchased and consumed should be raised from eighteen (18) to twenty one (21) years. (DR4: page 6)</p> <p>Reducing accessibility of alcohol through raising the legal age for purchasing and public consumption of alcohol from the age of 18 to the age of 21, e.g. through changing policy, legislation, protocols and practice in a harmonised manner nationally; developmental programmes relating to changes; assessing effects of changes. (DR15: page 90)</p> <p>Banning all sponsorship of sport, recreation, arts, cultural and related events by the alcohol industry, e.g. through changing policy, legislation, protocols and practice in a harmonised manner nationally; running developmental programmes relating to changes; assessing effects of changes. (DR15: page 95)</p> <p>Prohibit advertising, marketing and promotion of alcohol products and companies at all events organised by the WCG. (DR18: page 27)</p> <p>Banning all sponsorship by the alcohol industry for sports, recreation, arts and cultural and related events. (DR9: page 13)</p>
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	<p>All broadcast television channels should advertise at night, from 22:00- 06:00; remove content appealing to youth in alcohol advertising such as using of sport stars, models, etc. Branding of liquor premises and delivery trucks and/ or cars should be prohibited; and counter advertisement which identifies the harmful effects of liquor abuse, for example, car crashes and victims, ailments caused by liquor, family violence and other social ills. (DR4: page 24)</p> <p>Support the application of (national) levies on marketing and promotional spending to cover alcohol-related harms counter-messaging. (DR18: page 28)</p> <p>Imposing a mandatory contribution by the liquor industry to a fund that will be dedicated to work to prevent and treat alcohol abuse. (DR9: page 11)</p> <p>Provincially determine a set maximum limits for trading hours in line with the alcohol-related harms reduction approach of reducing consumption. Provision for exceptions would allow for flexibility based on set criteria, and the relevant authorities would be able to reduce trading hours within the framework. (DR18: page 29)</p> <p>Imposing restrictions on the time and days of the week that alcohol can be legally sold. These restrictions must be uniform, that is, they must be applicable in all provinces. (DR9: page 11)</p> <p>The set uniform trading hours within the norms and standards should be integrated in national, provincial and municipal legislation. (DR4: page 25)</p> <p>Imposing restrictions on the times and days of the week that alcohol can be sold legally, e.g. through changing policy, legislation, protocols and practice in a harmonised manner nationally; developmental programmes relating to changes; assessing effects of changes. (DR15: page 90)</p> <p>Reduce the availability of alcohol by regulating density of outlets (zoning requirements and population density) and regulating trading days and hours. (DR18: page 29)</p> <p>Implementing laws and regulations that will reduce the number of liquor outlets, including shebeens, taverns and liquor stores in specific geographical areas. These laws and regulations should include stricter licensing laws and qualifying criteria and specific zoning laws and regulations that will prescribe the locations of different types of economic activity that can take place in residential areas. The zoning laws should for example, ensure that no liquor outlets are located near schools, libraries and places of worship. (DR9: page 11)</p>
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	<p>Implementing laws and regulations that will reduce the number of liquor outlets including shebeens, e.g. through changing policy, legislation, protocols and practice in a harmonised manner nationally; developmental programmes relating to changes; assessing effects of changes. (DR15: page 91)</p> <p>Regulating the density of alcohol outlets is an effort to minimise excessive alcohol consumption and related harms. Outlet density may be regulated through licensing and zoning regulations. (DR4: page 25)</p> <p>Lobby the national government to incentivise the reduction of the ethanol content in alcohol beverages. (DR18: page 33)</p> <p>Prescribing measures for alcohol containers such as the form of container, warning labels and the percentage alcohol content. (DR9: page 11)</p> <p>Lobby national government to increase the price of alcohol through increasing excise tax and/or introducing minimum unit pricing and consider a provincial tax. The increased tax revenue would be ring-fenced for alcohol-harms reduction investments. (DR18: page 31)</p> <p>Prescribing measures for alcohol containers, e.g. through changing policy, legislation, protocols and practice in a harmonised manner nationally; running developmental programmes relating to changes; assessing effects of changes; form of containers; warning labels; percentage of alcohol content. (DR15: page 93)</p> <p>Lobby the national government to implement a tracking system of liquor products. (DR18: page 33)</p> <p>Raising of duties and taxes on alcohol products to deter the purchasing of alcohol. The tariffs should be implemented on a sliding scale commensurate with the alcoholic content. (DR9: page 11)</p> <p>Raising duties and taxes on alcohol products to deter the purchasing of alcohol, e.g. through changing policy, legislation, protocols and practice in a harmonised manner nationally; running developmental programmes relating to changes; assessing effects of changes; implementing sliding-scale tariffs commensurate with alcoholic content. (DR15: page 92)</p>
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		<p>Take steps to bring some responsible unlicensed liquor outlets into the regulated space in a sustainable and responsible manner to facilitate compliance with minimum requirements. Create awareness of alternative economic opportunities to currently unlicensed outlet owners who cannot be accommodated within the applicable zoning scheme. (DR18: pages 34 and 35)</p> <p>Identify mechanisms and criteria, working with municipalities that will enable the rezoning of outlets for liquor sales in appropriate residential areas. Prioritise upstream interventions targeting suppliers to the unlicensed liquor industry and the illicit liquor trade. (DR18: page 35)</p> <p>Change legislation to enable some of the unlicensed outlets to be licensed and therefore regulated. Increase enforcement of under-age drinking laws. Implement innovative strategies to reduce harms from problematic outlets. Promote the involvement of communities themselves through interactive opportunities to access the Western Cape Liquor Authority (WCLA) complaints mechanisms. (DR18: pages 37-39)</p> <p>Clamp down on unlicensed outlets and the supply of liquor to unlicensed outlets. All spheres of government and relevant departments must contribute to the clamp-down. Information from community-based organisations and structures as well as the enforcement opportunities from municipal zoning schemes, the Western Cape Land Use Planning Act, 2014 (Act 3 of 2014) (LUPA), and the Spatial Planning and Land Use Management Act, 2013 (Act 16 of 2013) (SPLUMA), must be leveraged to aid the law-enforcement agencies. (DR18: page 38)</p> <p>Lobby for well-prepared police dockets for the prosecution of liquor-related matters by providing evidence of the link between crime and alcohol – and provide evidence, where appropriate, to support the prosecutions process. (DR18: page39)</p>
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### **Additional file 2.3:** Blanket clauses that can be attributed to the management FASD

Themes	Sub-themes	Codes from various sources
management	Education	<p>Learner Assessment and Screening: Assessments during the foundation phase focus primarily on identifying health barriers to learning, as well as identifying children who have or are at risk for long-term health, psychosocial or other problems. The following assessments will be done on all foundation phase learners: conduct vision, speech and basic hearing screening; measurement of height, weight and Body Mass Index (BMI); appropriate nutritional interventions must be planned accordingly; check for fine and gross locomotor problems; conduct oral health screening; screen for chronic illness or long-term health conditions - this includes both communicable diseases (such</p>

		<p>as TB and HIV/AIDS) as well as non-communicable diseases; and perform a basic mental health and/or psychosocial risk assessment. (DR22: page 13)</p> <p>Learners in the senior and FET phases should also be screened for weight and body mass index, vision, oral health, chronic illness or long-term health conditions and mental/ psychosocial health issues. (DR22: page 13)</p> <p>The Screening, Identification, Assessment and Support policy specifically aims to identify (1) the barriers to learning experienced, (2) the support needs that arise from barriers experienced and (3) to develop the support programme that needs to be in place to address the impact of the barrier on the learning process. (DR16: page 4)</p> <p>Provision of early childhood development services. Provision of comprehensive quality early childhood development programme. Provision of universal developmentally appropriate early learning opportunities for young children from birth. Develop and fund multiple early childhood development service delivery programmes and prioritise home and community based services. Inclusion and support for children with disabilities within all early childhood development programmes. Prioritise vulnerable children to ensure equitable access. (DR25: pages 54-55, 64, 66, 68-69)</p> <p>Universal access to two years of early childhood development. Increase the quality of education so that all children have at least two years of preschool education and all children in grade 3 can read and write. (DR30: pages 33 and 37)</p> <p>The organisation of early identification and early intervention services will be a key focus in Early Childhood Development (ECD) in both the 0 to 4-year programmes, as well as in Grade R (DR16: page 19)</p> <p>Opportunities to develop fine motor skills; encouragement of language through talking, being read to, singing; activities that will develop a sense of mastery; experimentation with pre-writing and pre-reading skills; hands on exploration for learning through action; opportunities for taking responsibility and making choices; encouragement to develop self-control, cooperation and persistence in completing projects; support for their sense of self-worth; opportunities for self-expression; and encouragement of creativity. (DR14: page 38)</p> <p>Integrated Pre-Grade R programmes for special groups of 4 year olds: the delivery of inclusive and integrated Pre-Reception Year programmes can ensure that all children have significantly improved opportunities for growth and development. This will provide opportunities to foster children's emotional, social, intellectual, physical, spiritual and moral development and to use play as the primary vehicle for achieving this. (DR14: page 39)</p>
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		<p>Transforming all aspects of the education system, developing an integrated system of education, infusing 'special needs and support services' throughout the system. (DR3: page 6)</p> <p>Improve the school system, including increasing the number of students achieving above 50 percent in literacy and mathematics, increasing learner retention rates to 90 percent and bolstering teacher training. (DR30: page 33)</p> <p>Provide a stimulating environment to enhance the development of the child. Provide special classes in normal schools and special schools for intellectual children and adolescents. (DR11: page 23)</p> <p>Curriculum and practitioner development for pre-Reception Year. Particular care will be taken to ensure that when addressing children's intellectual developmental needs, practitioners make use of developmentally appropriate practice. (DR14: page 39)</p> <p>Alternate Assessments Based on Grade-level Attainment of Knowledge (content, concepts and skills) for learners with disabilities or learning difficulties that need testing formats or procedures that provide them with equal opportunities to demonstrate their attainment of content which is at the same grade-level as the general assessment. Target learners can include learners who are blind, have communication difficulties, physical disabilities, learners who are dyslexic or with hearing loss and who need additional time, alternate formats, readers, amanuensis, electronic equipment, etc. as outlined in the policy document, National policy on the conduct, administration and management of the National Senior. (DR33: page 19)</p> <p>As a teacher gets to know her learners, and as learner differences emerge, assessment needs to become more differentiated. The goal is to meet learners where they are and to help them progress to the next step in their learning. Thus it is a cyclical process: assessment and instruction support and inform each other. (DR33: page 13)</p> <p>Teachers will incrementally be trained on the various curriculum differentiation methodologies so as to be able to apply the various adaptive and supportive assessment measures in school-based as well as formal assessment. (DR33: page 19)</p> <p>Training of all ECD practitioners will include a component on the SIAS Policy. (DR16: page 19)</p> <p>Training in teaching methods; regular and systematic monitoring; adequate support to practitioners; provision of more reading books and improvement of the professional status of ECD practitioners. (DR14: page 26)</p>
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		<p>Five specific support provision areas are identified: Specialist support staff, assistive devices, specialised equipment and teaching and learning support materials, curriculum differentiation to meet the individual needs of learners. (DR16: page 8)</p> <p>Specialised support resources, personnel, programmes and facilities that are needed on a lower-frequency basis, are holistic and teacher-focused, more portable and requiring less operational and organisational planning, will be provided at circuit or district level to be accessed by learners at ordinary schools, e.g. learning support, remedial education, assistive devices, counselling, rehabilitation and therapeutic services. (DR16: page 12)</p> <p>Special Schools must ensure that they support the families of learners enrolled in their schools. Such support may include educational guidance and support, psychological and emotional guidance and support, etc. Schools must advise parents on the best possible career opportunities available to learners. (DR32: page 6)</p> <p>Schools-based and out of school programme to programme; parenting-support to reduce adolescent problem behaviour, including substance abuse and aggression. (DR12: page 8)</p> <p>Educational support systems should make use of and promote the establishment of a network of support through the Care and Support for Teaching and Learning (CSTL) framework, which coordinates all existing services, including other government departments, community services, private professionals, non-government organisations (NGOs), disabled people organisations (DPOs), early intervention providers and community-based rehabilitation services. (DR16: page 18)</p> <p>The Screening, Identification, Assessment and Support Policy aims to facilitate the shift from individual learner disability as the driving organiser for support provision to that of the range, nature and level of support programmes, services, personnel and resources that will be made available for special and ordinary schools to increase learner participation in the learning process. (DR16: page 12)</p>
	Health	<p>Screening and early detection of disability, diagnostic and therapeutic support service, 24 hour service and specialist support. (DR2: page 22)</p> <p>Referral system: referral to social and Welfare Support Services. (DR2: page 24)</p> <p>Health care and nutrition programmes; social protection programmes. (DR25: pages 56-57)</p> <p>Nutrition intervention for pregnant women and young children. Ensure household food and nutrition security. (DR30: pages 33 and 37)</p>

	Social	<p>Strengthen youth service programmes and introduce new, community-based programmes to offer young people life-skills training, entrepreneurship training and opportunities to participate in community development programmes. Efforts to ensure relevant and accessible skills development programmes for people with disabilities, coupled with equal opportunities for their productive and gainful employment, must be prioritised. (DR30: pages 33 and 52)</p> <p>Developing and implementing empowerment programmes for People with disabilities on issues pertaining to Life and social skills, positive self-image and self-perception, positive inter-personal relations and communication, coping and parenting skills and understanding and comprehending relevant policies and available social services. (DR31: page 32)</p> <p>Ensure that an intellectual disabled child or adolescent is in the hands of an effective carer; where possible, ensure that the natural parents are the primary caregivers for intellectually disabled children and adolescent; provide ongoing emotional and (if necessary) material and human resource support for the parents and other caregivers; provide a stimulating environment to enhance the development of the child. (DR11: page 23)</p> <p>Support for pregnant women, new mothers/fathers and children under 2 years of age. Parent support programmes; opportunities for learning. (DR25: pages 58, 59, 62)</p> <p>Work collaboratively with community organisations and structures including disabled people's organisations, parent organisations, teacher unions, NGOs, Disabled people's organisation (DPOs), traditional healers, parents, grandparents and caregivers in providing teaching and learning support. Work with the community on advocacy and awareness-raising programmes aimed at changing negative attitudes towards people with disabilities and supporting the implementation of an inclusive education system. (DR32: page 21)</p> <p>The Department of Sport and Recreation, together with the Department of Cooperative Governance and Traditional Affairs, should provide a plan on how sport and recreation facilities will be established maintained and protected from vandals. (DR26: page 24)</p> <p>Fostering holistic and integrated support provision through intersectoral collaboration. (DR3: page 6)</p> <p>To establish inter-sectoral collaborations with relevant stakeholders such as the Departments of Education, Labour, Welfare (Social Development), the private sector, NPOs and CBOs. Collaboration with other Departments (e.g. Education) and sub-directorates (e.g. mental health) Community and NGO liaison. (DR2: page 11)</p>
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		<p>Entrench a social security system covering all working people, with social protection for the poor and other groups in need, such as children and people with disabilities. (DR30: pages 34)</p> <p>Developing service delivery norms and standards to ensure the protection and promotion of the rights of People with Disabilities. Developing a technical guide on procedures to promote better understanding to the service providers and beneficiaries, of the social security system. Developing and implementing a communication strategy that will inform people with disabilities of social security services available to them, thereby increasing their access to the services. (DR31: page 31)</p>
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## CHAPTER FIVE

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The Distribution of Available Prevention and Management Interventions for Fetal Alcohol Spectrum Disorder (2007 to 2017): Implications for Collaborative Actions. *International journal of environmental research and public health*. 2019 Jan;16(12):2244.

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### **Abstract**

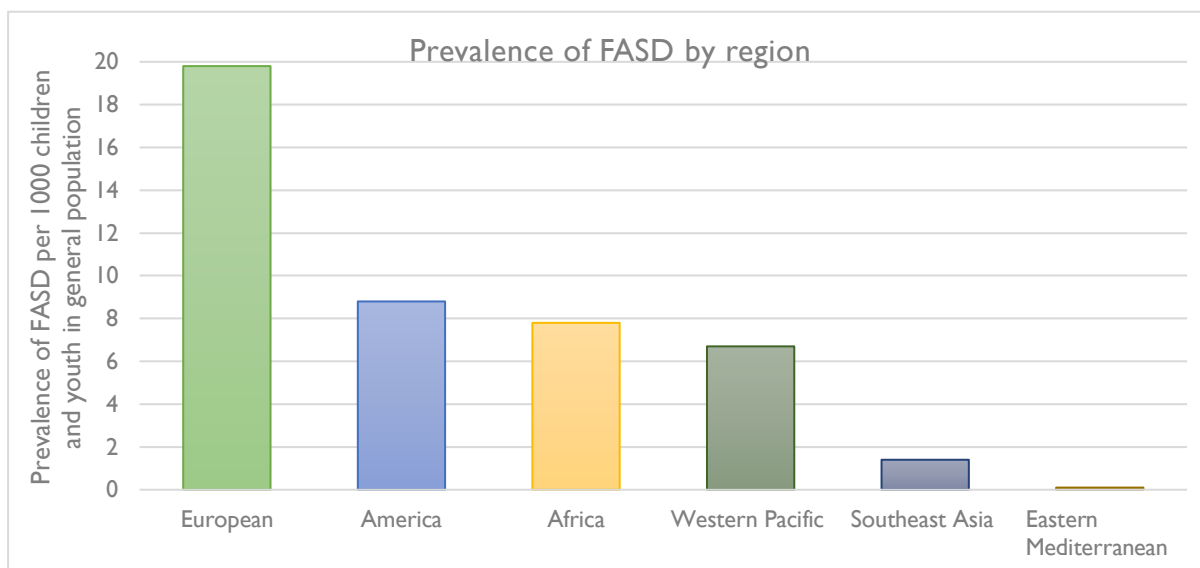
The global prevalence of Fetal Alcohol Spectrum Disorder (FASD) remains high despite the various preventive and management interventions that have been designed and implemented to tackle the issue in various settings. The aim of the scoping review is to identify and classify prevention and management interventions of FASD reported globally across the life span and to map the concentration of these interventions across the globe. We searched some selected databases with predefined terms. Framework and narrative approaches were used to synthesize and report on the findings. Thirty-two prevention intervention studies and 41 management interventions studies were identified. All the interventions were reported to be effective or showed promising outcomes for the prevention and management of FASD, except four. Although Europe and Africa have a relatively higher prevalence of FASD, the lowest number of interventions to address FASD were identified in these regions. Most of the interventions for FASD were reported in North America with comparatively lower FASD prevalence. The uneven distribution of interventions designed for FASD vis-à-vis the burden of FASD in the different regions calls for a concerted effort for knowledge and intervention sharing to enhance the design of contextually sensitive preventive and management policy in the different regions.



## Introduction

Fetal alcohol spectrum disorder (FASD) is a diagnostic term used to describe a range of conditions affecting individuals exposed to alcohol prenatally [1]. FASD can manifest as fetal alcohol syndrome (FAS), partial FAS, alcohol-related neurodevelopmental disorder (ARND) and alcohol-related birth defects (ARBD) [2,3]. FASD may result in primary and secondary disabilities for individuals prenatally exposed to alcohol. Primary disabilities may include abnormal facial features, learning disabilities, attention difficulties, poor memory, poor reasoning and judgment skills, hyperactive behavior and poor coordination [4]. Without appropriate interventions to mitigate primary disabilities, secondary disabilities may develop. Secondary disabilities may include mental health problems, disrupted school experience, trouble with the law, confinement, inappropriate sexual behavior and alcohol/drug problems [5].

One in 13 alcohol-exposed pregnancies results in diagnosable FASD and the global prevalence of FASD is estimated at eight per 1000 children and youth [6]. A systematic review using 2012 data estimated the prevalence of FASD around the world among children and youth in general population using World Health Organization (WHO) regions [6] as shown in the chart below (**Figure 1**).



**Figure 1: Prevalence of fetal alcohol spectrum disorder (FASD) by region.**

The World Health Organization (WHO) recognizes FASD as a public health issue and has developed a guideline for the identification and management of substance use and substance use disorders in pregnancy [7]. The guideline recommends that health professionals should ask all pregnant women about their use of alcohol and brief intervention should be given to all pregnant women using alcohol. The Center for Disease Control and Prevention (CDC) has also identified and supported the implementation of two interventions in preventing and reducing the prevalence of FASD [8]. One of the interventions is alcohol screening and brief intervention (SBI)—an intervention that identifies and helps individuals who are drinking excessively. The second intervention is the CHOICES program—an evidence-based intervention that increases motivation and commitment to reduce or stop drinking and/or use contraception effectively [8].

In addition to the efforts of WHO and CDC, researchers have developed and implemented various interventions such as universal prevention, brief intervention, motivational interview, case management, and service provider training for the prevention of FASD [9–13]. These interventions have been found effective or have shown promising outcomes in preventing FASD and/or reducing

the risk of prenatal alcohol exposure [9–13]. Although, the conclusions drawn from the reviews were limited by the poor methodological quality and paucity of studies as indicated by the authors [14,15]. Psychological and educational interventions and other interventions delivered during antenatal care have potentials to increase abstinence and reduce alcohol consumption among pregnant women [14,15]. On the other hand, various barriers have been found to mitigate the effectiveness of these interventions. These barriers may include conflicting messages in the media, stigmatization of people with alcohol use disorders and birth mothers, fear of losing child custody (which may prevent women from seeking help) and lack of skills by service providers to discuss alcohol use with women who are pregnant [16]. The challenges regarding the prevention of prenatal alcohol exposure during pregnancy and unplanned pregnancy through the use of contraceptives necessitate interventions to manage primary disabilities and prevent or minimize the impacts of secondary disabilities.

Pei et al. [17] and Jirikowic et al. [18] suggested that because the needs of individuals with FASD are diverse, their assessment and management should be personalized. Most importantly, early diagnosis and intervention could minimize the impact of some of the problems that arise from prenatal alcohol exposure [19–24]. Reid et al. [22] showed that there is growing evidence supporting the effectiveness of FASD management interventions in improving outcomes for early to middle childhood. However, there is a dearth of management interventions for individuals with FASD beyond early and middle childhood [22] suggesting inadequate management plans for these individuals. Peadon et al. [23] reported that pharmacological and non-pharmacological management interventions have shown some benefit among children with FASD. While Paley and O'Connor [25] confirmed that behavioral interventions showed immediate post-intervention effects, they did not ascertain the long-term follow-up outcomes.

Systematic reviews have been published on interventions for the prevention [14,15] and management of FASD [22,23] and other literature reviews for management interventions [25–29]. The

systematic reviews on the prevention of FASD focused mainly on interventions for pregnant women, women planning a pregnancy and indigenous community without considering women in other groups [14,15,30]. One of the systematic reviews for management interventions includes both pharmacological and non-pharmacological interventions for children with FASD only [23]. The second systematic review on management interventions for FASD examined the effectiveness of interventions across the life span, however, only non-pharmacological interventions were included [22]. From the reviews above, we observed that there is a lack of a review for prevention of FASD outside those who are pregnant, planning a pregnancy and indigenous community. In addition, we discovered the lack of review for both pharmacological and non-pharmacological interventions that assessed methodological rigor across the life span. FASD interventions need to be diverse and include prevention and both pharmacological and non-pharmacological management approaches across the life span as the negative effects of prenatal alcohol exposure can manifest across all ages. Therefore, the need to address the gap of a study exploring the prevention interventions for all women and the management interventions across life span necessitates this current scoping review.

In addition to the above motives for this scoping review, Premji et al. [31], in their study on research-based interventions for individuals with FASD, found weak scientific evidence for the effectiveness of interventions across the life span. Therefore, they called on researchers, service providers, and policymakers to collaborate and develop appropriate interventions for individuals with FASD. For this to be achieved, knowledge of available interventions for the prevention and management of FASD and the assessment of their effectiveness should be known.

To this end, we aimed to conduct a scoping review that will serve four purposes. First, the review will help to identify the prevention and management interventions of FASD reported in the literature across the life span to address the above-mentioned gaps in interventions for FASD. Secondly, we sought to map the concentration of these interventions across the globe vis-à-vis the burden of FASD

in the different regions. Thirdly, to update previous reviews and lastly to provide current information to help inform policy development [32–35].

## Methods

We conducted a scoping review to identify and classify the prevention and management interventions of FASD reported in the literature across the life span that may be included in the policy for FASD. We adapted five steps for conducting reviews as proposed by Arksey and O'Malley [36] to suit the aim of this study. The five steps include (1) framing of questions for the review; (2) identifying relevant work; (3) assessing the quality of studies; (4) summarizing the evidence; (5) interpreting the findings.

### Step 1: Framing of questions for the review

We formulated the review question using the PICO mnemonics (Population, Intervention, Comparison, and Outcome) [37]. What are the prevention and management interventions of FASD available globally?

**Table 1: Characteristics and criteria for PICO**

Characteristic	Criteria
<b>Population</b>	Individuals with FASD, young people, adult, women and children
<b>Intervention</b>	Any strategy aimed at preventing or managing FASD
<b>Comparison</b>	Individuals who do not receive interventions
<b>Outcome</b>	Effective in preventing or managing FASD

### Step 2: Identifying relevant work

We searched the following Ebsco Host embedded databases; Academic Search Complete, ERIC, SoINDEX, Health Source: Nursing/Academic Edition, CINAHL, Medline and Psych-ARTICLES. In addition, we searched Sabinet, SAGE Journals, and PubMed databases. The following standard Boolean phrase was applied to all the databases: (“fetal alcohol spectrum disorder” OR “fetal alcohol syndrome” OR “alcohol-related neurodevelopmental disorder” OR “alcohol-related birth defects” OR “partial fetal alcohol syndrome” OR “prenatal alcohol exposure”) AND (“intervention” OR “strategy” OR “treatment” OR program” OR “management” OR “prevention” OR “therapy”). From the results of the search, the titles and abstracts of the articles were screened by two of the authors (B.O.A. and C.E.) for possible inclusion using the following criteria.

***Inclusion criteria:***

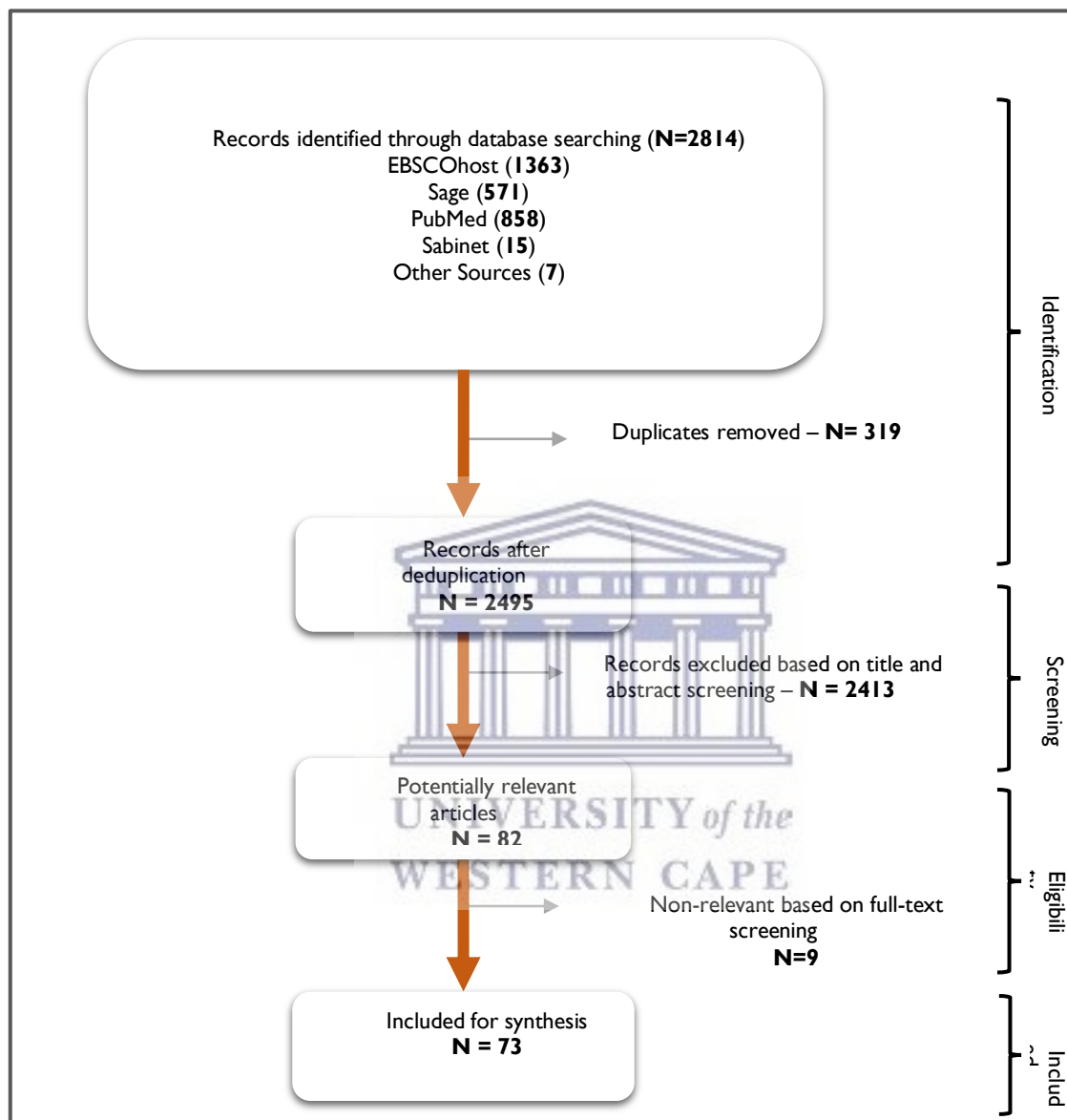
- The interventions (both pharmacological and non-pharmacological) must aim at preventing or improving the outcome of prenatal exposure to alcohol;
- Articles published in the English Language;
- Articles published from 2007 to 2017 (we chose this period to provide current information to help inform policy development);
- The target population must be women, young people, and individuals with FASD;
- All the types (randomized controlled trials (RCT), quasi RCT, non-randomized controlled trials and cohort studies with pre- and post-intervention);
- Interventions targeting any age group.

***Exclusion criteria:***

- Studies that do not report on the effectiveness of the interventions;
- Animal studies;
- Other systematic and scoping reviews;
- Unpublished prevention and management interventions;

- Articles published before 2007 and after 2017.

The flow chart of the selection process is presented in **Figure 2**.



**Figure 2: PRISMA flow diagram for the selection process**

The database search yielded 2814 articles and 2495 were included after removal of the duplicates. Eight-two articles were potentially relevant articles after the title and abstract screening and 73 after retrieval of the full text. Seventy-three articles met the inclusion criteria for the final



synthesis. B.O.A. and F.C.M. independently searched and screened the included articles and all the disagreements were resolved by C.E. (see **Figure 2**).

This study was approved by the research ethics committee of the University of the Western Cape (BM/16/4/4)

### Step 3: Accessing the quality of studies

We used a study design-based quality checklist: The Effective Public Health Practice Project (EPHPP) assessment tool. This tool was developed to assess the methodological rigor of primary studies in public health [38]. The EPHPP assessment tool comprises of six quality components: selection bias, study design, confounders, blinding, data collection methods, and withdrawals and dropouts. Each study was rated using the “strong,” “moderate,” or “weak” scale (see Table 2). Herein the overall rating of the quality of the studies assessed was not done. Additionally, the rating was not used to determine the studies to be included in this review. This is because Juni et al. [39] recommended that studies should be assessed independently and the total score should not be used. This recommendation was supported by other authors [22]. The importance of the assessment is to provide support to the findings and conclusion drawn from this study. The findings from this study should interpreted with a due consideration to the assessment. B.O.A. and C.E. independently assessed the included articles and all the disagreements were resolved by F.C.M. (see **Table S1**).

**Table 2: Quality Assessment Components and Ratings for Effective Public Health Project Instrument.**

Components	Strong	Moderate	Weak
<b>Selection bias</b>	Very likely to be representative of the target population and >80% participation rate	Somewhat likely to be representative of the target population and 60 to 79% participation rate	Not likely to be representative (i.e., self-referred), <60% participation rate or not stated
<b>Design</b>	Randomized controlled trial and controlled clinical trial	Cohort analytic, case-control, cohort, or an interrupted time series	All other designs or designs not stated

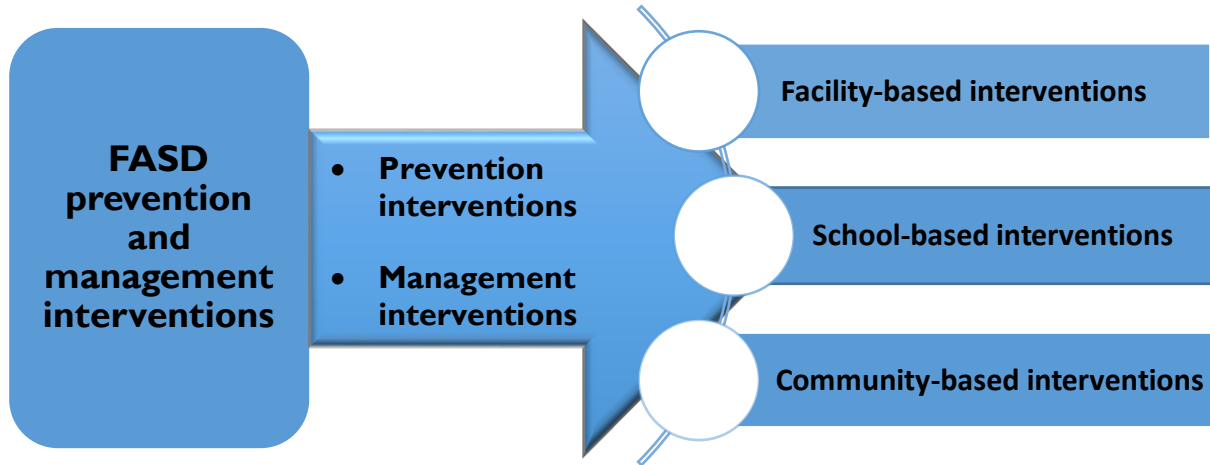
<b>Cofounders</b>	Controlled for at least 80% of cofounders	Controlled for 60 to 79% of cofounders	Cofounders not controlled for, or not Stated
<b>Blinding</b>	Blinding of outcome assessor and study participants to intervention status and/or research question	Blinding of either outcome assessor or study participants or blinding is not described	Outcome assessor and study participants are aware of intervention status and/or research question
<b>Data collection methods</b>	Tools are valid and reliable	Tools are valid but have not been shown to be reliable	No evidence of validity or reliability
<b>Withdrawals and dropouts</b>	Follow-up rate of >80% of participants	Follow-up rate of 60 to 79% of participants	Follow-up rate of <60% of participants or withdrawals and dropouts not described

The qualities of the studies were assessed, and only two studies were rated “strong” for selection bias. Studies were rated “strong” if the participants were randomly selected from the target population, “moderate” if the participants were recruited from a clinic and “weak” if the participants were self-referred. Forty studies were rated “strong” for study design, which represents the number of randomized controlled trials that were included. Studies were rated “strong” if the studies were randomized controlled trials or controlled clinical trials “moderate” if the studies were cohort analytic, case-control, cohort, or an interrupted time series and “weak” if the studies were other designs or designs not stated. Sixty-six studies were rated “strong” for data collection. Studies were rated “strong” if the tools were valid and reliable “moderate” if the tools were valid but had not been shown to be reliable and “weak” if the tools were not reliable or valid. **Table S1** contains the details of the quality assessments of the studies included.

#### Step 4: Summarising the evidence

We summarized the data by tabulating the study characteristics, intervention approach and results of the studies (see **Table S2**). We employed a type of narrative synthesis [40] called thematic summaries. Thematic summaries allow for categorization of studies into thematic groups and tabulation of the

findings into a thematic framework based on the predefined categories (framework) [41]. Therefore, we used the framework method [42] to develop themes for data analysis (see **Figure 3**).



**Figure 3: Heuristic classification framework applied to summarise the data**

## Results

The characteristics of the studies included in the review are illustrated in **table 3**.

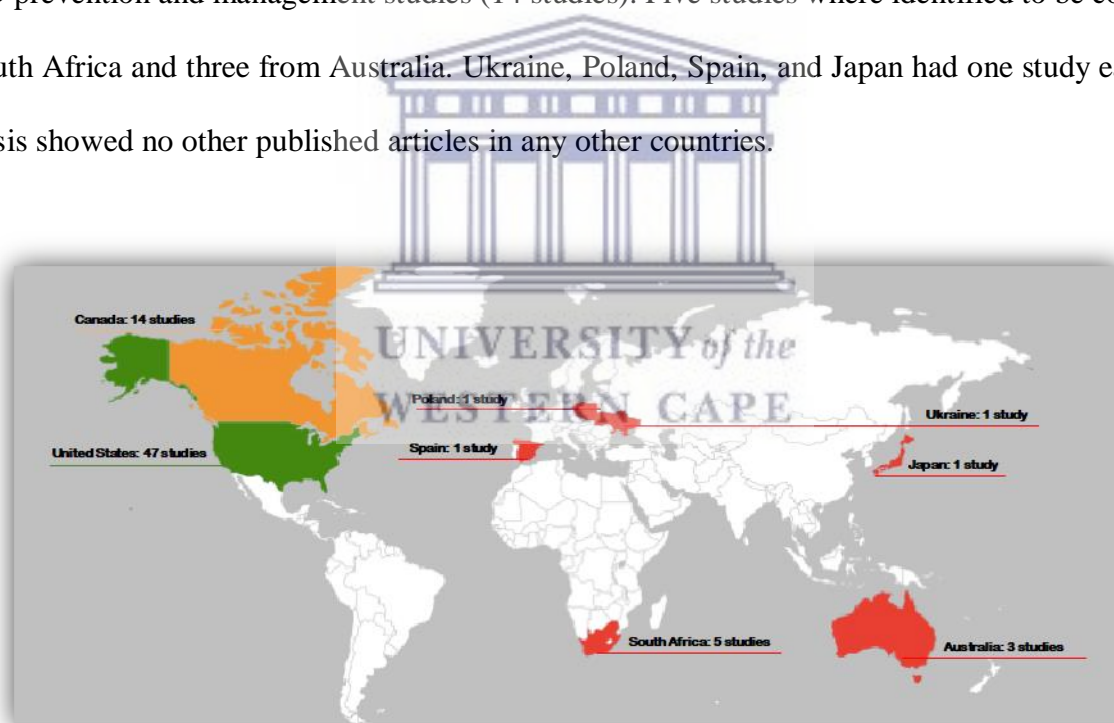
**Table 3: Characteristics of the study included in the review**

Characteristics	Number of Studies
<b>Research approach</b>	
Quantitative	72
Mixed method	1
<b>Study design</b>	
Mixed method	1
Descriptive longitudinal study	1
Prospective	3
Survey	2
Dichotomized control trial	2
Retrospective case analysis	4
Pre-post-test	13
Non-randomized control trial	2
Randomized control trial	40
Quasi-experimental	2
Case study	2
Cohort analytic	1

<b>Type of intervention</b>	
Prevention	32
Management	41
<b>Study setting (continent)</b>	
North America	61
Africa	5
Europe	3
Australia	3
Asia	1

### Global Distribution of FASD Prevention and Management Interventions

We mapped the distribution of the prevention and management interventions based on settings within which each of the identified studies were conducted (Figure 4). Most of the studies were conducted in the United States (47 of the 73 studies). Canada recorded the second highest studies on FASD prevention and management studies (14 studies). Five studies were identified to be conducted in South Africa and three from Australia. Ukraine, Poland, Spain, and Japan had one study each. Our analysis showed no other published articles in any other countries.



**Figure 4.** A global representation of the prevention and management intervention studies by countries.

## Prevention interventions

Prevention interventions were identified as interventions aimed at either preventing or reducing the prevalence of FASD. We classified these interventions as facilities-based, school-based/education-based and community-based depending on where the interventions had been carried out (Table 4). However, interventions that took place in more than one setting were classified in the one that seemed to be most appropriate for easy presentation of findings.

**Table 4: Themes generated from the prevention interventions**

Prevention Interventions			
Nature of Interventions	Numbers of Studies and Citation	Interventions	Outcomes of Interventions
Facility-based	Joya et al. [43]	Single-session motivational interview for pregnant women	Decreased alcohol consumption during pregnancy
	Velasquez et al. [44]	Dual-focused approach (motivation interviewing on alcohol and contraception)	Reduced the risk for alcohol-exposed pregnancy (AEP) by increasing the effective use of contraception and decreasing alcohol use
	Payne et al. [45]	Educational resources on FASD for Health professionals	Increased practitioners' knowledge of FASD
	Mwansa-Kambafwile et al. [13]	Training course on FASD capacity building for service providers	Built service providers' capacity to prevent and manage women at risk for AEP
	Ondersma et al. [46]	Computer-Delivered Screening and Brief Intervention for pregnant women	Demonstrated efficacy for favorable birth outcome
	Delrahim-Howlett et al. [47]	Web-based alcohol assessment and personalized feedback for women of reproductive age	Reduced number of risky alcohol consumption
	Tzilos et al. [48]	Brief Computer-Delivered Intervention for pregnant women	Significantly decreased alcohol use
	Hutton et al. [49]	Project CHOICES intervention for women	Decreased the AEP risk in the through effective use of contraception and decrease alcohol use
	Osterman et al. [50]	Single-session of motivational interviewing (MI) for women	MI was not found effective in decreasing alcohol use
	Osterman and Dyehouse [51]	Motivational interview intervention for pregnant women	MI was not found effective in decreasing alcohol use
School-based/education-based	LaChausse [52]	Multimedia presentation on FASD for high school students	Increased the students' knowledge of FASD
	Boulter [53]	Peer-delivered educational presentation on FASD for youth	Increased youths' knowledge about FASD
	Toyama and Sudo [54]	Tailored leaflet educational intervention	Improved knowledge of pregnant women re FASD

<b>Community-based</b>	Hanson et al. [55]	Preconception prevention program (motivational interview techniques) for at-risk women	Reduced the risk for AEP by increasing contraception use
	Farrell-Carnahan et al. [56]	One-session motivational interview for non-treatment-seeking community women	Decreased the AEP risk in the community by increasing contraception use and decreasing alcohol use
	Hanson et al. [11]	Motivational interview-based intervention for women	Modified self-reported drinking and contraception behavior positively
	O'Connor and Whaley [10]	Brief intervention (10–15 min counseling sessions) for pregnant women	Promoted abstinence from alcohol by increasing motivation to change unhealthy behavior
	Letourneau et al. [57]	Mail-based prevention program for at-risk women	Reduced the risk for AEP by increasing the effective use of contraception
	Tenkku et al. [58]	Web-based intervention using tailored motivational messaging for women	Reduced the risk of an AEP by increasing the effective use of contraception and decreasing alcohol use
	De Vries et al. [12]	Case management intervention for heavy drinking pregnant women	Helped women to stop drinking and reduced the risk of FASD
	Montag et al. [59]	Targeted Screening, Brief Intervention, and Referral to Treatment (SBIRT) intervention for women	Decreased risky drinking behavior and vulnerability to AEP
	May et al. [60]	Case management intervention for heavy drinking pregnant women	Reduced maternal alcohol drinking at critical times
	France et al. [61]	Threat-based and self-efficacy based message on alcohol for women	Promoted women's intentions to abstain from alcohol
	Wilton et al. [62]	Telephone-based brief intervention (counseling sessions)	Reduced the risk of an AEP by increasing contraception use and decreasing alcohol use
	Rasmussen et al. [63]	Mentorship program for at-risk women	Reduced the risk of an AEP by increasing contraception use
	Floyd et al. [64]	Brief motivational intervention for women	Reduced the risk of an AEP by increasing contraception use and decreasing alcohol use
	Chersich et al. [9]	Universal intervention (highlighting FASD using local media and health promotion talks at health facilities)	Reduced the prevalence of FASD by increasing knowledge of harms of maternal drinking
	Dresser et al. [65]	Training program on FASD for alcohol-server	Reduced serving of alcohol to pregnant women
	Hanson et al. [66]	Media campaign on FASD for women	Increased knowledge of FASD and decreased actual drinking
	May et al. [67]	Case management intervention for women	Helped women to stop drinking and reduced the risk of FASD
	Ingersoll et al. [68]	Pre-conceptional motivational interviewing interventions for women	Decreased DDD (drinks per drinking day), ineffective contraception rate and AEP risk
	Russell et al. [69]	Project CHOICES intervention for youth and adult	Demonstrated increased effectiveness of birth control use and decreased use and abuse of alcohol



## **Facility-based prevention interventions**

The review identified 10 facility-based interventions [13, 43–51]. Eight of the facility-based interventions [43, 44, 46–51] targeted women while the other two were aimed at service providers [13,45]. We identified three motivational interviews [43, 50, 51] (single-session motivational interviews [43, 50] and a motivational interview [51]). One of the interviews decreased alcohol consumption during pregnancy [43] whereas the remaining two were not found effective in decreasing alcohol use [50,51]. Another study described the effectiveness of the use of a dual-focused approach (motivational interviewing and the trans theoretical model) in reducing the risk for an alcohol-exposed pregnancy (AEP) [44]. In addition, Project CHOICES intervention for women decreased the AEP risk through the effective use of contraception and decreased alcohol use [49]. We found a web-based alcohol assessment and personalized feedback for women of reproductive age to reduce the amount of risky alcohol consumption [47]. We identified a short training course based on brief motivational interviewing principles to build service provider capacity for the better management of women at risk for AEP [13]. Another study described the distribution of educational resources to increase health professionals' knowledge, change health professionals' attitudes' and practice on FASD and improve the quality of advice the health professionals provide to pregnant women vis-à-vis alcohol consumption [45]. We also found two brief interventions for pregnant women [46,48] (Computer-Delivered Screening and Brief Intervention and Brief Computer-Delivered Intervention). The first intervention demonstrated efficacy for favorable birth outcome [46] whereas the other significantly decreased alcohol use [48].

## **School-based/education-based prevention interventions**



Three school-based interventions [52–54] were identified and reported to have the potential of preventing FASD. We found a peer-led 40-minute pilot multimedia presentation intervention among middle and high school students that increased the students' knowledge about the effects of alcohol consumption during pregnancy [52]. We also found multimedia, peer-delivered educational presentation for youth (Fetal Alcohol Spectrum Teaching and Research Awareness Campaign) improved youths' knowledge about FASD [53]. In addition, the third education-based intervention, educational leaflet improved women's knowledge of FASD [54].

### **Community-based prevention interventions**

Nineteen community-based interventions [9–12,55–69] aimed at either preventing FASD or reducing the prevalence of FASD were identified. We found three CHOICE programs [55,57,69]. The first program (the Oglala Sioux Tribe CHOICES) is the motivational interview techniques based pre-conceptional prevention of AEP and the program reduced risky drinking in women at risk for AEP and/or preventing unintended pregnancy [55]. The second program (the Project Healthy CHOICES) is a self-administered, mail-based prevention intervention and it was found effective in minimizing the risk of AEP [57]. The third Project CHOICES intervention for youth and adult demonstrated increased effectiveness of birth control use and decreased use and abuse of alcohol [69]. Three case management prevention interventions [12,60,67] were identified. Two case management intervention (intervention activities that incorporated life management, Motivational Interviewing techniques and the Community Reinforcement Approach (CRA)) that helped women to stop drinking or drink less while pregnant, thereby decreasing the risk of FASD [12,67]. The third case management intervention study was found effective in reducing maternal drinking at critical times and therefore decreased the fetal alcohol exposure level [60].

We identified four brief interventions [10,59,62,64] aimed at either preventing FASD or reducing the prevalence of FASD. We found a brief intervention with a potential of promoting abstinence to alcohol among women [10]. In another study, the Targeted Screening, Brief Intervention, and Referral to Treatment (SBIRT) intervention decreased risky drinking behavior and vulnerability to AEP among women [59]. A different study found a telephone-based brief intervention to be successful and cost-effective in reducing the risk of AEP in women [62]. The last study reported brief motivational intervention to be effective in minimizing the risk of AEP in women [64].

Only two web-based interventions [11,58] were identified. In the first intervention, the risk of AEP was diminished using tailored motivational messages [58]. The second intervention was based on a motivational interview in which participants received intervention materials through email was effective in modifying self-reported drinking and contraception behavior [11].

Our review also identified a training program [65], media campaign [66] and parent program based in the community [63]. We found an alcohol-server training program on responsible beverage service to be effective in reducing the serving of alcohol to visibly pregnant women [65]. Another study reported that a media campaign (including posters, radio ads, and other materials such as brochures and pens) decreased risky drinking behavior among women [66]. The First Step Program (a mentorship program model after the Parent-Child Assistance Program) demonstrated promising outcomes for women at-risk for giving birth to a child with FASD [63]. In addition, we identified pre-conceptional motivational interviewing interventions for women to decrease DDD (drinks per drinking day), ineffective contraception rate, and AEP risk [68].

We also identified a combination of two threat concepts and one positive concept based on self-efficacy with promising potentials to promote women's intentions to abstain from alcohol during pregnancy [61]. In another study, the risk of AEP was reduced in the community by one-session, remote-delivered, preconception, motivational interviewing-based intervention for non-treatment-

seeking community women [56]. In addition, it was reported in a study that universal intervention can reduce the prevalence of FASD, especially where knowledge of harms of maternal drinking is low [9].

## Management interventions

In a similar manner, we classified the management interventions as facilities-based, school-based/education-based and community-based depending on where the interventions were carried out (Table 5). However, interventions that took place in more than one setting were classified in the one that seemed to be most appropriate for easy presentation of findings.

**Table 5: Themes generated from the management interventions**

Management Interventions			
Nature of Interventions	Numbers of Studies and Citation	Interventions	Outcomes of Interventions
Facility-based	Nguyen et al. [70]	Use of choline supplement for children	Did not improve cognitive performance
	Zarnegar et al. [71]	Use of neuro-developmentally informed intervention for children	Improved developmental deficit in several domains
	Wozniak et al. [72]	Use of choline supplement for children	Improved neurocognitive functioning
	Wozniak et al. [73]	Use of choline supplement for children	Has potential to improve neurocognitive functioning
	Wilczynski et al. [74]	Use of sensory integration (SI) therapy for children	Improved gross motor function
	Yazdani et al. [75]	An early intervention program for mother and young children	Mitigated cognitive deficit
	Kable et al. [76]	Use of choline supplement with multivitamin/mineral for children	Impacted brain development positively
	Connolly et al. [77]	Applied behavior analysis (ABA)-based verbal behavior treatment program for children	Showed rapid skill acquisition in communication adaptive emotional/behavioral functioning
	Nash et al. [78]	Individual designated therapy room for children	Ameliorated executive functioning deficits
	Soh et al. [79]	Sensory integration and cognitive behavioral training	Improved self-regulation skills and brain development
	Keiver et al. [80]	Physical activity program for children with FASD	Showed differences in cortisol levels in children with FASD compared to Controls
	Nash et al. [81]	Alert® Program for Self-Regulation for behavioral regulation for children	Improved functional integrity in the neural circuitry for behavioral regulation
	Doig et al. [82]	Attention-deficit/hyperactivity disorder (ADHD) treatment for children	Inattention may be less responsive to ADHD medication

<b>School-based/education-based</b>	Coles et al. [83]	Educational intervention for specific learning and behavior need for children	Improved both mathematical skill and behavior
	Kerns et al. [84]	Use of computerized attention training for children	Improved cognitive performance
	Jirikowic et al. [85]	Intervention to increase compliance with motor function in children	Improved sensory adaptation, balance and motor performance
	Adnams et al. [86]	Classroom language and literacy intervention for children	Improved cognitive in targeted brain areas
	Kable et al. [87]	The educational intervention focused on behavior mathematical functions for children	Remediated mathematical deficits
	Kable et al. [88]	Computerized instruction for children	Improved self-regulation
	McCoy et al. [89]	Sensorimotor Training for children	Increased postural sway velocity
	Keil et al. [90]	Social skills intervention	Improved deficits in social information-processing
	Schonfeld et al. [91]	Social-skills and play-therapy	Improved social skills and reduced problem behaviors
	Wells et al. [92]	Group therapy intervention for foster and adoptive caregivers and children	Improved the executive functioning and emotional problem-solving
	O'Connor et al. [93]	Alcohol reduction intervention for adolescents with FASD	Reduced and prevented alcohol use and some secondary disabilities
	Kerns et al. [94]	Game-based process specific intervention for children	Improved cognitive development
	Coles et al. [95]	Computer game for a metacognitive control strategy for children	Reduced disruptive behaviors
	Coles et al. [96]	Virtual reality game of fire safety and street safety for children	Showed significantly better knowledge of the game to which they were exposed
	Loomes et al. [97]	Rehearsal training on working memory span of children	Showed improvement in digit span in children receiving rehearsal training
<b>Community-based</b>	Clark et al. [98]	Professional development program for teachers	Provided support for the effectiveness of the professional development program for teachers
	Leenaars et al. [99]	Families intervention program	Assisted families to cope with stress
	O'Connor et al. [100]	Social-skills and play-therapy for children and parents	Improved knowledge of appropriate social skills, and parent-reported social skills
	Petrenko et al. [101]	Tailored intervention for children and caregivers	Improved child self-regulation and caregiver behavior
	Reid et al. [102]	Home-based program for high-risk, vulnerable families	Improved self-regulatory skills
	Petrenko et al. [103]	Program targeting key risk and protective factors for children and families	Showed promising result for the prevention of secondary conditions and improves the family adaptation
	Millians and Coles [104]	A program developed to address neurocognitive mathematical impairments for children	Remediated learning problems
	Kable et al. [105]	Mathematical skills intervention for children	Improved mathematical skill
	Pomeroy and Parrish [106]	Online training on FASD for Court Appointed Special Advocates	Improved FASD knowledge

Hanlon- Dearman et al. [107]	Use of community home-based attachment intervention for caregivers	Improved communication of needs
Kable et al. [108]	Caregiver Education and Training for Behavioral Regulation for children	Improved caregivers' knowledge of FASD
Pelech et al. [109]	Intervention to enhance practice at child welfare and improve placement stability	Significant decline in number of placement changes
Denys et al. [110]	Step by Step mentor program for parents	Significant reduction in client's needs and significant increase in client's goals

### Facility-based management interventions

We identified 13 facility-based management interventions [70–74,76–82] aimed at managing the FASD. Five of the facility-based management interventions were pharmacological interventions [70,72,73,76,82]. The four studies discussed the use of choline supplements to improve cognitive performance [70], neurocognitive functioning, particularly hippocampal-dependent memory [72], tolerability for FASD management [73] and brain development [76] in children with FASD. Three of the interventions showed promising outcomes while choline supplement was not effective in improving memory, executive function and attention deficits in children with FASD. The last study reported that attention-deficit/hyperactivity disorder (ADHD) in children with FASD may be less responsive to ADHD medication [82].

Four of the facility-based management interventions improved a certain aspect of brain functions [74,78,79,81]. The use of sensory integration (SI) therapy [74] showed high efficacy on gross motor function and individual designated therapy room [78] (a room with varieties of therapy materials for the Alert Program for Self-Regulation) demonstrated effectiveness in correcting the executive function disabilities in children with FASD. In addition, sensory integration and cognitive behavioral training improved self-regulation skills and brain development [79] and the Alert® Program (TherapyWorks Inc., Albuquerque, New Mexico, USA) for Self-Regulation improved functional integrity in the neural circuitry for behavioral regulation [81].

We also identified another study that demonstrated the potential usefulness of neuro-developmentally informed intervention in a real-world setting with young children with FASD in improving developmental deficit in several domains [71]. In another study, the use of an early intervention program for drug and alcohol addicted mothers and their young children (Breaking the Cycle) was effective to mitigate some of the well-described damages caused by heavy in utero alcohol exposure [75]. A different study reported that verbal behavior treatment program (applied behavior analysis) resulted in rapid skill acquisition across several areas of functioning (communication and functional skills) in a child with FASD [77]. Furthermore, physical activity program for children with FASD showed differences in cortisol levels in children with FASD compared to Controls [80].

### **School-based/education-based management interventions**

Our review identified 16 school/education-based management interventions [83–93, 96–98]. Two of the above-mentioned management interventions aimed at improving mathematical skills and behavior in children with FASD [83, 87]. Both interventions were found effective in improving mathematical skills and the behavior of children with FASD.

We identified four game/computer interventions [88,94–96] as a part of the school-based management interventions. The three interventions include the use of a computerized instruction for children with FASD consistent with their parent training, a game-based process and a serious game designed to teach a metacognitive control strategy in a computer game environment for children with FASD. The three interventions verified to be useful in improving self-regulation [88], cognitive [94] and reducing disruptive behaviors [95]. In the last game intervention, the virtual reality game of fire safety and street safety, children showed significantly better knowledge of the game to which they were exposed [96].



Three pieces of training were identified as a part of the education-based interventions [84,89,97]. The computerized attention training [84] and the Sensorimotor Training to Affect Balance, Engagement, and Learning (STABEL) (an intervention designed to train sensory control during balance) [89] and rehearsal training on working memory span of children [97]. The pieces of training were effective in improving cognitive performance [84] increasing postural sway velocity [89] in children with FASD and improving the digit span in children [97]. Additionally, we also found a program effective for the professional development of teachers [98].

We identified two social skill interventions [90,91] as a part of education-based management interventions. The social skills intervention for social information-processing among individuals with FASD [90] and a 12-session, social-skills and play-therapy outpatient treatment for elementary school-aged children with FASD and their parents [91] (the Children's Friendship Training (CFT)) [91]. The former improved social information-processing while the latter improved social skills and led to a reduction in problem behaviors in children with FASD.

We identified an intervention developed to reduce alcohol consumption and alcohol-related negative outcomes among adolescents with FASD [93], a highly motivating modality intervention [85], the classroom language and literacy intervention [86] and group therapy for foster and adoptive caregivers and their children affected with FASD [68]. These interventions reduced the alcohol use and prevented secondary disabilities among adolescents with FASD [70], improved sensory adaptation, balance and motor performance [85], cognitive [86], executive functioning and emotional problem-solving [92] in children with FASD respectively.

### **Community-based management interventions**



Twelve community-based management interventions [99–110] aimed at managing the FASD were found. Two of the community-based management interventions studies discussed the use of a neurocognitive [104] and community translation [105] Math Interactive Learning Experience (MILE) program (Claire and Coles, Atlanta, Georgia, USA) to improve mathematics skills in children with FASD. Both interventions improved mathematics skills in children with FASD.

Three of the community-based management interventions [99,102,103] identified focused on the family. These family-based interventions include support, education, advocacy and refer families to available services [99], a home-based program for high-risk and vulnerable families [102] and a program targeting key risk and protective factors for children with FASD and their families [103]. These interventions were effective in assisting families of children with FASD [99], improving children with FASD's self-regulatory skills by focusing on the parent-child relationship [102] and preventing secondary conditions and improving family adaptation [103].

We also identified a 12-session, social-skills and play-therapy outpatient treatment for elementary school-aged children with FASD and their parents [100], emotional understanding intervention [101], an online training on FASD for Court Appointed Special Advocates (CASA) [106] and community home-based attachment intervention for caregivers of children with FASD [107]. These interventions improved knowledge of appropriate social skills, self-concept and parent-reported social skills in children with FASD [100], self-regulation in children with FASD and caregiver behavior [101], the CASA workers knowledge of FASD [106] and children's ability to communicate their needs better [107].

Furthermore, we identified three other community-based management interventions [108–110]. The caregiver education and training for behavioral regulation improved caregivers' knowledge of FASD [108]. Another intervention reported is the Step by Step mentor program for parents [110]. The intervention significantly reduced the client's needs and significantly increased the client's goals

[110]. The last of the three interventions was conducted to enhance practice regarding child welfare and improve placement stability [109]. The result of the intervention showed a significant decline in the number of placement changes [109].

## **Step 5: Interpreting the findings**

### **Discussion**

Seventy-three studies, of which 32 were prevention interventions studies and 41 management interventions, were included in this review. We found the interventions (prevention and management) effective or to show promising outcomes in either preventing or managing FASD. Although, four of the interventions that met the inclusion criteria and were classified as facility-based interventions (two prevention and two management) were not effective because they require further research to determine their effectiveness.

Although, this review targeted interventions across the life span for both prevention and management interventions, we could not find studies for management interventions that include participants above 18 years of age for this period (2007–2017). Most of the management interventions reported targeted children. These findings aligned with the outcome of the recent systematic review, which reported the paucity of the management interventions across the life span, especially beyond childhood [22]. The demerit of the lack of interventions beyond childhood is that secondary disabilities can more easily manifest. This is because the issues of FASD are life long and multifaceted (containing educational, social and medical), which can manifest in primary and secondary disabilities [5]. Therefore, there is a need to develop multifaceted interventions—as FASD affects individuals across the life span [24]—and management interventions for the management of secondary disabilities in adolescents and adults with FASD. This is because it has been reported that early and age/culturally-

appropriate interventions showed promising outcomes for the management of FASD [22]. Furthermore, we encourage the publication of ongoing efforts to prevent and manage FASD across the life span.

Despite calls from researchers for urgent needs for both prevention and management interventions [31, 111], they remain scant in regions with high prevalence [6]. In this scoping review, most of the prevention and management intervention studies were conducted in America, precisely the United States of America (see Table 3) with a comparatively lower prevalence of FASD compared to Europe. A total of six (three each) prevention and management interventions studies were conducted in Australia and Europe, although Europe has an overwhelmingly high prevalence of FASD (20/1000 children and youth in the general population) [6]. We found out that only five prevention and management interventions studies were conducted in Africa. These interventions studies were conducted only in South Africa. This huge uneven distribution of intervention has public health implications for the prevention and management of FASD, particularly in settings like Europe and Africa. This could further demonstrate the reason for the increasing prevalence of FASD [6].

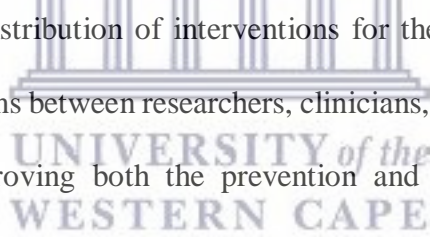
Motivational interviewing was the most reported intervention adopted for preventing FASD in this study. It was effective in reducing alcohol consumption during pregnancy by empowering participants to make the necessary behavioral changes [11–13, 43, 44, 50, 51, 55, 56, 60]. Although it was not effective in two studies, a different study has found motivational interviewing to be an effective intervention in the addiction field [112]. The use of motivational interviewing has seen an increase in health-promoting behaviors such as oral health, safe sexual practices, diet modification and physical exercise [113, 114]. In addition to motivational interviewing, the brief intervention was similarly found effective in preventing FASD [10,46,48,59,62,64]. The CDC has also found Alcohol Screening and Brief Intervention effective in reducing alcohol use for all adults, including pregnant women in the medical and other settings [8].

The case management approach to preventing FASD was also found effective in reducing alcohol consumption during pregnancy [12,60,67]. The case management activities incorporated life management, Motivational Interviewing techniques and the Community Reinforcement Approach. The finding supports the call for integrated care in the prevention and management of chronic conditions [115]. In addition to case management, the training and education of relevant service providers and individuals with FASD were found effective in the prevention of FASD [9,13,52,53,65,66]. These findings support the previous study that found training and education to be effective for health promotional activities in achieving behavioral changes [116].

We found management interventions such as social skills interventions [90,91,100], school-based interventions [83–93] and family-centered interventions [91,99,100,102,103] effective for the management of FASD. Social skills interventions were effective in managing information-processing deficits in individuals with FASD [90,91,100]. Studies have previously reported social skills interventions to be effective in managing other conditions with behavioral problems such as Autism Spectrum Disorder, schizophrenia and Down syndrome [117–119]. The use of school-based interventions was also found effective in improving specific educational skills, cognitive and motor performance, social skills and regulation of behavior [59–65,68–71]. The school-based interventions have been found effective in managing a similar disorder such as attention deficit hyperactivity disorders [120]. In addition, family-centered interventions were found to be effective in reducing problem behavior and improving social skills [91,99,100,102,103]. The effectiveness of family-centered intervention in the management of problem behaviors in children and adolescents has been earlier reported in another study [121].

Prevention and management interventions that have been developed, implemented and evaluated and found effective in preventing and/or managing FASD in a particular setting can be modified for implementation in other settings, especially settings that have high prevalence such as

Europe and Africa. Nevertheless, attention should be paid to address those context-related differences, which may impact on the effectiveness of the interventions. Therefore, various context-specific adaptations should be considered during implementation to ensure the effectiveness of the interventions. Our finding aligns with that of Petrenko and Alto [27] on the need to address the barriers to the implementation of FASD interventions, especially cultural barriers as highlighted in their work. We support the call for collaboration among researchers, cultural experts, and local stakeholders to facilitate implementation, which will enhance the effectiveness of interventions and promotes sustainability. We agree with their suggestion on the use of purveyors as cultural liaisons between researchers and local stakeholders to facilitate buy-in from the latter and the community at large. The importance of the above is to encourage tailored interventions to maximize efficacy. In addition, we believe that interventions work best when the motivations and methods reflect the communities' world view and culture.

The logo of the University of the Western Cape is centered in the background of the text. It features a stylized illustration of a classical building with a pediment and columns. Below the illustration, the text "UNIVERSITY of the" is written in a serif font, and "WESTERN CAPE" is written in a bold, sans-serif font.

In addition, the uneven distribution of interventions for the prevention and management of FASD calls for collaborative actions between researchers, clinicians, service providers and community members across the globe. Improving both the prevention and management of FASD requires evidence-based approaches to community-based and clinic-based service delivery that can overcome the geographic, regional and cultural diversity contexts in which women become pregnant. Although FASD seems to be a priority for communities and governments in America, especially the United States of America, research capacity has not been available to support the development of the context-specific knowledge needed to inform policy and practice in other regions such as Europe and Africa that have a high prevalence of FASD. Moreover, there have not been adequate mechanisms for transferring practice-based knowledge from the information-rich areas such as Canada and the United States of America to researchers and service providers in the South to inform their own policy and practice. We argue, in agreement with Salmon and Clarren [122] for a globalization approach—interconnectedness and interdependence across the different regions of the world to share their

experiences and knowledge in supporting multi-directional capacity building in FASD prevention and management.

## **Strengths and Limitations**

One of the strengths of this study is that we aimed to include studies on the prevention and management interventions across the life span. In addition, thematic analysis was used to analyze the data (using a framework developed in accordance with the aim of the study), which allowed interventions to be categorized as prevention interventions and management interventions.

The results of this review should be considered in light of the following limitations. A weakness is that this current scoping review selected studies that are published only in English from the selected databases. Some of the studies selected were limited by sample size and others were pilot studies, which required to be tested with larger samples. This review only focused on evidence published from 2007 to 2017 as was stipulated in the study objective. As is with other systematized reviews with a large number of articles, it takes some time to screen all the full data, classify the strength of the evidence, extract and analyze the data and then prepare the manuscript for submission. To avoid disruptions through these processes, we decided to focus our scoping review up to 2017. Inherent to reviews addressing the effectiveness of a program, intervention or policy is the issue of how to report efficacy. In this review, it was difficult to standardize the measure or assessment of effectiveness due to the variation of study designs used in the selected articles. For instance, we found that it was difficult to compare the effectiveness of a program obtained through a pre-post study finding to that obtained from an RCT in a comparable manner.

## **Conclusion**



Despite FASD being preventable, its prevalence remains high around the world. Therefore, more efforts should be geared toward prevention. FASD is a lifelong disability with various educational, medical and social issues facing individuals affected by the disorders, however, there is a paucity of interventions for adolescents and adults. The lack of appropriate interventions for these age groups promotes the development of secondary disabilities. There is also a paucity of interventions developed and implemented in countries with a higher prevalence of FASD such as Europe and Africa. Therefore, there is a great need to share and implement context/culturally appropriate interventions for the prevention and management of FASD.

## Supplementary Materials

The following are available online at [www.mdpi.com/xxx/s1](http://www.mdpi.com/xxx/s1), s2. Table S1: Quality assessment results for included studies, Table S2: Data extracted from the included studies.



## Author Contributions

Conceptualization, B.O.A., F.C.M. and C.E.; methodology, B.O.A., F.C.M. and C.E.; software, B.O.A.; validation, B.O.A. and F.C.M.; formal analysis, B.O.A. and F.C.M.; investigation, B.O.A., F.C.M. and C.E.; resources, B.O.A.; data curation, B.O.A.; writing—original draft preparation, B.O.A.; writing—review and editing, B.O.A., F.C.M. and C.E.; visualization, B.O.A., F.C.M.; supervision, F.C.B. and C.E.; project administration, B.O.A.; funding acquisition, B.O.A.

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## **Conflicts of Interest**

The authors declare no conflict of interest.



## Reference

1. Cook, J.L.; Green, C.R.; Lilley, C.M.; Anderson, S.M.; Baldwin, M.E.; Chudley, A.E.; Conry, J.L.; LeBlanc, N.; Looock, C.A.; Lutke, J.; et al. Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan. *CMAJ* **2016**, *188*, 191–197.
2. Chudley, A.E., Conry, J., Cook, J.L., Looock, C., Rosales, T. and LeBlanc, N., 2005. Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *CAMJ* **2005**, *172*(5 suppl), pp.S1-S21.
3. Chudley, A.E. Fetal Alcohol Spectrum Disorder—high rates, high needs, high time for action. *JAMA Pediatrics*, **2017**, pp. 940–941.
4. Centers for Disease Control and Prevention (CDC). Basics about FASDs | FASD | NCBDDD | CDC. <https://www.cdc.gov/ncbddd/fasd/facts.html> (2018, accessed 16 July 2018).
5. Streissguth, A. P., Barr, H. M., Kogan, J., Bookstein, F. L. Understanding the occurrence of secondary disabilities in clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). Centers for Disease Control and Prevention: Atlanta, GA, USA, **1996**, 96–6.
6. Lange, S., Probst, C., Gmel, G., Rehm, J., Burd, L., Popova, S. Global Prevalence of Fetal Alcohol Spectrum Disorder Among Children and Youth. *JAMA Pediatr* **2017**, *171*: 948-956
7. World Health Organization. Management of Substance Abuse Team. *Guidelines for the identification and management of substance use and substance use disorders in pregnancy*; World Health Organization: Geneva, Switzerland, **2014**.
8. Centers for Disease Control and Prevention (CDC). Fetal Alcohol Spectrum Disorders (FASDs) | NCBDDD | CDC. <https://www.cdc.gov/ncbddd/fasd/index.html> (2018, accessed 7 May 2018).
9. Chersich, M. F., Urban, M., Olivier, L., Davies, L. A., Chetty, C., Viljoen, D. Universal prevention is associated with lower prevalence of fetal alcohol spectrum disorders in Northern Cape, South Africa: a multicentre before-after study. *Alcohol and Alcoholism* **2012**, *47*: 67–74.

10. O'Connor, M.J, Whaley, S.E. Brief intervention for alcohol use by pregnant women. *Am J Public Health* **2007**, 97: 252–258.
11. Hanson, J. D., Miller, A. L., Winberg, A., Elliott, A. J. Prevention of Alcohol-Exposed Pregnancies among nonpregnant American Indian women. *Am J Heal Promot* **2013**, 27: S66–S73.
12. de Vries, M., Joubert, B., Cloete, M., Roux, S., Baca, B., Hasken, J., Barnard, R., Buckley, D., Kalberg, W., Snell, C., et al. Indicated prevention of Fetal Alcohol Spectrum Disorders in South Africa: effectiveness of case management. *Int J Environ Res Public Health* **2015**, 13: 76.
13. Mwansa-Kambafwile, J., Rendall-Mkosi, K., Jacobs, R., Nel, E., & London, L. Evaluation of a service provider short course for prevention of fetal alcohol syndrome. *J Stud Alcohol Drugs* **2011**, 72: 530–535.
14. Stade, B.C., Bailey, C., Dzendoletas, D., Sgro, M., Dowswell, T. and Bennett, D. Psychological and/or educational interventions for reducing alcohol consumption in pregnant women and women planning pregnancy. *Cochrane Database of Systematic Reviews* **2009**, (2).
15. Gilinsky, A., Swanson, V., Power, K. Interventions delivered during antenatal care to reduce alcohol consumption during pregnancy: a systematic review. *Addict Res Theory* **2011**, 19: 235–250.
16. Poole, N., Schmidt, R. A., Green, C., & Hemsing, N. Prevention of fetal alcohol spectrum disorder: current Canadian efforts and analysis of gaps. *Subst Abuse* **2016**, 10: 1–11.
17. Pei, J., Baugh, L., Andrew, G., & Rasmussen, C. Intervention recommendations and subsequent access to services following clinical assessment for fetal alcohol spectrum disorders. *Res Dev Disabil* **2017**, 60: 176–186.
18. Jirikowic T, Gelo J, Astley S. Children and youth with fetal alcohol spectrum disorders: summary of intervention recommendations after clinical diagnosis. *Intellect Dev Disabil* **2010**, 48: 330–344.

19. Fitzpatrick, J.P., Latimer, J., Olson, H.C., Carter, M., Oscar, J., Lucas, B.R., Doney, R., Salter, C., Try, J., Hawkes, G. Prevalence and profile of neurodevelopment and fetal alcohol spectrum disorder (FASD) amongst Australian Aboriginal children living in remote communities. *Res Dev Disabil* **2017**, 65: 114–126.
20. Kodituwakku, P.W, Kodituwakku, E.L. From research to practice: an integrative framework for the development of interventions for children with Fetal Alcohol Spectrum Disorders. *Neuropsychol Rev* **2011**, 21: 204–223.
21. Olson, H.C., Montague, R.A. An innovative look at early intervention for children affected by prenatal Alcohol Exposure. *In Prenatal Alcohol Use and FASD: diagnosis, assessment and new directions in research and multimodal treatment*; Bentham Science Publishers: Sharjah, UAE, **2011**; Chapter 4, pp. 64–107.
22. Reid, N., Dawe, S., Shelton, D., Harnett, P., Warner, J., Armstrong, E., LeGros, K., O’Callaghan, F. Systematic review of fetal alcohol spectrum disorder interventions across the life span. *Alcohol Clin Exp Res* **2015**, 39: 2283–2295.
23. Peadon, E., Rhys-Jones, B., Bower, C., Elliott, E. J. Systematic review of interventions for children with Fetal Alcohol Spectrum Disorders. *BMC Pediatr* **2009**, 9: 35–43.
24. Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O’MALLEY, K. I. E. R. A. N., Young, J. K.,. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *J Dev Behav Pediatr* **2004**, 25: 228–238.
25. Paley B, O’Connor MJ. Behavioral interventions for children and adolescents with fetal alcohol spectrum disorders. *Alcohol Res Health* **2011**, 34: 64–75.
26. Petrenko, C.L.M. Positive Behavioral Interventions and Family Support for Fetal Alcohol Spectrum Disorders. *Curr Dev Disord reports* **2015**, 2: 199–209.

27. Petrenko, C.L.M, Alto, M.E. Interventions in fetal alcohol spectrum disorders: An international perspective. *Eur J Med Genet* **2017**, 60: 79–91.
28. Chandrasena, A.N, Mukherjee, R.A.S, Turk, J. Fetal Alcohol Spectrum Disorders: An Overview of Interventions for Affected Individuals. *Child Adolesc Ment Health* **2009**, 14: 162–167.
29. Bertrand, J. Interventions for children with fetal alcohol spectrum disorders (FASDs): Overview of findings for five innovative research projects. *Res Dev Disabil* **2009**, 30: 986–1006.
30. Symons, M., Pedruzzi, R.A., Bruce, K., Milne, E. A systematic review of prevention interventions to reduce prenatal alcohol exposure and fetal alcohol spectrum disorder in indigenous communities. *BMC Public Health* **2018**, 18: 1227.
31. Premji, S., Benzies, K., Serrett, K., Hayden, K. A. Research-based interventions for children and youth with a fetal alcohol spectrum disorder: revealing the gap. *Child Care Health Dev* **2007**; 33: 389–397.
32. Adebiyi, B.O., Mukumbang, F.C., Cloete, L.G., Beytell, A.M. Exploring service providers' perspectives on the prevention and management of fetal alcohol spectrum disorders in South Africa: a qualitative study. *BMC public health* **2018**, 18(1), p.1238.
33. Adebiyi, B.O., Mukumbang, F.C., Cloete, L.G., Beytell, A.M. Policymakers' Perspectives Towards Developing a Guideline to Inform Policy on Fetal Alcohol Spectrum Disorder: A Qualitative Study. *Int J Environ Res Public Health* **2019**, 16: 945.
34. Adebiyi, B.O., Mukumbang, F.C., Okop K.J., Beytell, A.M. A modified Delphi study towards developing a guideline to inform policy on fetal alcohol spectrum disorders in South Africa: a study protocol. *BMJ Open* **2018**, 8: e019907.

35. Adebiyi, B.O., Mukumbang, F.C., Beytell, AM. To what extent is Fetal Alcohol Spectrum Disorder considered in policy-related documents in South Africa? A document review. *Heal Res Policy Syst* 2019, 17: 46.
36. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* **2005**, 8: 19–32.
37. Schardt, C., Adams, M. B., Owens, T., Keitz, S., Fontelo, P. Utilization of the PICO framework to improve searching PubMed for clinical questions. *BMC Med Inform Decis Mak* **2007**, 7: 16.
38. Thomas, B. H., Ciliska, D., Dobbins, M., Micucci, S. A process for systematically reviewing the literature: providing the research evidence for public health nursing interventions. *Worldviews Evidence-Based Nurs* **2004**, 1: 176–184.
39. Jüni, P., Witschi, A., Bloch, R., Egger, M. The hazards of scoring the quality of clinical trials for meta-analysis. *JAMA* **1999**, 282: 1054–1060.
40. Rodgers, M., Sowden, A., Petticrew, M., Arai, L., Roberts, H., Britten, N., Popay, J. Testing Methodological Guidance on the Conduct of Narrative Synthesis in Systematic Reviews. *Evaluation* **2009**, 15: 49–73.
41. Snilstveit B, Oliver S, Vojtkova M. Narrative approaches to systematic review and synthesis of evidence for international development policy and practice. *J Dev Eff* **2012**, 4: 409–429.
42. Gale, N. K., Heath, G., Cameron, E., Rashid, S., Redwood, S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* **2013**, 13: 117.
43. Joya, X., Mazarico, E., Ramis, J., Pacifici, R., Salat-Batlle, J., Mortali, C., García-Algar, O., Pichini, S. Segmental hair analysis to assess effectiveness of single-session motivational intervention to stop ethanol use during pregnancy. *Drug Alcohol Depend* **2016**, 158: 45–51.

44. Velasquez, M.M., von Sternberg, K., Parrish, D.E. CHOICES: an integrated behavioral intervention to prevent alcohol-exposed pregnancies among high-risk women in community settings. *Soc Work Public Health* **2013**, 28: 224–233.
45. Payne, J., France, K., Henley, N., D'antoine, H., Bartu, A., O'leary, C., Elliott, E., Bower, C. Changes in health professionals' knowledge, attitudes and practice following provision of educational resources about prevention of Prenatal Alcohol Exposure and Fetal Alcohol Spectrum Disorder. *Paediatr Perinat Epidemiol* **2011**, 25: 316–327.
46. Ondersma, S.J., Beatty, J.R., Svikis, D.S., Strickler, R.C., Tzilos, G.K., Chang, G., Divine, G.W., Taylor, A.R., Sokol, R.J. Computer-Delivered Screening and Brief Intervention for Alcohol Use in Pregnancy: A Pilot Randomized Trial. *Alcohol Clin Exp Res* **2015**, 39: 1219–26.
47. Delrahim-Howlett, K., Chambers, C.D., Clapp, J.D., Xu, R., Duke, K., Moyer III, R.J., Van Sickle, D. Web-Based Assessment and Brief Intervention for Alcohol Use in Women of Childbearing Potential: A Report of the Primary Findings. *Alcohol Clin Exp Res* **2011**, 35: 1331–1338.
48. Tzilos, G.K., Sokol, R.J., Ondersma, S.J. A randomized phase I trial of a brief computer-delivered intervention for alcohol use during pregnancy. *J Womens Health (Larchmt)* **2011**, 20: 1517–24.
49. Hutton, H.E., Chander, G., Green, P.P., Hutsell, C.A., Weingarten, K., Peterson, K.L. A novel integration effort to reduce the risk for alcohol-exposed pregnancy among women attending urban STD clinics. *Public Health Rep* **2014**, 129 Suppl 1: 56–62.
50. Osterman, R. Feasibility of Using Motivational Interviewing to Decrease Alcohol Consumption During Pregnancy. *J Addict Nurs* **2011**, 22: 93–102.
51. Osterman, R.L., Dyehouse, J. Effects of a Motivational Interviewing Intervention to Decrease Prenatal Alcohol Use. *West J Nurs Res* **2012**, 34: 434–454.



52. LaChausse, R. G. The effectiveness of a multimedia program to prevent Fetal Alcohol Syndrome. *Health Promot Pract* **2008**, 9: 289–293.
53. Boulter, L. The effectiveness of peer-led FAS/FAE prevention presentations in middle and high schools. *J Alcohol Drug Educ* **2007**, 51: 7–26.
54. Toyama, N., Sudo, N. Educational effects of a tailored leaflet addressing drinking during pregnancy. *Clin Med insights Reprod Heal* **2014**, 8: 5–14.
55. Hanson, J.D., Nelson, M.E., Jensen, J.L., Willman, A., Jacobs-Knight, J., Ingersoll, K., Impact of the choices intervention in preventing Alcohol-Exposed Pregnancies in American Indian women. *Alcohol Clin Exp Res* **2017**, 41: 828–835.
56. Farrell-Carnahan, L., Hettema, J., Jackson, J., Kamalanathan, S., Ritterband, L. M., Ingersoll, K. S. Feasibility and promise of a remote-delivered preconception motivational interviewing intervention to reduce risk for Alcohol-Exposed Pregnancy. *Telemed e-Health* **2013**, 19: 597–604.
57. Letourneau, B., Sobell, L. C., Sobell, M. B., Johnson, K., Heinecke, N., Robinson, S. M. Preventing Alcohol-Exposed Pregnancies among Hispanic women. *J Ethn Subst Abuse* **2017**, 16: 109–121.
58. Tenkku, L. E., Mengel, M. B., Nicholson, R. A., Hile, M. G., Morris, D. S., Salas, J. A web-based intervention to reduce Alcohol-Exposed Pregnancies in the community. *Heal Educ Behav* **2011**, 38: 563–573.
59. Montag, A.C., Brodine, S.K., Alcaraz, J.E., Clapp, J.D., Allison, M.A., Calac, D.J., Hull, A.D., Gorman, J.R., Jones, K.L., Chambers, C.D. Preventing Alcohol-Exposed Pregnancy among an American Indian/Alaska native population: effect of a screening, brief intervention, and referral to treatment intervention. *Alcohol Clin Exp Res* **2015**, 39: 126–135.

60. May, P.A., Marais, A.S., Gossage, J.P., Barnard, R., Joubert, B., Cloete, M., Hendricks, N., Roux, S., Blom, A., Steenekamp, J., et al. Case management reduces drinking during pregnancy among high risk women. *Int J Alcohol Drug Res* **2013**, 2: 61–70.
61. France, K. E., Donovan, R. J., Bower, C., Elliott, E. J., Payne, J. M., D’Antoine, H., Bartu, A. E. Messages that increase women’s intentions to abstain from alcohol during pregnancy: results from quantitative testing of advertising concepts. *BMC Public Health* **2014**, 14: 30.
62. Wilton, G., Moberg, D. P., Van Stelle, K. R., Dold, L. L., Obmascher, K., & Goodrich, J. A randomized trial comparing telephone versus in-person brief intervention to reduce the risk of an Alcohol-Exposed Pregnancy. *J Subst Abuse Treat* **2013**, 45: 389–394.
63. Rasmussen, C., Kully-Martens, K., Denys, K., Badry, D., Henneveld, D., Wyper, K., & Grant, T. The effectiveness of a community-based intervention program for women at-risk for giving birth to a child with Fetal Alcohol Spectrum Disorder (FASD). *Community Ment Health J* **2012**, 48: 12–21.
64. Floyd, R.L., Sobell, M., Velasquez, M.M., Ingersoll, K., Nettleman, M., Sobell, L., Mullen, P.D., Ceperich, S., von Sternberg, K., Bolton, B. Preventing alcohol-exposed pregnancies: a randomized controlled trial. *Am J Prev Med* **2007**, 32: 360–360.
65. Dresser, J., Starling, R., Woodall, W. G., Stanghetta, P., May, P. A. Field trial of alcohol-server training for prevention of Fetal Alcohol Syndrome. *J Stud Alcohol Drugs* **2011**, 72: 490–496.
66. Hanson, J.D, Winberg, A., Elliott, A. Development of a Media Campaign on Fetal Alcohol Spectrum Disorders for Northern Plains American Indian Communities. *Health Promot Pract* **2012**, 13: 842–847.

67. May, P.A., Miller, J.H., Goodhart, K.A., Maestas, O.R., Buckley, D., Trujillo, P.M., Gossage, J.P. Enhanced Case Management to Prevent Fetal Alcohol Spectrum Disorders in Northern Plains Communities. *Matern Child Health J* **2008**, 12: 747–759.
68. Ingersoll, K.S., Ceperich, S.D., Hettema, J.E., Farrell-Carnahan, L., Penberthy, J.K. Preconceptional motivational interviewing interventions to reduce alcohol-exposed pregnancy risk. *J Subst Abuse Treat* **2013**, 44: 407–416.
69. Russell, T.T., Craddock, C.S., Kodatt, S.A. and Ramirez, D.M. Preventing Fetal Alcohol Spectrum Disorders: An Evidence-Based Prevention Program for Adolescent and Adult Hispanic Females in the South Texas Border Region. *Online Submission* **2017**.
70. Nguyen, T. T., Risbud, R. D., Mattson, S. N., Chambers, C. D., Thomas, J. D. Randomized, double-blind, placebo-controlled clinical trial of choline supplementation in school-aged children with fetal alcohol spectrum disorders. *Am J Clin Nutr* **2016**; 104: 1683–1692.
71. Zarnegar, Z., Hambrick, E. P., Perry, B. D., Azen, S. P., Peterson, C. Clinical improvements in adopted children with Fetal Alcohol Spectrum Disorders through neurodevelopmentally informed clinical intervention: a pilot study. *Clin Child Psychol Psychiatry* **2016**; 21: 551–567.
72. Wozniak, J.R., Fuglestad, A.J., Eckerle, J.K., Fink, B.A., Hoecker, H.L., Boys, C.J., Radke, J.P., Kroupina, M.G., Miller, N.C., Brearley, A.M. Choline supplementation in children with Fetal Alcohol Spectrum Disorders: a randomized, double-blind, placebo-controlled trial. *Am J Clin Nutr* **2015**; 102: 1113–1125.
73. Wozniak, J.R., Fuglestad, A.J., Eckerle, J.K., Kroupina, M.G., Miller, N.C., Boys, C.J., Brearley, A.M., Fink, B.A., Hoecker, H.L., Zeisel, S.H. Choline supplementation in children with fetal alcohol spectrum disorders has high feasibility and tolerability. *Nutr Res* **2013**; 33: 897–904.

74. Wilczyński, J, Zawada, K. The impact of sensory integration therapy on gross motor function in children after prenatal exposure to alcohol. *Med Stud* **2015**; 1: 10–17.
75. Yazdani P, Motz M, Koren G. Estimating the neurocognitive effects of an early intervention program for children with Prenatal Alcohol Exposure. *Can J Clin Pharmacol* **2009**, 16, 453–459.
76. Kable, J.A., Coles, C.D., Keen, C.L., Uriu-Adams, J.Y., Jones, K.L., Yevtushok, L., Kulikovsky, Y., Wertelecki, W., Pedersen, T.L., Chambers, C.D. The impact of micronutrient supplementation in Alcohol-Exposed Pregnancies on information processing skills in Ukrainian infants. *Alcohol* **2015**, 49: 647–656.
77. Connolly, S. C., Millians, M., Peterman, R., Shillingsburg, M. A. The clinical application of applied behavior analysis in a child with partial fetal alcohol syndrome: A case study. *Clin Case Stud* **2016**, 15: 225–242.
78. Nash, K., Stevens, S., Greenbaum, R., Weiner, J., Koren, G., Rovet, J. Improving executive functioning in children with Fetal Alcohol Spectrum Disorders. *Child Neuropsychol* **2015**, 21: 191–209.
79. Soh, D.W., Skocic, J., Nash, K., Stevens, S., Turner, G.R. and Rovet, J. Self-regulation therapy increases frontal gray matter in children with fetal alcohol spectrum disorder: evaluation by voxel-based morphometry. *Front Hum Neurosci* **2015**, 9: 108.
80. Keiver, K., Bertram, C.P., Orr, A.P., Clarren, S. Salivary cortisol levels are elevated in the afternoon and at bedtime in children with prenatal alcohol exposure. *Alcohol* **2015**, 49: 79–87.
81. Nash, K., Stevens, S., Clairman, H., Rovet, J. Preliminary Findings that a Targeted Intervention Leads to Altered Brain Function in Children with Fetal Alcohol Spectrum Disorder. *Brain Sci* **2017**, 8: 7.

82. Doig, J., McLennan, J.D., Gibbard, W.B. Medication Effects on Symptoms of Attention-Deficit/Hyperactivity Disorder in Children with Fetal Alcohol Spectrum Disorder. *J Child Adolesc Psychopharmacol* **2008**, 18: 365–371.
83. Coles, C.D, Kable J.A, Taddeo E. Math performance and behavior problems in children affected by prenatal alcohol exposure: intervention and follow-up. *J Dev Behav Pediatr* **2009**, 30: 7–15.
84. Kerns, K. A., MacSween, J., Vander Wekken, S., Gruppuso, V. Investigating the efficacy of an attention training program in children with foetal alcohol spectrum disorder. *Dev Neurorehabil* **2010**, 13: 413–422.
85. Jirikowic, T., McCoy, S. W., Price, R., Ciol, M. A., Hsu, L. Y., Kartin, D. Virtual sensorimotor training for balance. *Pediatr Phys Ther* **2016**, 28: 460–468.
86. Adnams, C.M., Sorour, P., Kalberg, W.O., Kodituwakku, P., Perold, M.D., Kotze, A., September, S., Castle, B., Gossage, J., May, P.A. Language and literacy outcomes from a pilot intervention study for children with Fetal Alcohol Spectrum Disorders in South Africa. *Alcohol* **2007**, 41: 403–414.
87. Kable, J.A, Coles, C.D, Taddeo, E. Socio-cognitive habilitation using the Math interactive learning experience program for alcohol-affected children. *Alcohol Clin Exp Res* **2007**, 31: 1425–1434.
88. Kable, J. A., Taddeo, E., Strickland, D., Coles, and C.D. Improving FASD children's self-regulation: piloting phase 1 of the GoFAR intervention. *Child Fam Behav Ther* **2016**, 38: 124–141.
89. McCoy, S.W., Jirikowic, T., Price, R., Ciol, M.A., Hsu, L.Y., Dellon, B., Kartin, D. Virtual sensorimotor balance training for children with Fetal Alcohol Spectrum Disorders: feasibility study. *Phys Ther* **2015**, 95: 1569–1581.

90. Keil, V., Paley, B., Frankel, F., O'Connor, M. J. Impact of a social skills intervention on the hostile attributions of children with Prenatal Alcohol Exposure. *Alcohol Clin Exp Res* **2010**, 34: 231–241.
91. Schonfeld, A. M., Paley, B., Frankel, F., O'Connor, M. J. Behavioral Regulation as a Predictor of Response to Children's Friendship Training in Children with Fetal Alcohol Spectrum Disorders. *Clin Neuropsychol* **2009**, 23: 428–445.
92. Wells, A. M., Chas off, I. J., Schmidt, C. A., Telford, E., Schwartz, L. D. Neurocognitive Habilitation Therapy for Children With Fetal Alcohol Spectrum Disorders: An Adaptation of the Alert Program(R). *Am J Occup Ther* **2012**; 66: 24–34.
93. O'connor, M. J., Quattlebaum, J., Castañeda, M., Dipple, K. M. Alcohol Intervention for adolescents with Fetal Alcohol Spectrum Disorders: project step up, a treatment development study. *Alcohol Clin Exp Res* **2016**, 40: 1744–1751.
94. Kerns, K. A., Macoun, S., MacSween, J., Pei, J., Hutchison, M. Attention and working memory training: A feasibility study in children with neurodevelopmental disorders. *Appl Neuropsychol Child* **2017**, 6: 120–137.
95. Coles, C. D., Kable, J. A., Taddeo, E., Strickland, D. C. A Metacognitive Strategy for Reducing Disruptive Behavior in Children with Fetal Alcohol Spectrum Disorders: GoFAR Pilot. *Alcohol Clin Exp Res* **2015**, 39: 2224–2233.
96. Coles, C.D., Strickland, D.C., Padgett, L., Bellmoff, L. Games that “work”: Using computer games to teach alcohol-affected children about fire and street safety. *Res Dev Disabil* **2007**, 28: 518–530.
97. Loomes, C., Rasmussen, C., Pei, J., Manji, S. and Andrew, G. The effect of rehearsal training on working memory span of children with fetal alcohol spectrum disorder. *Res Dev Disabil* **2008**, 29: 113–124.



98. Clark, E., George, M.A., Hardy, C., Hall, W.A., MacMillan, P.D., Wakabayashi, S., Hughes, K. Exploratory study of the effectiveness of a professional development program on the academic achievement and classroom behavior of students with Fetal Alcohol Spectrum Disorder in British Columbia, Canada. *Int J Alcohol Drug Res* **2014**, 3: 25.
99. Leenaars, L. S., Denys, K., Henneveld, D., Rasmussen, C. The impact of Fetal Alcohol Spectrum Disorders on families: evaluation of a family intervention program. *Community Ment Health J* **2012**, 48: 431–435.
100. O'Connor, M. J., Laugeson, E. A., Mogil, C., Lowe, E., Welch-Torres, K., Keil, V., Paley, B. Translation of an evidence-based social skills intervention for children with Prenatal Alcohol Exposure in a community mental health setting. *Alcohol Clin Exp Res* **2012**, 36: 141–152.
101. Petrenko, C. L., Pandolfino, M. E., Quamma, J., Olson, H. C. Emotional understanding in school-aged children with Fetal Alcohol Spectrum Disorders: a promising target for intervention. *J Popul Ther Clin Pharmacol* **2017**, 24: e21–e31.
102. Reid, N., Dawe, S., Harnett, P., Shelton, D., Hutton, L., O'Callaghan, F. Feasibility study of a family-focused intervention to improve outcomes for children with FASD. *Res Dev Disabil* **2017**, 67: 34–46.
103. Petrenko, C.L.M, Pandolfino, M.E, Robinson, L.K. Findings from the families on track intervention pilot trial for children with Fetal Alcohol Spectrum Disorders and their families. *Alcohol Clin Exp Res* **2017**, 41: 1340–1351.
104. Millians, M.N, Coles, C.D. Case study: Saturday cognitive habilitation program for children with prenatal alcohol exposure. *Psychol Neurosci* **2014**, 7: 163–173.
105. Kable, J. A., Taddeo, E., Strickland, D., Coles, C. D. Community translation of the Math interactive learning experience program for children with FASD. *Res Dev Disabil* **2015**, 39: 1–11.



106. Pomeroy, E.C., Parrish, D.E. Online training on Fetal Alcohol Spectrum Disorders for court-appointed special advocates volunteers. *Health Soc Work* **2013**, 38: 159–165.
107. Hanlon-Dearman, A., Malik, S., Wellwood, J., Johnston, K., Gammon, H., Andrew, K.N., Maxwell, B., Longstaffe, S. A descriptive study of a community-based home-visiting program with preschool children prenatally exposed to alcohol. *J Popul Ther Clin Pharmacol* **2017**, 24: e61–e71.
108. Kable, J.A., Coles, C.D., Strickland, D. and Taddeo, E. Comparing the Effectiveness of On-Line versus In-Person Caregiver Education and Training for Behavioral Regulation in Families of Children with FASD. *Int J Ment Health Addict* **2012**, 10: 791–803.
109. Pelech, W., Badry, D., Daoust, G. It takes a team: Improving placement stability among children and youth with Fetal Alcohol Spectrum Disorder in care in Canada. *Child Youth Serv Rev* **2013**, 35: 120–127.
110. Denys, K., Rasmussen, C., Henneveld, D. The Effectiveness of a Community-Based Intervention for Parents with FASD. *Community Ment Health J* **2011**, 47: 209–219.
111. Olivier, L., Curfs, L.M.G, Viljoen, D.L. Fetal alcohol spectrum disorders: prevalence rates in South Africa. *South African Med J* **2016**, 106: 103–106.
112. Dunn, C, Deroo, L, Rivara, F.P. The use of brief interventions adapted from motivational interviewing across behavioral domains: a systematic review. *Addiction* **2001**, 96: 1725–1742.
113. Burke, B.L, Arkowitz, H, Menchola, M. The efficacy of motivational interviewing: a meta-analysis of controlled clinical trials. *J Consult Clin Psychol* **2003**; 71: 843–861.
114. Martins RK, McNeil DW. Review of motivational interviewing in promoting health behaviors. *Clin Psychol Rev* **2009**; 29: 283–293.

115. Nolte, Ellen Mckee M. *Caring for people with chronic conditions*. [http://www.euro.who.int/\\_data/assets/pdf\\_file/0006/96468/E91878.pdf](http://www.euro.who.int/_data/assets/pdf_file/0006/96468/E91878.pdf) (2008, accessed 17 May 2018).
116. Jepson, R. G., Harris, F. M., Platt, S., Tannahill, C. The effectiveness of interventions to change six health behaviors: a review of reviews. *BMC Public Health* **2010**; 10: 538.
117. Barati H, Tajrishi P, Sajedi F. The effect of social skills training on socialization skills in children with Down syndrome. *Iran Rehabil J* **2012**; 10: 35-38. <https://irj.uswr.ac.ir/article-1-240-en.pdf> (2012, accessed 17 May 2018).
118. Olsson, N.C., Flygare, O., Coco, C., Görling, A., Råde, A., Chen, Q., Lindstedt, K., Berggren, S., Serlachius, E., Jonsson, U. Social skills training for children and adolescents with Autism Spectrum Disorder: a randomized controlled trial. *J Am Acad Child Adolesc Psychiatry* **2017**; 56: 585–592.
119. Rus-Calafell, M., Gutiérrez-Maldonado, J., Ribas-Sabaté, J., Lemos-Giráldez, S. Social skills training for people with schizophrenia: what do we train? *Behav Psychol / Psicol Conduct* **2014**; 22: 461–477.
120. DuPaul, G.J, Weyandt, L.L, Janusis, G.M. ADHD in the classroom: effective intervention strategies. *Theory Pract* **2011**; 50: 35–42.
121. Johnson, M.H., George, P., Armstrong, M.I., Lyman, D.R., Dougherty, R.H., Daniels, A.S., Ghose, S.S., Delphin-Rittmon, M.E. Behavioral management for children and adolescents: assessing the evidence. *Psychiatr Serv* **2014**; 65: 580–590.
122. Salmon, A., Clarren, S.K. Developing effective, culturally appropriate avenues to FASD diagnosis and prevention in northern Canada. *Int J Circumpolar Health* **2011**; 70: 428–433.

**Table S1: Quality assessment results for included studies**

Author	Selection bias	Design	Cofounders	Blinding	Data collection methods	Withdrawals and dropouts
<b>Prevention intervention</b>						
<b>Clinical</b>						
Mwansa-Kambafwile et al., 2011	Moderate	Weak	Weak	N/A	Moderate	Weak
Joya et al., 2016	Moderate	Strong	Strong	Moderate	Strong	Strong
Velasquez et al., 2010	Moderate	Strong	Strong	Moderate	Strong	Moderate
Payne et al., 2011	Moderate	Weak	N/A	N/A	Strong	Weak
Ondersma et al., 2015	Moderate	Strong	Strong	Moderate	Strong	Strong
Delrahim-Howlett et al., 2011	Moderate	Strong	Strong	Moderate	Strong	Strong
Tzilos et al., 2011	Moderate	Strong	Strong	Moderate	Strong	Strong
Hutton et al., 2014	Moderate	Strong	Strong	Weak	Strong	Moderate
Osterman et al., 2014	Moderate	Strong	Strong	Moderate	Strong	Weak
Osterman and Dyehouse, 2012	Moderate	Strong	Strong	Moderate	Strong	Strong
<b>Educational</b>						
Boulter, 2007	Moderate	Weak	N/A	N/A	Moderate	Weak
LaChausse, 2008	Strong	Weak	Strong	Moderate	Strong	Strong
Toyama and Sudo, 2013	Moderate	Weak	Strong	Moderate	Moderate	Weak
<b>Social</b>						
De Vries et al., 2013	Moderate	Moderate	N/A	N/A	Strong	Moderate
Montag et al., 2015	Moderate	Strong	Strong	Moderate	Strong	Strong
May et al., 2013	Moderate	Moderate	N/A	N/A	Strong	Moderate
Wilton et al., 2013	Moderate	Strong	Strong	Moderate	Strong	Moderate

Rasmussen et al., 2012	Weak	Moderate	N/A	N/A	Strong	N/A
Floyd et al., 2007	Weak	Strong	Strong	Moderate	Strong	Moderate
Hanson et al., 2012	Weak	Weak	N/A	N/A	Strong	Weak
Hanson et al., 2017	Weak	Weak	N/A	N/A	Strong	Weak
Letourneau et al., 2017	Strong	Weak	N/A	N/A	Strong	Strong
O'Connor and Whaley, 2007	Moderate	Strong	Strong	Moderate	Strong	Moderate
Hanson et al., 2013	Weak	Weak	N/A	N/A	Strong	weak
Farrell-Carnahan et al., 2013	Weak	Moderate	N/A	N/A	Strong	Moderate
France et al., 2014	Weak	Strong	Strong	Moderate	Strong	Weak
Dresser et al., 2011	Weak	Weak	Strong	Moderate	Moderate	Weak
Chersich et al., 2012	Weak	Weak	N/A	N/A	Strong	Strong
Tenkku et al., 2011	Weak	Weak	Strong	Moderate	Strong	Moderate
May et al., 2008	Moderate	Weak	N/A	N/A	Strong	Moderate
Ingersoll et al., 2013	Weak	Strong	Strong	Moderate	Strong	Strong
Russell et al., 2017	Moderate	Moderate	N/A	N/A	Strong	Moderate
<b>Management interventions</b>						
<b>Clinical</b>						
Nguyen et al., 2016	Strong	Strong	Strong	Strong	Strong	Strong
Zarnegar et al., 2016	Weak	Weak	N/A	N/A	Strong	Moderate
Wozniak et al., 2015	Moderate	Strong	Strong	Strong	Strong	Strong
Wozniak et al., 2013	Moderate	Strong	Strong	Strong	Strong	strong
Wilczynski et al., 2015	Weak	Weak	N/A	N/A	Strong	Strong
Yazdani et al., 2009	Strong	Weak	Strong	N/A	Strong	N/A
Kable et al., 2015	Moderate	Strong	Strong	Moderate	Strong	Weak
Connolly et al., 2016	Moderate	Weak	N/A	N/A	Strong	N/A
Nash et al., 2015	Weak	Strong	Strong	Moderate	Strong	Strong
Soh et al., 2015	Weak	Strong	Strong	Moderate	Strong	Moderate

Keiver et al., 2015	Weak	Strong	Strong	N/A	Strong	Strong
Nash et al., 2017	Moderate	Strong	Strong	Moderate	Strong	Weak
Doig et al., 2017	Moderate	Weak	Strong	Moderate	Strong	Weak
<b>Educational</b>						
Coles et al., 2009	Moderate	Strong	Strong	Moderate	Strong	Strong
Kerns et al., 2010	Weak	Moderate	N/A	N/A	Strong	Strong
Jirikowic et al., 2016	Moderate	Strong	Strong	Moderate	Strong	Strong
Adnams et al., 2007	Moderate	Strong	Strong	Moderate	Strong	Strong
Kable et al., 2007	Weak	Weak	Strong	Moderate	Strong	Strong
Kable et al., 2016	Moderate	Strong	Strong	Moderate	Strong	Strong
McCoy et al., 2015	Moderate	Weak	N/A	N/A	Strong	Weak
Kerns et al., 2017	Weak	Weak	N/A	N/A	Strong	Moderate
Coles et al., 2015	Moderate	Strong	Strong	Moderate	Strong	Strong
Wells et al., 2012	Moderate	Strong	Strong	Moderate	Strong	Strong
Keil et al., 2010	Weak	Strong	Strong	Moderate	Strong	Strong
O'Connor et al., 2016	Weak	Strong	Strong	Moderate	Strong	Strong
Schonfeld et al., 2009	Weak	Strong	Strong	Moderate	Strong	Weak
Coles et al., 2007	Weak	Strong	Strong	Moderate	Moderate	Strong
Loomes et al., 2008	Moderate	Strong	Strong	N/A	Strong	Strong
Clark et al., 2014	Moderate	Strong	Weak	Moderate	Strong	Strong
<b>Social</b>						
Leenaars et al., 2012	Moderate	weak	N/A	N/A	Moderate	N/A
O'Connor et al., 2012	Moderate	Strong	Strong	Moderate	Strong	Moderate
Petrenko et al., 2017	Moderate	Strong	Strong	Moderate	Strong	Weak
Reid et al., 2017	Moderate	Weak	N/A	N/A	Strong	Moderate
Petrenko et al., 2017	Moderate	Strong	Strong	Moderate	Strong	Strong
Millians and Coles, 2014	Moderate	Weak	N/A	N/A	Strong	N/A
Kable et al., 2015	Weak	Strong	Strong	Moderate	Strong	Strong
Pomeroy and Parrish, 2013	Moderate	Weak	N/A	N/A	Strong	Moderate

Hanlon-Dearman et al., 2017	Moderate	Strong	Strong	Moderate	Strong	Moderate
Kable et al., 2012	Moderate	Strong	Weak	Moderate	Strong	Moderate
Pelech et al., 2013	Moderate	Moderate	Strong	Moderate	Strong	Moderate
Denys et al., 2011	Moderate	Weak	N/A	N/A	Moderate	N/A

Confounders were not assessed for one-group studies, blinding was not assessed for one-group studies and case study and withdrawals/dropouts were not assessed for a case or retrospective studies

**Table S2: Data extracted from the included studies**

Author	Country	Study design	Sample size and population	Approach and follow up	Result
<b>Prevention intervention</b>					
<b>Clinical</b>					
Mwansa-Kambafwile et al., 2011	South Africa	Pre-post-test design	86 service providers with 23 control group	Training on the importance of a brief interview in the treatment of alcohol problems, the importance of contraception for AEP, and ways to improve the referral system. No follow-up reported	The finding showed the effectiveness of a brief motivational interview in building the capacity of service providers to be able to prevent and manage FASD.
Joya et al., 2016	Spain	Randomized control trial	168 pregnant women attending antenatal visit were included in the study	Some participants received single session motivational Intervention and other educational control condition. Mothers completed the Ethanol Timeline Follow-back for Ethanol consumption from the time of study enrolment until delivery. Follow up reported at 2 <sup>nd</sup> and 3 <sup>rd</sup> trimester of the pregnancy.	Single-session MI helped in decreasing alcohol consumption during pregnancy.
Velasquez et al., 2010	USA	Randomized control trial	830 women were randomized to either the motivational counselling (information plus counselling; IPC) group (n = 416) or the information only (IO) group (n= 414).	Each participant was offered four counseling sessions, plus the visit to a contraception provider, delivered over the course of 10 weeks. Women were also given informational brochures on alcohol, health, and available birth control methods. Follow-up was reported at 9 months.	Project CHOICES demonstrated the efficacy of a dual-focused adaptation of motivational interviewing to reduce the risk for AEP.
Payne et al., 2011	Australia	Survey	1483 health professionals	Educational resources were delivered to health professionals, Follow-up reported at 6 months.	Increased health professionals' knowledge, changed in attitudes



					and practice about FASD, and the advice they give to pregnant women about alcohol consumption.
Ondersma et al., 2015	USA	Randomised control trial	48 pregnant women who screened positive for alcohol risk at an urban prenatal care clinic. Participants were randomized by the software using simple randomization to either e-SBI or control conditions in a 1:1 ratio	The e-SBI intervention was built on principles of motivational interviewing and sought to facilitate self-change and/or treatment-seeking through a 20-minute interactive session, using various techniques. The three tailored mailings were sent. All mailings were tailored based on participant age, gestational age, race, quit goal, level of social support for stopping alcohol use, frequency of binge drinking, and self-efficacy for quitting. The control condition provided a time-matched (20 minutes) and moderately interactive intervention focused on infant nutrition, with no mention of alcohol use during pregnancy.	This pilot trial demonstrated the acceptability and preliminary efficacy of a computer-delivered screening and brief intervention (e-SBI) plus tailored mailings for alcohol use in pregnancy.
Delrahim-Howlett et al., 2011	USA	Double blinded randomized trial	150 non-pregnant women between ages 18 to 44 were randomized into 2 groups.	Participants in the intervention group received feedback on their alcohol consumption, health risks associated with risky alcohol use, and social norms information. Participants in the control group received general information (non-personalised) about alcohol consumption. Follow-up consisted of telephone based assessment of current drinking at 1 and 2 months post baseline assessment and intervention.	The results of this study demonstrate that web-based assessment of alcohol consumption among low-income women of reproductive age, as represented by WIC clients, is feasible and acceptable. The findings also suggest that detailed and interactive assessments of alcohol consumption may be sufficient for the reduction of risky drinking within this population without personalized feedback.
Tzilos et al., 2011	USA	Randomized control trial	Participants were 50 pregnant women ages 18 and 45 attending an inner-city prenatal care clinic.	The intervention group received the computer-based brief motivational intervention specifically tailored to pregnant women in a number of ways. The participants in the control group were administered a series of questions about television show preferences and viewed a brief series of videos of popular entertainers/shows. Also, they were given a brochure specifically designed to facilitate reductions in drinking during pregnancy. Follow up at 1 month	Participants in both conditions significantly decreased alcohol use at follow-up, with no group differences; however, birth weights for infants born to women in the intervention group were significantly higher



Hutton et al, 2014	USA	Randomized control trial	426 women (18–44 years of age) were enrolled at two STD clinics	Participants received a two-session counseling model, two booster phone calls and one contraception visit. Follow-up visit at 3 and 6 month	The outcome data from this demonstration project show that Project CHOICES can successfully be translated into the STD clinic setting and is effective.
Osterman et al., 2014	USA	Randomized control trial	Pregnant women who drank any amount of alcohol in the previous year (n=122) were randomized to an intervention or comparison group.	Women randomized to the MI group received a one-time session of MI which lasted approximately 30 minutes. Follow at 30 day post-baseline and 30 day postpartum	MI was not found effective in decreasing alcohol use, low levels of reported alcohol use
Osterman and Dyehouse 2012	USA	Randomized control trial	67 pregnant women who reported previous-year alcohol use were randomly assigned to an MI intervention or comparison group	The MI intervention based on the four principles of MI—establishing empathy, developing discrepancy, rolling with resistance, and supporting self-efficacy lasted approximately 30 minutes. Both groups were assessed at baseline and 4- to 6-week follow-up for alcohol use and mechanisms of behavior change	MI was not found effective in decreasing prenatal drinking behaviors
<b>Educational</b>					
Boulter, 2007	USA	Non-randomized controlled trial	642 students (267 males, 375 females) from five different middle schools and one high school	40 minutes presentation, presented in a series of sequential steps. Follow-up reported at six weeks	Increased middle school and high school students' knowledge Of the effects of alcohol consumption during pregnancy.
LaChausse, 2008	USA	Longitudinal quasi-experimental design (two groups)	114 culturally diverse youth	Teen peer educators used the Fetal Alcohol Spectrum Teaching and Research Awareness Campaign (FASTRAC) to teach their fellow students. The FASTRAC intervention solely consisted of this 45-minute PowerPoint presentation. No additional learning activities or materials were used. Follow up reported at 1 week	The program increased participants' knowledge regarding FAS but had no significant effect on participants' attitudes, beliefs about the dangers of FASD or intention to use alcohol during pregnancy.
Toyama and Sudo, 2013	Japan	Pre-post-test design	257 pregnant women were divided into three groups (tailored leaflet [84], non-tailor leaflet [102] and control group [71])	Participants were asked to read tailored and non-tailor educational leaflets on FASD. Follow-up at 3 to 4 month	Our follow-up survey after delivery showed that women retained their knowledge for a long time after reading the leaflets
<b>Social</b>					
De Vries et al., 2013	South Africa	Prospective study	67 women (pregnant women) between ages 18 to 40 years	Self-Administered Questionnaire (SAQ) and the Alcohol Use	Alcohol consumption drops significantly when compared before

			who are at high risk for bearing a child with FASD	Disorders Identification Test (AUDIT) were used to assess alcohol use. Follow up reported at 6, 12, and 18 months respectively	pregnancy to the second and third trimesters
Montag et al., 2015	USA	Randomized control trial	263 women American of Indian/Alaska Native (AIAN) descents were recruited	Baseline, web-based and follow up questionnaires were used to access information on birth control use and alcohol consumption. Follow up reported at 1, 2, and 6 months	Randomization to the SBIRT did not result in a significantly different change in risky drinking behaviors
May et al., 2103	South Africa	Prospective study	41 women (pregnant women) between ages 18 to 40 years who are at high risk for bearing a child with FASD	The Alcohol Use Disorders Identification Test (AUDIT) was used to access the drinking problem. The Happiness Scale and Psychological Pain were used to access the participants' mental health. Blood Alcohol Concentrations (BAC) were estimated by the BACCUS technique. Follow up reported at 6, 12, and 18 months respectively.	Case management was particularly valuable for pregnant women, as statistically significant reductions in alcohol risk were obtained.
Wilton et al., 2013	USA	Randomized control trial	Women between the ages of 18 and 44 who were drinking above recommended levels	A timeline follow-back (TLFB) methodology was used to document the alcohol consumption and sexual intercourse of participating women. Follow up reported at 6 months	Telephone-based brief intervention may be equally successful and cost-effective in reducing the risk of an alcohol-exposed pregnancy and thus fetal alcohol syndrome.
Rasmussen et al., 2012	Canada	Retrospective analysis	70 women between the ages of 18 and 41	Clients were then assigned a program mentor who began to build a relationship with the client. Mentors collected additional intake assessment data within the first few weeks of the program (including Needs Assessments and Goals Assessments). Follow up reported up to 28 months	The First Steps program demonstrated promising outcomes for women at-risk for giving birth to a child with FASD
Floyd et al., 2007	USA	Randomized control trial	830 non-pregnant women, aged 18 – 44 years	The intervention was delivered over 14 weeks, with approximately 2 to 3 weeks between sessions. The counseling sessions and the contraception consultation visit were each 45 to 60 minutes.	Brief motivational intervention can reduce the risk of an AEP.
Hanson et al., 2012	USA	Survey	119 American Indian women of childbearing age (18-44)	The participants were asked to respond to the Likert-scale questions regarding the media campaign. No follow-up Reported	The finding indicated that the campaign decreases the participants' drinking behaviors.
Hanson et al., 2017	USA	Pre-post-test design	A total of 193 non-pregnant American Indian women enrolled in the OST CHOICES	Interventionists provided 2 or 4 CHOICES sessions, per the preference of the site and stakeholder input.	Findings showed a significant decrease in AEP risk from baseline at both 3- and 6-month follow-ups.

			Program, and all were at risk for AEP because of binge drinking and being at risk for unintended pregnancy.	The sessions were held approximately 1 to 2 weeks apart. Follow up reported at 3 and 6 months	
Letourneau et al., 2017	USA	Dichotomized control trial	89 women who identified as Hispanic between the ages of 18-46 years	The Timeline Followback (TLFB) was used to assess daily drinking and The Quick Drinking Screen (QDS) was used to measure alcohol use and collect aggregate drinking data. Follow up reported at 6 months	The finding showed at the 6-month follow-up, two thirds (66 %) of all Hispanic women had reduced their overall risk of an AEP, primarily by practicing effective birth control.
O'Connor and Whaley, 2007	USA	Randomized control trial	345 pregnant women who were participants in the Public Health Foundation Enterprises Management Solutions Special Supplemental Nutrition Program for Women, Infants, and Children	Participants received brief intervention consisted of 10- to 15-minute sessions of counseling by a nutritionist, who used a scripted manual to guide the intervention. Follow up reported at 3 <sup>rd</sup> trimester of the pregnancy.	Increased individual's motivation to change unhealthy behavior.
Hanson et al., 2013	USA	Descriptive longitudinal study	231 non-pregnant American Indian women	Participants responded to drinking and contraception questions through the telephone and then received intervention materials via mail. Follow up reported at 3, 6, 9, and 12 months	The intervention was successful in modifying self-reported drinking and contraception behaviors.
Farrell-Carnahan et al., 2013	USA	Prospective	Women between the ages of 18 and 44 years who drink and who also have sex	The intervention was conducted during one 60-min telephone call and consisted of the EARLY intervention translated into a mail and telephone-administered format. Follow up reported at 3 and 6 months	Remote delivery of intervention was feasible, and the translated remote intervention may reduce AEP risk
France et al., 2014	Australia	Randomized control trial	354 women of childbearing age who were not pregnant (n = 354) and 116 pregnant women	Intentions and confidence were measured by single-item questions that were measured on a five-point scale. The AUDIT-C alcohol screening tool was used to access the drinking problem. No follow Up reported	Finding provides important insights into the components that enhance the persuasiveness and effectiveness of messages aimed at preventing prenatal alcohol exposure

Dresser et al., 2011	USA	Pre-post-test (two groups)	Experimental (n = 148) and comparison (n = 183) licensed alcohol establishments staff. 1330 alcohol servers were provided comprehensive FAS prevention training	Each person attending the 2-hour training session received a stipend and a laminated card with FAS facts and strategies for servers. Follow up reported at 1, 6, and 12 months	Supplemental responsible beverage service training for alcohol can be effective in reducing the serving of alcohol to visibly pregnant women.
Chersich et al., 2012	South Africa	Pre-post-test design	809 children were enrolled	A pamphlet and poster were designed and distributed everywhere in the community. Regular articles focusing on FASD prevention were published in local community newspapers. Follow up reported at 9 and 18 months	Universal prevention might reduce FASD by ~30% and have population-level effects.
Tenkku et al., 2011	USA	Pre-post intervention	458 women between the ages of 18 and 44 who were at risk for an AEP were eligible for participation	The intervention was designed using tailored motivational messaging and consisted of four modules—Where Am I Now, Decisional Analysis, Goal Setting and Planning, and Overcoming Barriers. Follow up reported at 4 months	Mail and online versions of the intervention were equally successful at reducing the risk for an AEP
May et al., 2008	USA	Non-randomized	172 women with an average age of 25 years	Two field staff members (a prevention site manager and a case manager) were hired at each of the four prevention communities to carry out all three levels of the prevention activities. Follow-up at 6, 12, 18, and 24 month	70% of the women who were not currently pregnant were protected from having a child with FAS by not drinking, using birth control, or both Enhanced CM can be an efficacious intervention for women at high risk for births of children with an FASD.
Ingersoll et al., 2013	USA	Randomized control trial	Sexually active women, ages 18–44, at risk for AEP (N=217) were randomized to motivational interviewing plus assessment feedback (EARLY), informational video, or informational brochure conditions.	EARLY was a 60-minute, face-to-face, individual, one-session, MI plus assessment feedback counseling intervention. Participants in the informational video condition viewed three videos about women and alcohol misuse, AEP and FASD, and general women's health. Participants in the informational brochure condition received informational brochures with content on FASD, contraception options, and local women's health, mental health, and substance abuse treatment agencies. Follow-up at 3 and 6 months	All interventions were associated with decreased DDD, ineffective contraception rate, and AEP risk

Russell et al., 2017	USA	Pre-post-test	239 youth and adult Hispanic females, ages 15 – 44 years participants who were receiving substance use intervention and/or treatment services from at least one of seven different programs operated by a single non-profit social services agency	Participants received four counseling sessions and one contraception visit. Follow-up at 12 month	FASD Prevention Program demonstrated increased effectiveness of birth control use and decreased use and abuse of alcohol.
<b>Management intervention</b>					
<b>Clinical</b>					
Nguyen et al., 2016	USA	Randomized, double-blind, placebo-controlled clinical trial	55 children between age 5 to 10 years participated. Choline (n = 29) or placebo (n = 26) treatment arms.	Participants in the choline group received 625 mg choline/d for 6 weeks, whereas subjects in the placebo group received an equivalent dose of an inactive placebo treatment. No follow-up reported.	The finding shows the current study does not support that choline, administered at a dose of 625 mg/d for 6 weeks, is an effective intervention for school-aged (5–10 y old) children with FASD.
Zarnegar et al., 2016	USA	Pre-post-test design	Children's ages ranged from 10 to 53 months. Caregivers' ages were between 32 and 58 years	Children and caregivers received Child-Parent Psychotherapy (CPP), and caregivers also received Mindful Parenting Education (MPE). Follow-up reported at 6 month	Findings show that children's adaptive, motor, communication, and cognitive skills have improved in a short amount of time.
Wozniak et al., 2015	USA	Double-blind, randomized, placebo-controlled.	Children (2.5–5 years at enrollment) with FASD (n = 60) who received 500 mg choline or a placebo daily for 9 months	Children with FASD (n = 60) who received 500 mg choline or a placebo daily for 9 mo. Outcome measures were Mullen Scales of Early Learning (primary) and the elicited imitation (EI) memory paradigm. No follow-up reported.	Finding shows that the administration proved feasible, and choline was well tolerated.

Wozniak et al., 2013	USA	Double-blind, randomized, placebo-controlled.	20 children ages 2.5–4.9 years Participants were randomly assigned to 500 mg. choline or placebo daily for nine months	Participants were randomly assigned to 500 mg. choline or placebo daily for nine months (10 active; 10 placebo). No follow-up reported.	The finding shows that choline supplementation at 500 mg per day for nine months in children ages 2–5 is feasible and has high tolerability
Wilczynski et al., 2015	Poland	Pre-post-test design	20 children (14 boys, 6 girls) aged 4–5 years	9 school-term months of treatment, general scholastic tests, teacher and parent questionnaires, classroom observations and specific language and literacy tests were administered to the participants. No follow-up reported.	The finding shows significant cognitive improvements in specific areas targeted by classroom interventions
Yazdani et al., 2009	Canada	Dichotomized control trial	Mother with alcohol used during pregnancy (n=28) and Mother without alcohol used during pregnancy (n=10)	Children were tested on either the BSID-III or WPPSI-III assessment tool. No follow-up reported	This pilot suggests that early intervention may mitigate some of the well-described damages caused by heavy in utero alcohol exposure.
Kable et al., 2015	Ukraine	Randomized controlled trial	Women of moderate to heavy drinking (n = 301) and low/unexposed (N = 313)	Alcohol-using and nondrinking women were randomized to one of three multivitamin/mineral supplement groups: none, multivitamins/minerals (MVM), and multivitamin/minerals plus choline. Children (N = 367) were tested at 6 months with the Bayley Scales of Infant Development (2nd ED. Follow-up reported at 6 months	Multivitamin/mineral supplementation can reduce the negative impact of alcohol use during pregnancy on specific developmental outcomes
Connolly et al., 2016	USA	Case study	One child (3 years 10 months)	The child received 15-hr of intensive one-on-one applied behavior analysis (ABA) therapy each week for 23 months. Reported follow-up at 9 months	Finding the indicated rapid skill acquisition across several areas of functioning.
Nash et al., 2015	Canada	Randomized control trial	Twenty-five children aged 8–12 years diagnosed with an FASD were assigned in alternating sequence to either an immediate treatment (TXT) or a delayed treatment control (DTC) group	Children received 12 one hour sessions over 14 weeks treatment specifically designed to target self-regulation, a component of executive functions (EF). Reported follow up at 6 months.	The result shows EF disabilities in children with FASD can be remediated through a targeted treatment approach aimed at facilitating self-regulation skills.
Soh et al., 2015	Canada	Randomized control trial	Twenty-nine children with FASD were assigned to either an immediate-treatment (TX) or delayed-treatment control (DTC) group (DTC).	All received a structural MRI scan and baseline neuropsychological testing, following which the TX group underwent 12 weekly 1.5-h sessions of the Alert Program for Self-Regulation. After treatment or	Results suggest that Alert led to improvements in post-intervention testing of self-regulation skills and typical brain development in treated children.



				a period of 14 weeks, all received a repeat scan and post-intervention testing.	
Keiver et al., 2015	Canada	Randomized control trial	Twenty-six children (ages 6-14) years with FASD (treatment) and twenty 24 children without FASD (Control) (ages 6-14) years	The treatment group participated in 8-weeks motor skills intervention—consist of two 1.5-hour sessions per week for 8 weeks. Pre/post-testing	Cortisol levels were significantly higher in the afternoon and at bedtime in children with FASD with confirmed prenatal exposure to high levels of alcohol, compared with Control children or children with FASD with exposure to low or unknown levels of alcohol.
Nash et al., 2017	Canada	Randomized control trial	Twenty-one children with FASD aged 8–12 years were randomized to the Alert® treatment (TXT; n = 10) or waitlist-control (WL; n = 11) conditions.	Participants received 12 individualized 1.5-h weekly sessions that provide program-specified activities focusing on emotion sensitization and recognition, behavioral regulation, and social problem solving.	Findings suggest Alert® does improve functional integrity in the neural circuitry for behavioral regulation in children with FASD.
Doig et al., 2017	Canada	Retrospective study	27 children with FASD. Participants were primarily male and ranged in age from 5 years 6 months to 14 years 5 months.	Data were extracted from the medical records of 27 children with FASD who had been referred to an ADHD medication service	Findings suggest that inattention may be less responsive to ADHD medication.
<b>Educational</b>					
Coles et al., 2009	USA	Randomized control trial	Children between the age of 3 to 10 years with FASD, their caregivers and teachers participated in the programme. 87 children were recruited, 61 children participated in the intervention, 56 children completed study 1 post testing and 54 children participated in the study 2 post testing	The average duration between Pre-test and Post Test 2 was about 13 months For mathematics, intervention families were randomized to either the math intervention group or the standard psychoeducational treatment contrast. Standard psychoeducational treatment consisted of a comprehensive neurodevelopmental evaluation and assistance with educational placement and development of the individualized educational plan within the context of their home school. In addition to these services, those in the math intervention group received 6-weeks of tutoring services. Follow-up reported at 6 months	Findings show that the current study provides evidence that the initial results were not transitory as might be a concern for such a short-term intervention. And, it appears that providing parents with appropriate tools for working with their children can result in significant improvement in child behavior in both home and school.
Kerns et al., 2010	Canada	Quasi-experimental design	12 students were identified and enrolled in the study. The final sample was comprised of 10	The intervention program was delivered via a laptop computer for adopted parents and teachers. They	Results show improvement in cognitive performance in children with FASD on measures of



			children (six males, four females) Two dropped out.	returned the short follow-up evaluation questionnaire. No follow-up reported.	distractibility, sustained attention, divided attention, working memory, math, and reading.
Jirikowic et al., 2016	USA	Randomized control trial	29 children with FASDs, aged 8 years to 15 years 8 months	Children with FASD received STABEL training in a university laboratory, or home, or were controls. The Movement Assessment Battery for Children–2nd edition (MABC-2) and Pediatric Clinical Test of Sensory Interaction for Balance–2 (P-CTSIB-2) were analyzed by group (lab, home, and control), session (pre-STABEL, 1-week post-STABEL, and 1-month post-STABEL), and group-by-session interaction. Reported follow-up after 1 week and 1 month	Preliminary results support improved sensory adaptation, balance, and motor performance.
Adnams et al., 2007	South Africa	Randomized control trial	65 third grade, nine-year-old children	9 school-term months of treatment, general scholastic tests, teacher and parent questionnaires, classroom observations and specific language and literacy tests were administered to the participants. No follow up reported	The finding shows significant cognitive improvements in specific areas targeted by classroom interventions.
Kable et al., 2007	USA	Pre-post-test design	61 children 3 to 10 years of age	Children received a neurodevelopmental evaluation to assist with their educational planning. Testing was done over 2 days, requiring approximately 4 to 5 hours to complete. No follow-up reported.	Finding reveals psych educational the program may help to remediate deficits associated with prenatal alcohol exposure.
Kable et al., 2016	USA	Randomized control trial	Children (n=30), ages 5 to 10, with FASD were recruited and randomly assigned to one of three groups.	Children assigned to one of the two intervention groups attended 5, 1-hour long individualized computer instructional sessions while their parents were being trained. No follow-up reported.	The result showed that children who received computerized instruction consistent with the parent training demonstrated greater self-regulation improvements than those receiving incongruent computerized instruction
McCoy et al., 2015	USA	Pre- and post-test design	Eleven children with FASD and 11 children with TD, aged 8 to 16 years	Children completed 30 minutes of STABEL training. The children answered questions about their experience using STABEL. No follow Up reported.	Children with FASD showed higher entrainment gain to vestibular stimuli
Kerns et al., 2017	Canada	Pre- and post-test	10 Children (ages 6–13)	Game-based process specific intervention as a potentially effective treatment and useful tool for supporting cognitive improvements in children with FASDs. No follow-up reported	EA provides children with instruction in metacognitive strategies to improve gameplay, with participants completing approximately 12 hours of training

					over an 8 to 12 school week period.
Coles et al., 2015	USA	Randomized control trial	30 children between the ages of 5 to 10 years	Volunteer families were randomly assigned to 1 of 3 groups: (i) GoFAR; (ii) FACELAND; or (iii) CONTROL. GoFAR group received instruction via a computer program that was designed specifically for the intervention, the FACELAND group received instruction via a computer program, and the control group received no interventions. No report on the long-term effect of the intervention.	Result suggests that GoFAR game supported positive behavior change and effective in reducing disruptive behaviors.
Wells et al., 2012	USA	Randomized control trial	78 children between 6 to 11.9 years participated in the program. 40 children in the treatment group and 38 in the control	Caregiver and child groups lasted approximately 75 minutes and were conducted concurrently by doctoral- and masters-level therapists, including an occupational therapist for 12 weeks. The Behaviour Rating Inventory of Executive Function was used to measure indicators for executive functioning. The Roberts Apperception Test for Children was used to measure adaptive and maladaptive functioning Follow-up measures were administered 7 months after enrolment.	The findings show improving executive functioning and emotional problem-solving in children with FAS or ARND.
Keil et al., 2010	USA	Randomized control trial	100 children (51% male) with PAE between the ages of 6 and 12 years	The CFT group received 12 sessions, of 90 minutes in length, delivered over the course of 12 weeks. 3-month follow-up reported.	Social skills intervention improves deficits in social information-processing among individuals with PAE.
O'Connor et al., 2016	USA	Randomized control trial	54 adolescents participated. 18 were classified moderate/light drinkers and 36 were classified as abstinent/infrequent drinkers	The intervention consisted of 6, 60-minute sessions delivered over the course of 6 weeks. Caregivers and adolescents attended separate but concurrent sessions. Reported follow-up at 3 months.	The finding shows a reduction in alcohol use and its negative consequences in adolescents with FASD who were more experienced in the use of alcohol.
Schonfeld et al., 2009	USA	Randomized control trial	100 children between the ages of 6 and 12	Children in the CFT group received 12 sessions, 90 minutes in length, delivered over the course of 12 weeks. Following a 12-week waiting period, children in the DTC group received treatment identical to the CFT group. No follow Up reported.	The objective was achieved. Finding shows the ability to control impulses, solve problems flexibly, and monitor emotional responses significantly predicted improvement in social skills and reduction in

					problem behaviors following Children's Friendship Training (CFT)
Cole et al., 2007	USA	Randomized control trial	32 children (ages 4-10 years) with FAS or pFAS. 16 children allocated to street safety and 16 to fire safety computer games,	Played a virtual reality game of fire safety and street safety. Follow-up test at 1 week	Children showed significantly better knowledge of the game to which they were exposed, immediately and at follow-up
Loomes et al., 2008	Canada	Randomized control trial	33 children previously diagnosed with ARND, neurobehavioral, or static encephalopathy. 17 Experimental, 16 controls; Age ranges from 4 to 11 (mean age of 7 years)	Experimental group-rehearsal training across 10 days.	Experimental group showed significant increase in digit span scores over the 3 sessions compared to the control group
Clark et al., 2014	Canada	Randomised control trial	Treatment group (6 teachers and 7 children). Comparison group (6 teachers and 6 children). The students were diagnosed with FAS. Age ranges from 6 to 12 (mean age of 7)	Teachers received professional development focused on classroom environment over one school year. They partook in 2 full-day and 4 half-day workshops and weekly mentor-teacher meetings. Pre-, mid- and post-testing	Substantial improvements in adaptive skills and substantial decreases in school problems as reported by the teachers
<b>Social</b>					
Leenaars et al., 2012	USA	Retrospective case analysis	186 families parenting at least one child with FASDs. Mean age was 46 years (Range 24-69 years). 30% of the caregivers were foster parents, 23% adoptive, 19% biological mother or father, 15% kinship or a biological relative, and 9% were permanent guardianship order	Participants rate Needs and Goals and Stress Scale and Client Satisfaction Surveys. No follow up reported	Result reveals a significant decrease in caregiver stress from pre- to post-program a significant decrease in needs and increase in goal attainment from pre- to post-program
O'Connor et al., 2012	USA	Randomized control trial	Of the 85 children were recruited 41 were assigned to the CFT condition and 44 were assigned to the SOC condition. Of that number, 67 children (CFT, n = 32; SOC, n = 35) completed the 12-week study	Both the CFT and the SOC conditions consisted of 12 sessions, of 90 minutes each, delivered over the course of 12 weeks. No follow Up reported.	The result showed children participating in CFT showed significantly improved knowledge of appropriate social skills, improved self-concept, and improvements in parent-reported social skills compared to children in the SOC condition.

Petrenko et al., 2017	USA	Randomized control trial	56 children (6–13 years) with FASD	EU was measured by the Kusche Affective Inventory-Revised (KAI-R25), as part of a larger test battery. Follow up reported at 17. 64 months	Treatments targeting emotional understanding (EU) may benefit children with FASD as components within a comprehensive, tailored intervention focused on child self-regulation and caregiver behavior management.
Reid et al., 2017	Australia	Mixed method	Three families with FASD children. Age ranges from 9 to 12 years	Families attended 1 to 2 hours weekly or fortnightly session. 86-item Behaviour Rating Inventory of Executive Function was used to evaluate Children's executive functioning abilities in their daily activities. The 64-item Youth Outcome Questionnaire –parent report was used as a repeated measure to evaluate the children's psychosocial distress. Parents were an interview. Follow up was reported at 3 months	The result provides preliminary support for the feasibility of an adapted version of the PuP program.
Petrenko et al., 2017	USA	Randomized control trial	30 children with FASD or prenatal alcohol exposure (PAE) (ages 4 to 8) and their primary caregivers were enrolled.	The 30-week intervention integrates scientifically validated bimonthly, in-home parent behavioral consultation, and weekly child skills groups. Follow-up reported at 9 months	Findings suggest that the Families on Track Program had the largest impact on the child-related outcomes of emotion regulation and self-esteem
Millians and Coles, 2014	USA	Case Study	Five children between the ages of 10 to 13 years. With FASD or suspected participated in the program	The program occurred for 20 Saturdays from September 2005 through May 2006. All of the children were administered the Matrix Analogies Test, Expanded Form (MAT: EF) Two children were administered the Test of Reading Comprehension, Third Edition (TORC-3). The Test of Word Reading Efficiency (TOWRE) was administered One child was administered the Gray Oral Reading Test, Fourth Edition. One Wechsler Individual Achievement Test, Second Edition (WIAT-II). Reported follow-up at 6months.	The program showed clinically significant gains in learning and academics.
Kable et al., 2015	USA	Randomized control trial	60 participants	60 participants were randomly assigned to one of the three treatment groups: the MILE program administered at a specialty care center (Center MILE)	The finding shows that MILE was well-received and effective in

				or in the community (Community MILE), or to parent math instruction only (Parent Instruction). Children received a neurodevelopmental evaluation to assist with their educational planning. Testing was done over 2 days, requiring approximately 4 to 5 hours to complete.	producing positive treatment outcomes.
Pomeroy and Parrish, 2013	USA	Pre- and post-test design	338 CASA volunteers and staff from 55 CASA locations in Texas,	A three-hour online FASD training on CASA workers' knowledge of FASD and their comfort and confidence in identifying children with FASD for referral, advocating for them, and linking. No follow up reported	The results support the potential of this online training to enhance CASA volunteers' ability to help children with FASD
Hanlon-Dearman et al., 2017	Canada	Randomized controlled trial.	Twelve caregiver-child dyads completed the FASD adapted COS intervention. Children's ages ranged from 2–5 years	The family received behavioural assessment and interventions focused on education regarding PAE related challenges, as well as proactive and reactive behavioral intervention strategies. Follow-up reported at 3 months.	Parents also showed an improvement in their ability to attend to their child's cues
Kable et al., 2012	USA	Randomized controlled trial	76 parents of children with FAS or pFAS (24 community standard; 23 workshop; 29 Internet training). Mean age of 7 years	Community standard received information only, workshop and Internet group received 2 x 2 hour sessions on behavior, information, and advocacy.	All groups reported improvement in knowledge of behavioral learning principles. Internet and workshop groups reported significant improvement in knowledge of FASD and parent advocacy.
Pelech et al., 2013	Canada	Cohort analytic	182 participants. 98 children and youth in care (intervention group) and 84 (comparison Group). The participants were either diagnosed or suspected of FASD. Mean age is 11 years	Promising practices enhanced child welfare practices to improve placement stability. Tracked placement changes during 15-month period prior and compared to placement changes during project implementation	Significant decline in number of placement changes among children in the intervention group
Denys et al., 2011	Canada	Retrospective case-file analysis	24 Parents with FASD or suspected FASD (1 male, 23 female). Age ranges from 19 to 47 range. (mean age of 30 years)	Step-by-step—3-year program; mentors work with families to help access support and services.	Significant reduction in client's needs (e.g., housing, financial issues, mental health issues, addiction) and significant increase in client's goals (e.g., parenting, personal skills management, assessment, self-care and health)

# SECTION III

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## **DEVELOPMENT AND IMPROVEMENT OF PROTOTYPE GUIDELINE**

This section encompasses the phases two and three of the study. It consists of only one chapter. The information gathered from the four studies in section II was used to develop a draft guideline. We used the draft to engage with local and international experts re FASD management and prevention. They provided guidance and comments to improve the prototype. After that, we invited the experts on FASD to participate in a modified Delphi approach to finalise the guidelines. The refined prototype was converted into statements and the experts rated these statements on a 5-point Likert scale in two rounds. The data generated from the above exercises formed the chapter six.





# CHAPTER SIX

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A Guideline for the Prevention and Management of Fetal Alcohol Spectrum Disorder in South Africa: A modified WHO's approach to guideline development. BMC Health Services Research (Under review)

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## Abstract

**Background:** Fetal Alcohol Spectrum Disorder (FASD) is a severe public health problem globally, with South Africa having the highest prevalence. Government programmes to prevent and manage FASD remain limited because of the lack of a specific policy. Therefore, we developed a guideline to inform policy on the prevention and management of FASD in South Africa.

**Methods:** We applied a modified version of the World Health Organization's approach to guideline development in three phases. In the first phase, we designed the initial guideline prototype. To do this, we conducted an in-depth interview with policymakers and a focus group with relevant service providers on policy requirements for FASD, a document review of policies on FASD and a scoping review of various interventions for FASD. In phase 2, we refined the initially formulated guideline prototype through a discursive approach with seven local and international experts on FASD. Phase 3 involved refining the prototype using a modified Delphi approach. Forty-three and forty-one experts participated in rounds 1 and 2 of the Delphi approach, respectively. The acceptable consensus for each included policy statement was 85%.

**Results:** We identified three aspects of the proposed guideline, which are the approaches and guiding principles, the prevention measures and the management measures. The guideline proposes that a FASD policy should consider lifespan needs, be culturally diverse and sensitive, collaborative,



evidence-based, multi-sectoral and address social determinants of health contributing to FASD. The essential components of FASD prevention policy consist of awareness and education of the dangers of drinking alcohol, access to treatment for alcohol problems and training of service providers. The management components include capacity building related to diagnosis, educating parents re the needs and management, appropriate referral pathways, training of teachers re classroom management, and support for parents and individuals with FASD.

**Conclusion:** FASD in South Africa deserves urgent attention, developing a specific policy to guide programmes could enhance and coordinate the efforts towards preventing and managing FASD. The guideline has the potential to assist policymakers in the development of a comprehensive and multi-sectoral policy for prevention and management of FASD, considering the consensus obtained from the experts.



## Introduction

Globally, one in every thirteen alcohol-exposed pregnancies results in a Fetal alcohol spectrum disorder (FASD) [1]. In 2017, the global prevalence of FASD was 8 per 1000 children and youth [1]. In 2016, the Foundation for Alcohol Related Research (FARR), estimated that six million individuals were affected by FASD in South Africa [2] ranging from 29 to 290 per 1000 live births [3]. The prevalence of FASD varies from one province to another, with the Western Cape and Northern Cape provinces the most affected. In 2017, the prevalence of FASD in Grade 1 pupils in the Western Cape was estimated to be 196 to 276 per 1000 [4], while in the Northern Cape the prevalence was estimated at 63.9 per 1000 Grade 1 pupils in 2015 [5].

FASD is considered a hidden disability because there are in most cases no noticeable physical manifestations [6–9] thus increasing the chances of missed diagnosis or misdiagnosis [10–13]. Misdiagnosis and missed diagnoses prevent individuals from accessing early and appropriate services [14]. To diagnose any of the FASD (fetal alcohol syndrome {FAS}, partial FAS, {PFAS}, alcohol-related neurodevelopmental disorder {ARND} and alcohol-related birth defects {ARBD}), individuals must meet all or some of the range of identified criteria [15–17]. These criteria include documented or undocumented prenatal alcohol exposure, prenatal and or postnatal growth deficiency, deficient brain growth and neurobehavioral impairment – with or without cognitive impairment [15–17]. The requirements for prevention, diagnosis and management suggests a multi-sectoral approach [3, 7, 18–21].

While the South African government endeavours to address the high prevalence of FASD, its responses through policy have not been adequate [22, 23]. Despite the availability of context-relevant evidence-based interventions such as case management and universal prevention approaches to prevent FASD [24, 25], there is a lack of policy and resources to guide the expansion and implementation of these interventions to many parts of the country. There is evidence that current prevention and

management interventions are informed by genetic-related and other generic policy documents [19, 26]. For instance, the Human Genetics Policy Guidelines for the Management and Prevention of Genetic Disorders, Birth Defects and Disabilities and the Mini Drug Master Plan covers FASD as a genetic disease. The National Department of Health also recognises FASD as one of the ten focal genetic conditions. The Western Cape government has listed FASD as a provincial health priority in its services regarding birth defects [27]. Because these documents reflect FASD in a generic manner, they do not support the holistic and comprehensive (multi-sectoral) approach required to address FASD [23, 28, 29].

In addition to the efforts of the South African national and provincial governments, non-profit organisations (NPO) provide various levels of contributions to address FASD in South Africa. The South African government provides partial funding to some of these organisations. These organisations function mainly in the Western Cape, though they have a presence in other provinces, especially Northern Cape and Eastern Cape. FARR, for example, provides services such as mentorship, creating social awareness, providing education and training programmes, conducting medical and psycho-social FASD-related research and providing support and diagnostic services [30]. FASfacts, as an NPO, offers FASD prevention programmes through experiential learning, advertising campaigns using churches, films and theatres to pass FASD messages and mentoring of pregnant women [31]. These organisations obtain funding from the government by aligning their programmes to the existing generic policies.

Different approaches have been proposed to develop relevant and effective FASD policies. One such approach proposed to prevent and manage FASD, is the decolonisation policy discourse [32]. The proponents of the decolonised policy discourse advocate that women should be seen as victims of the FASD problem, not as perpetrators [32]. They also propose that the socio-economic and socio-political circumstances that predispose women to alcohol consumption during pregnancy, which may

lead to FASD, should be addressed [32]. Other proposed approaches are the comprehensive (addressing all factors); inclusive (involving all sectors and all levels of the government); and the human rights-based approach (acknowledging the principles of non-discrimination, participation, inclusion, equity and access) [33]. A women-centred approach, which considers the needs of women in all aspects of design and delivery, including the location and accessibility of services, staffing, programme development, content and materials has also been proposed [33]. We propose that for an FASD policy to be truly comprehensive and multi-sectoral, all the above approaches should be scrutinised.

Having a multi-sectoral and comprehensive policy [19, 34], as demonstrated by the Canadian and Australian governments [33, 35, 36], has the potential to coordinate existing and new approaches and programmes for preventing and managing FASD. In South Africa, government programmes to address FASD remain limited partly because of the absence of a policy to inform prevention and management [27]. To this end, we sought to develop a guideline to inform the design of a comprehensive and multi-sectoral policy to address FASD in South Africa [37].



## Methods

In developing the guideline for the prevention and management of FASD, we adapted the World Health Organization's (WHO) approach (steps) as outlined in the study protocol [37]. We organised the steps proposed by the WHO [38, 39] in three phases. The first phase entailed designing the initial guideline prototype. In Phase 2, we refined the initially formulated guideline prototype. Phase 3 involved testing and confirming the refined prototype using a modified Delphi approach.

## **Phase 1: Designing the guideline prototype**

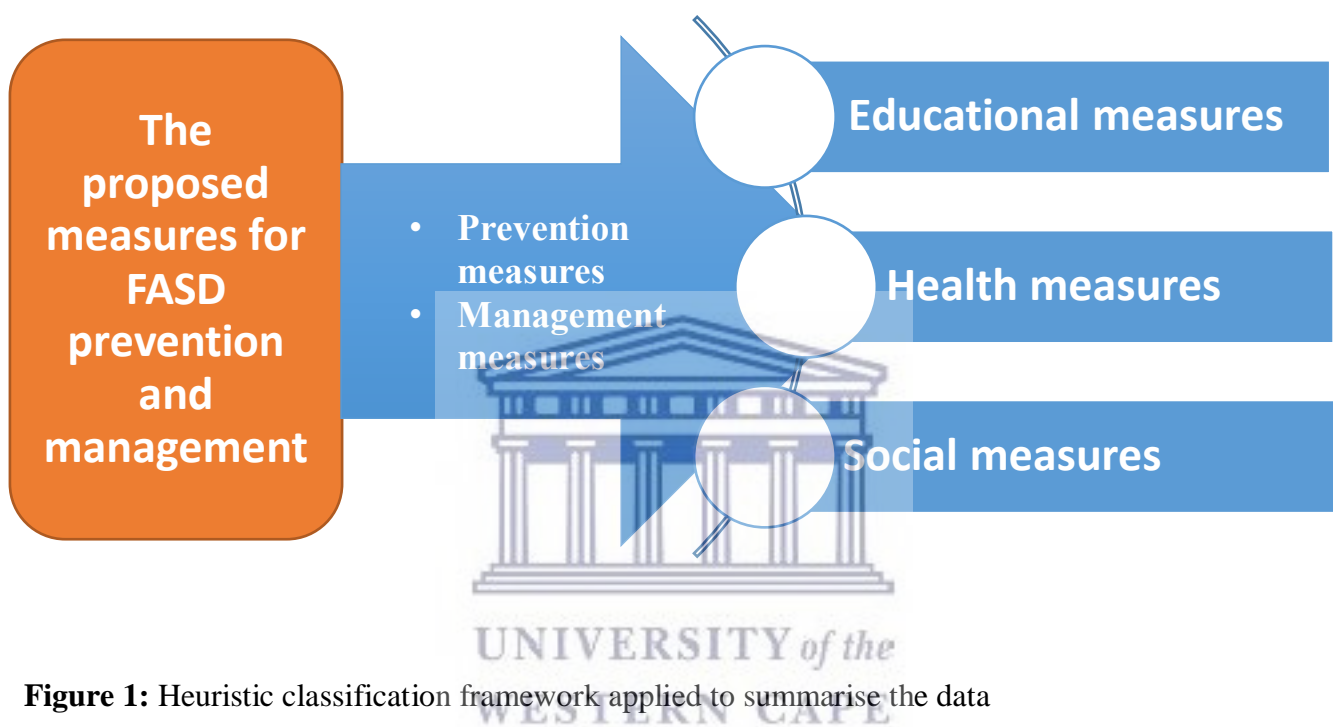
We conducted focus group discussions with service providers and in-depth interviews with policymakers to identify policy requirements for FASD in South Africa [23, 28]. The service providers included educators, health and allied health professionals as well as social service professionals providing services to women, especially pregnant women or individuals with FASD or related conditions. The policymakers included individuals working in the Departments of Social Welfare, Health and Education on FASD-relevant issues or related conditions. The service providers and the policymakers were asked various questions regarding current practices and interventions and policy requirements for FASD.

In addition to the focus group discussions and in-depth interviews, we conducted a document review. We identified clauses of FASD policy in various South African related policy documents [26]. We searched databases (PubMed and Google search engines) and the websites of South African national and provincial departments. We used the following search terms: foetal alcohol spectrum disorder, alcohol-related neurodevelopmental disorder, foetal alcohol syndrome, white paper, green paper, policy, action plan, gazette and South Africa. Though, we used “foetal” for the search, it includes documents with “fetal”. We also contacted the designated persons in the departments of Education, Health, Social Development and Trade and Industry via emails to request other relevant documents.

Furthermore, we conducted a scoping review to identify the prevention and management interventions of FASD globally that could be included in the policy. We searched the following Ebsco Host embedded databases: Academic Search Complete, ERIC, SoINDEX, Health Source. We also searched the Nursing/Academic Edition, CINAHL, Medline and Psych-ARTICLES, Springer Links, SAGE Journals and PubMed databases. The search terms used include foetal alcohol spectrum disorder, foetal alcohol syndrome, alcohol-related neurodevelopmental disorder, alcohol-related birth

defects, partial foetal alcohol syndrome, prenatal alcohol exposure, intervention, strategy, treatment, programme, management, prevention and therapy.

Data obtained from the various sources were analysed using content and thematic and framework analyses in the different studies. The findings from these studies were integrated towards developing the initial guideline prototype using the framework indicated in **Figure 1**.



**Figure 1:** Heuristic classification framework applied to summarise the data

The information gleaned from the various sections as represented in the framework were then rephrased into different statements to formulate a draft guideline.

## **Phase 2: Refining the initial guideline prototype**

The draft guideline developed in Phase 1 was used to engage with seven international and local experts (**Table 1**) for their opinions, comments and suggestions for improvement regarding each item and the overall guideline prototype. These experts were purposely sampled based on their availability and expertise. Emails were sent to them requesting their participation. We selected those who had


experience in conducting FASD research and those who had been involved in developing FASD policies.

**Table 1: Characteristics of international and local experts**

Type of expert	Gender	Position
International	Female	Professor
International	Female	Researcher
International	Female	Policymaker
International	Male	Researcher
Local	Male	Professor
Local	Female	Researcher
Local	Female	Lecturer

Following the engagement with the experts, we obtained a refined guideline prototype (Table 2).

**Table 2: The prototype guideline for the prevention and management of the FASD policy**

Approaches and guiding principles and approaches – the proposed FASD policy should be...	
Holistic	
User- and caregiver-focused	
Inter-departmental/multi-sectoral	
Considerate of needs across the lifespan	
Collaborative	
Human rights-based	
Based on a public health framework	
Culturally diverse and culturally sensitive	
Evidence-based	
Woman/family-centred	
Clear about referral pathways	
Designed to avoid victim blaming	
Cost-effective	
Driven by behavioural economics	
Education-related proposed prevention measure for FASD – the proposed FASD policy should...	
Enhance awareness of the dangers of drinking alcoholic beverages during pregnancy in schools including colleges and universities	
Assist individuals with alcohol-use problems in educational settings to access treatment	
Address barriers to access treatment for alcohol-related problems in educational settings	
Address stigma associated with alcohol abuse in educational settings	
Facilitate training of teachers re the FASD prevention/awareness programme	
Facilitate the development and implementation of FASD awareness programmes in schools (including colleges and universities)	
Facilitate the use of peer education for the FASD awareness programme in schools	
Promote a healthy lifestyle in schools through sport and other extra-curricular activities	
Make school events alcohol-free	
Discourage the establishment of liquor stores in the proximity of schools	
Promote the education of young individuals about healthy pregnancy in schools	
Health-related proposed prevention measures for FASD – should...	



Facilitate screening for alcohol use in clinics and hospitals
Encourage proper documentation of the alcohol history of women, especially pregnant women
Facilitate the inclusion of FASD prevention as a part of health promotion activities in clinics and hospitals
Facilitate the education of individuals and couples re the dangers of drinking alcoholic beverages during pregnancy in the pre-conception clinic
Facilitate the education of individuals and couples re the dangers of drinking alcoholic beverages during pregnancy in the reproductive clinic
Encourage the use of visible posters and pamphlets for FASD prevention campaigns in all clinics and hospitals
Facilitate training of healthcare professionals re FASD prevention
Facilitate early and appropriate referral to treatment for individuals (including women) with alcohol misuse issues
Empower health professionals with the skills to counsel and ask questions about safe and appropriate alcohol use
Promote the use of contraceptives to avoid unplanned pregnancy
<b>Community/social-related proposed prevention measures for FASD – should...</b>
Facilitate public awareness re the dangers of alcohol abuse
Facilitate the education of all people in the community re the dangers of drinking alcohol during pregnancy
Facilitate the education of individuals and couples re the dangers of drinking alcohol during pregnancy
Encourage the use of community groups for FASD prevention (education and awareness)
Facilitate the training of the community health/community-based workers and youth care/social workers re FASD prevention
Facilitate early intervention and assistance for individuals with alcohol-use problems in the community
Facilitate the creation of social programmes such as skills training and empowerment programmes for women in the community
Encourage awareness and education re FASD in the workplace, rural and urban areas and farming communities
Promote the use of multimedia such as posters, adverts, pamphlets, TV, social media and roadshows re FASD awareness in the communities
Promote enforcement of liquor laws and regulation of shebeens to control accessibility and availability of alcohol in the community
Provide access to treatment for people with alcohol-use problems in the community
Provide smooth aftercare and community reintegration to people who have attended alcohol rehab
Promote afterschool activities in the community to prevent early exposure of adolescents to alcohol
Discourage all advertisements that link alcohol to sport/other popular community events/activities
Mandate labels on alcohol containers to contain information re the dangers of drinking alcoholic beverages during pregnancy
Mandate that liquor stores display warning signs regarding alcohol and pregnancy
Enable the creation of support groups for individuals with alcohol misuse issues in the community
Facilitate the training of the community and religious leaders re FASD prevention
Promote collaboration and the use of non-profit organisations (NPO) re FASD prevention
Utilise community and religious leaders to increase FASD awareness among their communities
Promote the expansion and adoption of NPO evidence-based interventions re prevention in the community
Assist families to support individuals with alcohol-use problems
<b>Education-related proposed management measures for FASD – should...</b>
Facilitate the development of a curriculum that accommodates individuals with FASD
Facilitate training of teachers re the classroom management for individuals with FASD
Promote skilled schools for learners with learning disabilities (including individuals with FASD) who are not benefiting from formal education
Make provision for special assistance for individuals with FASD within mainstream schools
Facilitate the creation of the special schools for learners with a learning disability (including individuals with FASD) who are not benefiting from mainstream schooling
Facilitate the education of parents re the needs and management of individuals with FASD
<b>Health-related proposed management measures for FASD – should...</b>

Facilitate capacity building re diagnosis among health professionals
Facilitate FASD screening for all children who are known to have been prenatally exposed to alcohol
Make provision for diagnostic services for individuals
Promote diagnosis for school children, adolescents and adults to reduce rates of people who are left undiagnosed or misdiagnosed
Promote appropriate referral pathways to services after diagnosis
Facilitate the creation of diagnostic centres in clinics, hospitals and communities
Facilitate the creation of national surveillance for FASD via reports from health professionals
Make provision for integrated and individualised medical services for individuals with FASD
Encourage routine consideration of FASD in the diagnosis and management of mental illness and developmental disorders
<b>Community/social-related proposed management measures for FASD – should...</b>
Provide skills training and empowerment programmes for those in need among individuals with FASD
Facilitate appropriate employment opportunities for individuals with FASD
Facilitate the training of community health workers/community-based workers/youth care workers/social workers and professionals within judiciary system re FASD management
Facilitate the training of the biological and foster parents/caregivers regarding the management of FASD
Promote the empowerment of the parents/caregivers of individuals with FASD in the community
Promote the establishment of support systems for biological and foster parents/caregivers and individuals with FASD in the community
Promote the referral of parents and individuals with FASD to appropriate services
Make provision for effective counselling services for parents and individuals with FASD
Encourage family/community support for individuals with FASD
Provide support for individuals with FASD in child protection/foster care and the criminal justice system
Facilitate the creation of a structure and supportive environment at home, school and beyond

### Phase 3: Testing and finalising the guideline

We conducted a modified Delphi approach to improve the prototype guideline developed for policy on FASD.

#### *Development of questionnaire*

The statements in the refined prototype developed in Phase 2 (**Table 2**) were used to design Likert scale statements for the Delphi responses. We asked the respondents to rate their agreement with each statement on a 5-point Likert scale (from ‘strongly disagree’ to ‘strongly agree’) whereby they could answer ‘neutral’ when they were not sure how to rate a statement. The questionnaire was divided into three sections (principles and approaches to policy development, prevention considerations and

management consideration) and three sub-sections (education, health and social aspects). The participants were encouraged to provide further comments at the end of each section and sub-section. The questionnaire was piloted among international and local experts working on the prevention and management of FASD to ensure coherence, feasibility and validity.

### ***Recruitment of the participants***

Using purposive and snowball sampling techniques we obtained the study sample because a limited number of people have experience and or expertise on FASD. First, we purposively recruited 15 participants (policymakers, teachers, social service professionals, researchers and allied health professionals) as the seed participants. We used the following criteria for selecting the first batch of participants (i) having experience working with women (especially pregnant women) and or individuals with FASD or related conditions, (ii) experience in making or implementing FASD policy or related conditions, and (iii) having published articles or conducted FASD research or related conditions. Second, we asked the 15 participants to invite others in their networks (snowballing). Through purposive and snowball approaches, 43 participants completed round 1 of the Delphi study. We invited the 43 respondents who participated in round 1, and 41 completed the round 2 questionnaire. In **Table 3**, the characteristics of the participants in both rounds of the Delphi study are shown.

**Table 3: Characteristics of the participants**

<b>Characteristics</b>	<b>Round 1(n=43)</b>	<b>Round 2 (n=41)</b>
Gender		
Male	11	11
Female	32	30
Occupation		
Social services provider	14	13
Researcher	9	9
Policymaker	12	11
Allied health and health	5	5
Teacher	3	3

Highest level of education		
High school	1	1
College	3	3
University	39	37
Years of experience		
1-5	14	13
6-10	12	11
11-15	7	7
16 and above	10	10

### ***Data collection***

We created a Google form, which allowed the participants to respond online and invited them via email to follow the link to this form. Participants were given an initial period of two weeks to respond to the questionnaire. The two weeks were extended to two months to increase participation including the participants recruited by snowballing. We reminded those who had not responded before the end of the two weeks as well as weekly after the two months. The round 1 questionnaire allowed participants not only to agree or disagree with a set of statements but also to provide comments to improve the guideline. Before we administered the questionnaire, we agreed that if a statement reached at least 85% consensus from the participants, it would be endorsed. Statements not reaching the 85% consensus, and the new ones generated from the analysis of the comments of the participants in round 1, were prepared as a separate questionnaire and administered in round 2.

### ***Validity***

To ensure validity in this study, we consulted with local and international experts to ensure the content covered all the areas of the variable being measured. The experts' opinions were used to improve the guideline before it was used for the Delphi study. We also consulted questionnaires and surveys designed to measure similar concepts.

### ***Reliability***

To ensure reliability, we asked some of the participants to answer the questionnaire for a second time. Both their responses were compared to show consistency. Additionally, we calculated Cronbach's alpha for the study using the Statistical Package for Social Science (SPSS) software. The Cronbach's alpha for round 1 is 0.977, and round 2 is 0.796.

### ***Data analysis***

We analysed the quantitative data using SPSS. We generated descriptive statistics (frequencies) for each statement.

### **Ethical considerations**

The research ethics committee of the University of the Western Cape approved this study (BM/16/4/4). Approvals were also obtained from the Western Cape Department of Education (20161212-6937), Departments of Health (WC 2016RP29\_862) and Social Development (12/1/2/4). Eligible experts were invited to participate via email with the inclusion of an information sheet and a consent form. The experts were required to read the information sheet to understand the purpose of the study and what they need to do if they agreed to participate. Those who agreed to participate were asked to sign the consent form. The research team maintained confidentiality during the conduct of the research by the anonymity of the participants.

# RESULTS

## Guiding principle and approach

Three of the statements achieved 100% consensus in round 1 and none in round 2 (**Table 4**). Women/family-centeredness attained 84% consensus in round 1 and based on the comments made by some of the participants, we decided to separate family from women in round 2. The participants said having women-centred as one of the approaches and guiding principle could promote stigma and blame games. In round 2, family-centredness reached 95% consensus while women-centredness only achieved 68% agreement. However, the policy should be designed to avoid gender-focused interventions recorded the lowest consensus of 66%. There was no particular reason given by the participants for the latter.

**Table 4: Agreement with the statements on guiding principle and approach**

	<b>Statement</b>	<b>R1 (%)*</b>	<b>R2 (%)*</b>
1	Holistic	98	-
2	User- and caregiver-focused	98	-
3	Inter-departmental	98	-
4	Considerate of needs across the lifespan	100	-
5	Collaborative	98	-
6	Human rights-based	93	-
7	Based on a public health framework	93	-
8	Culturally diverse and culturally sensitive	100	-
9	Evidence-based	98	-
10	Woman/family centred	84	-
11	Clear about referral pathways	100	-
12	Designed to avoid victim blaming	95	-
13	Cost-effective	93	-
14	Driven by behavioural economics	79	81
15	Family-centred	-	95
16	Women-centred	-	68
17	Government-driven/led	-	68
18	Address social determinants of health contributing to FASD	-	95
19	Designed to give special consideration to the hot spot (rural area)	-	84
20	Incorporate home-based care	-	83
21	Considerate of input from individuals with FASD and their families	-	94
22	Designed to promote responsible parenting	-	98
23	Designed to avoid gender-focused interventions	-	66
24	Designed assign responsibilities	-	78

R1 – Round 1; R2 – Round 2; \*Represents 'agree and strongly agree'



## Proposed prevention measure

### Education-related proposed prevention measure

In round 1, only one of the statements attained 100% agreement from the respondents with none in round 2. However, most statements achieved 90% and greater in terms of agreement. The statement, 'Make school events alcohol-free' attained the lowest agreement at 81%. When administered in round 2, it only obtained an agreement rate of 78% (Table 5).

**Table 5: Agreement with statements on education-related proposed prevention measure**

Statement	R1 (%)*	R2 (%)*
1 Enhance awareness of the dangers of drinking alcoholic beverages during pregnancy in schools including colleges and universities	100	-
2 Assist individuals with alcohol-use problems in educational settings to access treatment	98	-
3 Address barriers to access treatment for alcohol-related problems in educational settings	98	-
4 Address stigma associated with alcohol abuse in educational settings	93	-
5 Facilitate the training of teachers re the FASD prevention/awareness programme	98	-
6 Facilitate the development and implementation of FASD awareness programmes in schools (including colleges and universities)	95	-
7 Facilitate the use of peer education re the FASD awareness programme in schools	91	-
8 Promote a healthy lifestyle in schools through sport and other extra-curricular activities	91	-
9 Make school events alcohol-free	81	78
10 Discourage the establishment of the liquor stores in the proximity of schools	88	-
11 Promote education of young individuals about healthy pregnancy in schools	96	-
12 Facilitate the teaching of responsible parenthood in educational settings	-	90
13 Facilitate the teaching of safe sex practices in educational settings	-	88

R1 – Round 1; R2 – Round 2; \*Represents 'agree and strongly agree'

### Health-related proposed prevention measures

Five of the statements on health-related proposed prevention measures reached 100% consensus among participants in round 1 (Table 6). The only statement generated from the comments made by participants in round 1 and administered in round 2 attained 93% agreement.

**Table 6: Agreement with statements on health-related proposed prevention measures**

Statement	R1 (%)*	R2 (%)*
1 Facilitate screening for alcohol use in clinics and hospitals	88	-
2 Encourage proper documentation of the alcohol history for women, especially pregnant women	95	-



3	Facilitate the inclusion of FASD prevention as a part of health promotion activities in clinics and hospitals	100	-
4	Facilitate the education of individuals and couples on the dangers of drinking alcoholic beverages during pregnancy in the pre-conception clinic	100	-
5	Facilitate the education of individuals and couples on the dangers of drinking alcoholic beverages during pregnancy in the reproductive clinic	100	-
6	Encourage the use of visible posters and pamphlets for FASD prevention campaigns in all clinics and hospitals	95	-
7	Facilitate the training of healthcare professionals on FASD prevention	98	-
8	Facilitate early and appropriate referral to treatment for individuals (including women) with alcohol misuse issues	100	-
9	Empower health professionals with the skills to counsel and ask questions about alcohol use in a safe and appropriate way	100	-
10	Promote the use of contraceptives to avoid unplanned pregnancy	95	-
11	Assist parents of individuals with FASD to avoid having another child with FASD	-	93

R1 – Round 1; R2 – Round 2; \*Represents 'agree and strongly agree'

### Community/social-related proposed prevention measures

Eight statements had 100% consensus in round 1 while one attained 100% agreement in round 2. The remaining statements achieved agreement in 90% and above except two (statements 14 and 23). 'Discourage all advertisements that link alcohol to sport/other popular community events/activities' was re-administered in round 2 and recorded a lower consensus (71%) than round 1. Some of the participants commented that a ban on the advertisement has little or no impact on reducing or preventing alcohol consumption during pregnancy in an area where drinking is rampant (Table 7).

**Table 7: Agreement with statements regarding community/social-related proposed prevention measures**

	Statement	R1 (%)*	R2 (%)*
1	Facilitate educating public awareness re the dangers of alcohol abuse	95	-
2	Facilitate the education of all people in the community re the dangers of drinking alcohol during pregnancy	100	-
3	Facilitate the education of individuals and couples re the dangers of drinking alcohol during pregnancy	100	-
4	Encourage the use of community groups for FASD prevention (education and awareness)	95	-
5	Facilitate the training of the community health/community-based workers and youth care/social workers re FASD prevention	100	-
6	Facilitate early intervention and assistance for individuals with alcohol use problems in the community	100	-
7	Facilitate the creation of social programmes such as skills training and empowerment programmes for women in the community	98	-

8	Encourage awareness and education re FASD in the workplace, rural and urban areas and farming communities	100	-
9	Promote the use of multimedia such as posters, adverts, pamphlets, TV, social media and road shows re FASD awareness in the communities	100	-
10	Promote enforcement of liquor laws and regulation of shebeens to control accessibility and availability of alcohol in the community	95	-
11	Provide access to treatment for people with alcohol-use problems in the community	100	-
12	Provide smooth aftercare and community reintegration for people who have attended alcohol rehab	95	-
13	Promote afterschool activities in the community to prevent early exposure of adolescents to alcohol	100	-
14	Discourage all advertisements that link alcohol to sport/other popular community events/activities	81	71
15	Mandate labels on alcohol containers to contain information re the dangers of drinking alcoholic beverages during pregnancy	95	-
16	Mandate that liquor stores have warning signs regarding alcohol and pregnancy	98	-
17	Enable the creation of support groups for individuals with alcohol misuse issues in the community	95	-
18	Facilitate the training of the community and religious leaders re FASD prevention	95	-
19	Promote collaboration and the use of non-profit organisations (NPO) for FASD prevention	98	-
20	Utilise community and religious leaders to increase FASD awareness in their communities	95	-
21	Promote the expansion and adoption of NPO evidence-based interventions for prevention in the community	98	-
22	Assist families to support individuals with alcohol-use problems	98	-
23	Facilitate the curbing of opening hours, increasing the price of alcohol and the legal age for drinking alcohol, and facilitate the limiting of liquor licences	-	73
24	Promote intervention services for mothers who have a child with FASD in the community	-	100

RI – Round 1; R2 – Round 2; \*Represents 'agree and strongly agree'

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## Proposed management measures

### Education-related proposed management measures

Of the six education-related proposed measures, only one attained 100% of agreement in round 1. The remaining statements also achieved a consensus rate of 90% and above (**Table 8**). Therefore, none of the statements was administered in round 2.

**Table 8: Agreement with statements regarding education-related proposed management measures**

	Statement	RI (%)*	R2 (%)*
1	Facilitate the development of a curriculum that accommodates individuals with FASD	93	-
2	Facilitate the training of teachers re the classroom management for individuals with FASD	95	-
3	Promote skilled schools for learners with learning disabilities (including individuals with FASD) who are not benefiting from formal education	98	-
4	Make provision for special assistance for individuals with FASD within mainstream schools	100	-

<b>5</b>	Facilitate the creation of the special schools for learners with a learning disability (including individuals with FASD) who are not benefiting from mainstream schooling	93	-
<b>6</b>	Facilitate the education of parents re the needs and management of individuals with FASD	98	-

R1 – Round 1; R2 – Round 2; \*Represents 'agree and strongly agree'

## Health-related proposed management measures

None of the health-related proposed management measures achieved 100% agreement in both rounds (**Table 9**). Five of the statements reached consensus at 90% and above. The remaining statements attained 85% or more consensus, except one. Although all the statements in this sub-section reached the acceptable consensus for this study, some of the participants raised concerns. They commented on the feasibility and practicality of diagnosing school children, adolescents and adults, individualised medical services and creating national surveillance. They cautioned that it is not advisable to diagnose without making provision for services after diagnosis. They reported that individualised services would be too expensive and appropriate logistics have to be implemented for national surveillance. In round 2, we decided to separate integrated and individualised medical services. Only integrated service reached the consensus (88) acceptable in this study.

**Table 9: Agreement with statements regarding health-related proposed management measures**

<b>Statement</b>	<b>R2 (N)</b>	<b>R2 (%)*</b>
<b>1</b> Facilitate capacity building re diagnosis among health professionals	98	-
<b>2</b> Facilitate FASD screening for all children who are known to have been prenatally exposed to alcohol	89	-
<b>3</b> Make provision for diagnostic services for individuals	95	-
<b>4</b> Promote diagnosis for school children, adolescents and adults to reduce rates of people who are left undiagnosed or misdiagnosed	86	-
<b>5</b> Promote appropriate referral pathways to services after diagnosis	98	-
<b>6</b> Facilitate the creation of diagnostic centres in clinics, hospitals and communities	91	-
<b>7</b> Facilitate the creation of national surveillance for FASD via reports from health professionals	88	-
<b>8</b> Make provision for integrated and individualised medical services for individuals with FASD	88	-
<b>9</b> Encourage routine consideration of FASD in the diagnosis and management of mental illness and developmental disorders	93	-
<b>10</b> Make provision for integrated medical services for individuals with FASD	-	88
<b>11</b> Make provision for individualised medical services for individuals with FASD	-	81

R1 – Round 1; R2 – Round 2; \*Represents 'agree and strongly agree'

## Community/social-related proposed management measures

None of the statements attained 100% consensus in round 1, whereas one reached 100% agreement in round 2 (**Table 10**). Besides one statement, all the others achieved a consensus of 90% or more. The promotion of grant/social welfare for individuals with FASD attained the lowest consensus (49%). One of the reasons given for the low consensus was that promoting grants and social welfare would encourage women to drink during pregnancy to receive these benefits.

**Table 10: Agreement with statements regarding community/social-related proposed management measures**

Statement	R1 (%)*	R2 (%)*
1 Provide skills training and empowerment programmes for those who need it among individuals with FASD	95	-
2 Facilitate appropriate employment opportunities for individuals with FASD	91	-
3 Facilitate the training of community health workers/community-based workers/ youth care workers/ social workers and professionals within judiciary system re FASD management	93	-
4 Facilitate the training of the biological and foster parents/caregivers regarding the management of FASD	98	-
5 Promote the empowerment of the parents/caregivers of individuals with FASD in the community	95	-
6 Promote the establishment of support systems for biological and foster parents/caregivers and individuals with FASD in the community	95	-
7 Promote the referral of parents and individuals with FASD to appropriate services	98	-
8 Make provision for effective counselling services for parents and individuals with FASD	98	-
9 Encourage family/community support for individuals with FASD	98	-
10 Provide support for individuals with FASD in child protection/foster care and criminal justice system	98	-
11 Facilitate the creation of structure and supportive environment at home, school and beyond	93	-
12 Promote grant/social welfare for individuals with FASD	-	49
13 Make provision for adequate information about individuals with for the adoptive parents	-	100

RI – Round 1; R2 – Round 2; \*Represents 'agree and strongly agree'

Following the two rounds of responses in the Delphi process, we selected only those statements that qualified by 85% in either round to be included in the guideline (Box 1).

### Box 1: A proposed guideline for policy on the prevention and management of FASD

#### Overall guiding principles of the policy

The panel agreed that policy to inform the prevention and management of FASD should

- Be holistic, considering the prevention, diagnosing and management of FASD.
- Consider the individual with FASD and their caregivers.
- Involve all relevant government departments such as the departments of health, education, justice, social development, trade and industry, labour.
- Consider the needs of individuals with FASD throughout their lifespan.

- Involve the collaborative action of various professionals (social service, justice and healthcare); healthcare professionals from the doctors, midwives, nurses, to the community healthcare workers.
- Adopt a human rights-based approach, which protects and promotes the rights of women, children, families and communities affected by FASD and recognises the principles of non-discrimination, participation, inclusion, equity and access.
- Adopt a public health framework, which acknowledges drinking during pregnancy and FASD are part of a complex interplay of biological, social, psychological, environmental and economic factors.
- Be culturally diverse and culturally sensitive, acknowledging the importance and strength of cultural values and norms.
- Use relevant and current evidence to inform practice and interventions to strengthen the knowledge base to effectively prevent and manage FASD.
- Establish clear referral pathways for the effectiveness of the prevention and management FASD
- Avoid victim blaming that is placing women at the centre of the FASD problem, which will not consider them as the perpetrators of the problem.
- Consider cost-effective interventions, which encourages a population-wide approach and enhances a wider coverage.
- Be family-centred, service providers must acknowledge and value the need for individuals within the family structure.
- Address social determinants of health contributing to FASD.
- Consider input from individuals with FASD and their families in developing a policy for the prevention and management of FASD.
- Promote responsible parenting, which recognises human values and enhance the development of individuals with FASD.

## **FASD prevention measures**

### **Education-related prevention measures for FASD**

The panel agreed that an FASD policy on education-related prevention should contain strategies to

- Increase awareness of the dangers of drinking alcoholic beverages during pregnancy in educational settings.
- Assist individuals with alcohol-use problems in educational settings to access treatment.
- Address the barriers to access treatment for alcohol-related problems in educational settings.
- Address stigma associated with alcohol abuse in educational settings.
- Improve training of teachers on FASD prevention/awareness programme.
- Facilitate the development and implementation of FASD awareness programmes in educational settings.
- Facilitate the use of peer education for FASD awareness programme in educational settings.
- Promote healthy lifestyle in schools through sport and other extra-curricular activities.
- Discourage the establishment of the liquor stores in the proximity of educational settings.
- Promote the education of young individuals about healthy pregnancy in educational settings.
- Facilitate the teaching of responsible parenthood in educational settings.
- Improve the teaching of safe sex practices in educational settings.

### **Health-related prevention measures for FASD**

The panel agreed that an FASD policy on health-related prevention should contain strategies to

- Improve the screening of alcohol use in clinics and hospitals.
- Improve documentation on the alcohol history for women, especially pregnant women.



- Facilitate the inclusion of FASD prevention as a part of health promotion activities in clinics and hospitals.
- Improve the education of individuals and couples on the dangers of drinking alcoholic beverages during pregnancy in the pre-conception clinic.
- Improve the education of individuals and couples on the dangers of drinking alcoholic beverages during pregnancy in the reproductive clinic.
- Encourage the use of visible posters and pamphlets for FASD prevention campaigns in all clinics and hospitals.
- Improve the training of healthcare professionals on FASD prevention.
- Improve early and appropriate referral to treatment for individuals (including women) with alcohol misuse issues.
- Empower health professionals with the skills to counsel and ask questions about alcohol use in a safe and appropriate way.
- Promote the use of contraceptives to avoid unplanned pregnancy.
- Improve assistance to parents of individuals with FASD to avoid having another child with FASD.

### Community/social-related prevention measures for FASD

The panel agreed that an FASD policy on community-related prevention should contain strategies to

- Improve education and public awareness of the dangers of alcohol abuse.
- Improve the education of all people in the community on the dangers of drinking alcohol during pregnancy.
- Improve the education of individuals and couples on the dangers of drinking alcohol during pregnancy in the community.
- Encourage the use of community groups for FASD prevention (education and awareness).
- Improve the training of the community health /community-based workers and youth care/social workers on FASD prevention.
- Facilitate early intervention and assistance for individuals with alcohol-use problems in the community.
- Facilitate the creation of social programmes such as skills training and empowerment programmes for women in the community.
- Improve awareness and education on FASD in the workplace, rural and urban areas and farming communities.
- Promote the use of multimedia such as posters, adverts, pamphlets, TV, social media and road shows for FASD awareness in the communities.
- Improve enforcement of liquor laws and regulation of shebeens to control accessibility and availability of alcohol in the community.
- Improve access to treatment for people with alcohol use problems in the community.
- Improve smooth aftercare and community reintegration for people who have attended alcohol rehab.
- Promote afterschool activities in the community to prevent early exposure of adolescents to alcohol.
- Mandate labels on alcohol containers to contain information on the dangers of drinking alcoholic beverages during pregnancy.
- Mandate that liquor stores have warning signs regarding alcohol and pregnancy.
- Enable the creation of support groups for individuals with alcohol misuse issues in the community.
- Facilitate the training of the community and religious leaders on FASD prevention.
- Promote collaboration and the use of non-profit organisation (NPO) for FASD prevention.
- Utilise the community and religious leaders to increase FASD awareness among their communities.
- Promote the expansion and adoption of NPO evidence-based interventions for prevention in the community.

- Improve assistance to families to support individuals with alcohol use problems.
- Improve interventions services for mothers who have a child with FASD in the community.

## **FASD management measures**

### **Education-related management measures for FASD**

The panel agreed that an FASD policy on education-related management should contain strategies to

- Facilitate the development of a curriculum that accommodates individuals with FASD.
- Improve the training of teachers on classroom management for individuals with FASD.
- Promote skill schools for learners with learning disabilities (including individuals with FASD) that are not benefiting from formal education.
- Provide special assistance for individuals with FASD within mainstream schools.
- Facilitate the creation of the special schools for learners with a learning disability (including individuals with FASD) that are not benefiting from mainstream schooling.
- Facilitate the education of parents on the needs and management of individuals with FASD.

### **Health-related management measures for FASD**

The panel agreed that an FASD policy on the health-related management should contain strategies to

- Increase capacity building re diagnosis among health professionals.
- Facilitate FASD screening for all children that are known to have been prenatally exposed to alcohol.
- Provide diagnostic services for individuals.
- Promote diagnosis for school children, adolescents and adults to reduce rates of people who are left undiagnosed or misdiagnosed.
- Promote appropriate referral pathways to services after diagnosis.
- Facilitate the creation of diagnostic centres in clinics, hospitals and communities.
- Facilitate the creation of national surveillance for FASD via reports from health professionals.
- Encourage routine consideration of FASD re the diagnosis and management of mental illness and developmental disorders.
- Provide integrated medical services for individuals with FASD.

### **Community/social-related management measures for FASD**

The panel agreed that an FASD policy on the community-related management should contain strategies to

- Provide skills training and empowerment programmes for those who need it among individuals with FASD.
- Facilitate appropriate employment opportunities for individuals with FASD.
- Facilitate the training of community health workers/community-based workers/ youth care workers/ social workers and professionals within the judiciary system re FASD management.
- Improve the training of the biological and foster parents/caregivers regarding the management of FASD.
- Promote the empowerment of the parents/caregivers of individuals with FASD in the community.
- Promote the establishment of support systems for biological and foster parents/caregivers and individuals with FASD in the community.
- Promote the referral of parents and individuals with FASD to appropriate services.
- Provide effective counselling services for parents and individuals with FASD.
- Encourage family/community support for individuals with FASD.



- Provide support for individuals with FASD in child protection/foster care and the criminal justice system.
- Facilitate the creation of structure and supportive environment at home, school and beyond.
- Facilitate the provision of adequate information about individuals with for the adoptive parents.

## Discussion

In this study, we aimed to develop a guideline that could assist policymakers in designing a holistic, comprehensive and multi-sectoral policy toward the prevention and management of FASD in South Africa. Therefore, we considered a guideline as a document that contains evidence-based recommendations for the prevention and management of FASD and systematically developed statements capable of guiding policymakers to develop a holistic policy. This guideline has the potential to assist South African policymakers in developing a policy that will address FASD considering the acceptable consensus (85%). Furthermore, it can be adapted or adopted to guide the development of policy for the prevention and management of FASD in other countries, especially sub-Saharan Africa.

Our findings indicated good support for the proposed approaches and principles of FASD policy. Thereby supporting our proposition that policies designed to guide the prevention and management of FASD should be holistic, user- and caregiver-focused, culturally diverse and sensitive, considerate of needs across the lifespan, collaborative, have clear referral pathways, and evidence-based and inter-departmental. These policies should also use the public health framework, and be human rights-based, inter-departmental, collaborative, culturally diverse and sensitive, evidence-based, cost-effective and family-centred [33, 35, 36]. If these perspectives are taken into consideration, the chances of obtaining a policy that enhances effective and sustainable programmes to prevent and manage FASD such as those developed in Australia and Canada are high [33, 35, 36].

While designing the initial guideline, based on the finding from previous phases, we considered adding that FASD policies should be women-centred. Nevertheless, the experts in the Delphi approach suggested that women-centeredness as a guiding principle has the tendency to promote stigmatisation and victim blaming of women. Stigma may also influence the prevention and management of FASD as has been reported [7]. The opinions expressed by these participants are consistent with the current policy discourses to re-contextualise and decolonise FASD policies and reframe the problem of FASD in a way that avoids victim blaming [32]. This principle supports the argument that drinking during pregnancy should not be criminalised [40]. Rather, women with alcohol problems should be assisted. Therefore, an FASD policy must address multiple factors (local and systemic) that predispose women to alcohol abuse [32]. An FASD policy should also address the social, structural and economic factors affecting health behaviour and examine the growing gap in health inequities [32]. Thus, the notion of having a policy which addresses upstream drivers (social determinants of health contributing to FASD) is in alignment with these factors [41].

An FASD prevention policy should support the training of teachers for FASD prevention and awareness as well as classroom management and the modification of curriculum for the benefit of individuals with FASD in an educational setting. These findings are supported by studies conducted to examine the relational experience of educators and the education needs of children with FASD [42, 43]. The authors of these studies recommend specialised training for educators empowering them to assist individuals with FASD in the classroom to maximise their potential [42, 43]. Adequately trained educators can address the challenges of FASD in the classroom [44]. Goal 2 and priority 3 of the Canadian framework for action on FASD and the Australian national strategy for FASD, respectively emphasised on capacity development [35, 36]. We also record strong agreement on special assistance for individuals with FASD within the mainstream schools, so that they can benefit from inclusive education. Authors have advocated for specialised FASD classrooms and inclusive classrooms with FASD support [8].

Increasing the education and raising awareness around FASD, especially on the dangers of consuming alcohol during pregnancy in educational settings, clinics, communities and public places should also form a part of an FASD prevention policy. The need for education and awareness programmes is accentuated as research supports the efficacy of awareness intervention, particularly in areas where they are low [24]. These findings echo the urgent call for awareness in South Africa on the dangers of prenatal alcohol exposure and the overwhelming consequence of FASD on the lives of children, families and communities [3]. Comprehensive awareness and health promotion efforts correspond to the first level of prevention – the four-part model of prevention for FASD [45]. Awareness is also a core part of FASD policy strategies in Australia and Canada [33, 35, 36]. Therefore, awareness should be an integral part of a policy guiding the prevention and management of FASD [21].

The first step toward managing FASD in a proposed policy should include the screening of all children who are known to have been prenatally exposed to alcohol. This targeted screening has also been supported by another study [46]. The respondents, nevertheless, cautioned that it is dangerous to screen and diagnose without adequate care and management services. We also found a high agreement with the idea that an FASD policy should include programmes for screening for alcohol use at clinics and hospitals and proper documentation of the history of alcohol use. Therefore, healthcare providers must be equipped with the necessary skills to have informed discussions on alcohol use with women [45, 47]. Discussing alcohol consumption and documenting its history also forms part of the recommendations of the Canadian framework for action on FASD, and the Australian action plans for FASD [33, 35, 36].

Training professionals (health care, social service, criminal justice and judiciary) regarding the prevention, screening, identification, diagnosis and management of FASD should also be considered in FASD policy. The continuous education and training of the professionals to improve their

knowledge regarding FASD have also been advocated by some authors [48–52]. The training of these professionals is important because the prevention and management of FASD require a highly skilled multidisciplinary team [10–13]. Training is also essential as it is difficult to manage FASD because of its negative educational, health and social outcomes [53]. The training of parents and caregivers re the needs and how to care for individual with FASD should also be considered when designing policies to inform the FASD programmes and interventions. Therefore, training is important, as the needs of individuals with FASD are enormous and parents/caregivers may not have sufficient knowledge of raising individuals with FASD [54]. Policies for FASD in other parts of the world have also considered training of professionals in addressing FASD [33, 35, 36].

Our findings indicated the inclusion of support to the parents, caregivers, and individuals with FASD in policy which is relevant. These findings reflect one of the practice points for primary healthcare providers [PHCP], stipulating that “PHCP should be aware of FASD support services in their community and refer families to educational and family supports early” [55]. These findings also correspond to level four of the four-part model for FASD (postpartum support for new mothers and supports for child assessments and development) [45]. The need for more support for families raising children with FASD has been indicated in a study [54]. Furthermore, Kapasi [56] found caregivers of individuals with FASD to have challenges, indicating the need for support. Challenges such as extra responsibility, difficulty in keeping a daily routine, feeling stigmatised and isolated, managing a child with antisocial behaviour problems and working with a child with diminished executive functioning [56]. Moreover, policies developed in Australia and Canada also advocated for support of the parents, caregivers, and individuals with FASD and community [33, 35, 36].

## Strengths and limitations

We followed a systematic empirical process to elicit information toward formulating the questionnaire. We developed the questionnaire using the findings of four different studies, with the aim of enhancing its content and quality. This process allowed us to gather credible information to be included in the questionnaire as all the participants had expertise/knowledge regarding FASD.

The questionnaire was also shared with local and international experts on FASD for comments and improvement through a discursive process to ensure the essential parts were covered before it was used for the Delphi approach. The use of the Delphi approach provides the opportunity for participants to provide their opinions without fear of having differing views with others. This approach led to a wide range of opinions, which improved the guideline. The Delphi approach provides a strong basis for the construct validity of the questionnaire with participants being able to validate their initial responses and identify areas of uncertainty. The Delphi approach used in this study also allows controlled feedback, which provided the researchers with an opportunity to organise information, if applicable remove duplicates before exchanging the information with the experts.

The purposive and snowballing sampling method used may not have provided the true representation of all the individuals who are knowledgeable or working in the area of FASD. Therefore, this method could have limited the conclusion drawn from the study. A lack of participation from criminal justice and judicial professionals is also a limitation of this study, as their perspectives have been considered essential in the literature. Additionally, we did not include individuals with FASD and their biological or foster parents and caregivers.

## Conclusion

FASD in South Africa deserves urgent attention, especially from the government in terms of the policy to coordinate relevant prevention and management programmes and interventions. Developing a comprehensive and inter-sectoral policy to guide programmes and interventions for the prevention and management of FASD could be a good starting point. The guideline developed has the potential to assist the policymakers in the development of a holistic, multi-sectoral and comprehensive policy for FASD or could streamline discussions on an FASD policy in other relevant contexts.

## Abbreviation

**FASD:** Fetal alcohol spectrum disorder, **NPO:** Non-profit Organisation, **WHO:** World Health Organization, **FAS:** Fetal alcohol syndrome, **PFAS:** Partial fetal alcohol syndrome, **ARND:** Alcohol-related neurodevelopmental disorder, **ARBD:** Alcohol-related birth defects, **FARR:** Foundation for alcohol related research, **SPSS:** Statistical Package for Social Science, **PHCP:** Primary healthcare providers

## Declaration

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## **Availability of data and materials**

More information on data from this study is available by contacting the corresponding author

## **Authors' contributions**

The study was conceived and conceptualised by BOA, FCM and AMB. BOA, FCM and AMB contributed to the development of the methodology of this study. BOA and FCM analysed and interpreted the data. BOA wrote the first draft of the manuscript. FCM and AMB provided editorial and content input to improve the manuscript. All the authors read and approved the final manuscript.

## **Authors' information**

Not applicable.



## **Ethics approval and consent to participate**

This study is a part of the larger study. The approval for the larger study was obtained from the research ethics committee of the University of the Western Cape, Cape Town, South Africa. (BM/16/4/4).

## **Consent for publication**

Not applicable.

## **Competing interests**

The authors declare that they have no competing interests.



## Reference

- [1] Lange S, Probst C, Gmel G, et al. Global Prevalence of Fetal Alcohol Spectrum Disorder Among Children and Youth. *JAMA Pediatr* 2017; 171: 948.
- [2] Home - FARR SA. <https://www.farrsa.org.za/> (accessed 7 January 2019).
- [3] Olivier L, Curfs LMG, Viljoen DL. Fetal alcohol spectrum disorders: prevalence rates in South Africa. *South African Med J* 2016; 106: 103–106.
- [4] May P, De Vries M, Marais A-S, et al. Replication of high fetal alcohol spectrum disorders prevalence rates, child characteristics, and maternal risk factors in a second sample of rural communities in South Africa. *Int J Environ Res Public Health* 2017; 14: 522.
- [5] Urban MF, Olivier L, Viljoen D, et al. Prevalence of fetal alcohol syndrome in a South African city with a predominantly black African population. *Alcohol Clin Exp Res* 2015; 39: 1016–1026.
- [6] Badry D, Choate P. *Social work & social sciences review*. Whiting & Birch Ltd. <https://journals.whitingbirch.net/index.php/SWSSR/article/view/795/867> (2015, accessed 7 January 2019).
- [7] Bell E, Andrew G, Di Pietro N, et al. It's a Shame! Stigma Against Fetal Alcohol Spectrum Disorder: Examining the Ethical Implications for Public Health Practices and Policies. *Public Health Ethics* 2016; 9: 65–77.
- [8] Millar JA, Thompson J, Schwab D, et al. Educating students with FASD: linking policy, research and practice. *J Res Spec Educ Needs* 2017; 17: 3–17.
- [9] Purick K. *The Preventable Disability*. <https://parliament.nt.gov.au/committees/previous/foetal-alcohol-spectrum-disorder> (2015, accessed 7 January 2019)

- [10] Chasnoff IJ, Wells AM, King L. Misdiagnosis and Missed Diagnoses in Foster and Adopted Children With Prenatal Alcohol Exposure. *Pediatrics* 2015; 135: 264–270.
- [11] Burd L. FASD and ADHD: Are they related and How? *BMC Psychiatry* 2016; 16: 325.
- [12] J Benz, C Rasmussen GA. History, challenges, and future directions. 2009; 14: 231–237.
- [13] Jamieson PA. ‘ *The challenge of supporting children with Fetal Alcohol Spectrum Disorder in Aotearoa New Zealand : A narrative literature review* ’. 2017.
- [14] Reid N, Dawe S, Shelton D, et al. Systematic review of fetal alcohol spectrum disorder interventions across the life span. *Alcohol Clin Exp Res* 2015; 39: 2283–2295.
- [15] Chudley AE, Conry J, Cook JL, et al. Fetal Alcohol Spectrum Disorder: Canadian guidelines for diagnosis. *CMAJ* 2005; 172: S1–S21.
- [16] Cook JL, Green CR, Lilley CM, et al. Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *CMAJ* 2016; 188: 191–197.
- [17] Hoyme HE, Kalberg WO, Elliott AJ, et al. Updated clinical guidelines for diagnosing fetal alcohol spectrum disorders. *Pediatrics* 2016; 138: e20154256–e20154256.
- [18] Jonsson E, Salmon A, Warren KR. The international charter on prevention of fetal alcohol spectrum disorder. *Lancet Glob Heal* 2014; 2: e135-7.
- [19] Rendall-Mkosi K, London L, Adnams C, et al. Fetal alcohol spectrum disorder in South Africa: situational and gap analysis. *UNICEF, Pretoria.*  
[https://www.unicef.org/southafrica/SAF\\_resources\\_fetalalcohol.pdf](https://www.unicef.org/southafrica/SAF_resources_fetalalcohol.pdf) (2008, accessed 14 September 2017).
- [20] Roozen S, Black D, Peters G-JY, et al. Fetal Alcohol Spectrum Disorders (FASD): an Approach

to Effective Prevention. *Curr Dev Disord Reports* 2016; 3: 229–234.

- [21] Rutman D. Becoming FASD Informed: Strengthening Practice and Programs Working with Women with FASD. *Subst Abuse* 2016; 10: 13–20.
- [22] Adebiyi BO, Mukumbang FC, Cloete LG, et al. Policymakers' Perspectives Towards Developing a Guideline to Inform Policy on Fetal Alcohol Spectrum Disorder: A Qualitative Study. *Int J Environ Res Public Health*; 16. Epub ahead of print 2019. DOI: 10.3390/ijerph16060945.
- [23] Adebiyi BO, Mukumbang FC, Cloete LG, et al. Exploring service providers' perspectives on the prevention and management of fetal alcohol spectrum disorders in South Africa: A qualitative study. *BMC Public Health*; 18. Epub ahead of print 2018. DOI: 10.1186/s12889-018-6126-x.
- [24] Chersich MF, Urban M, Olivier L, et al. Universal prevention is associated with lower prevalence of fetal alcohol spectrum disorders in Northern Cape, South Africa: a multicentre before-after study. *Alcohol Alcohol* 2012; 47: 67–74.
- [25] May PA, Marais A-S, Gossage JP, et al. Case management reduces drinking during pregnancy among high risk women. *Int J Alcohol Drug Res* 2013; 2: 61–70.
- [26] Adebiyi BO, Mukumbang FC, Beytell A-M. To what extent is Fetal Alcohol Spectrum Disorder considered in policy-related documents in South Africa? A document review. *Heal Res Policy Syst* 2019; 17: 46.
- [27] London leslie. South Africa fails to tackle its high foetal alcohol syndrome rate. <http://theconversation.com/south-africa-fails-to-tackle-its-high-foetal-alcohol-syndrome-rate-46791> (2015, accessed 18 December 2018).

- [28] Adebiyi BO, Mukumbang FC, Okop KJ, et al. A modified Delphi study towards developing a guideline to inform policy on fetal alcohol spectrum disorders in South Africa: a study protocol. *BMJ Open* 2018; 8: e019907.
- [29] Adebiyi BO, Mukumbang FC, Cloete LG, et al. Policymakers' Perspectives Towards Developing a Guideline to Inform Policy on Fetal Alcohol Spectrum Disorder: A Qualitative Study. *Int J Environ Res Public Health* 2019; 16: 945.
- [30] Foundation for Alcohol Related Research (FARR). What we Do - FARR SA. <https://www.farrsa.org.za/what-we-do/> (2018, accessed 16 July 2018).
- [31] FASfacts. FASfacts runs FAS prevention campaigns in schools and communities. <http://www.fasfacts.org.za/About-Us/FASfacts-Programmes> (2018, accessed 16 July 2018).
- [32] Hunting G, Browne AJ. Decolonizing policy discourse: reframing the 'Problem' of fetal alcohol spectrum disorder. *Women's Heal Urban Life* 2012; 11: 35–53.
- [33] Foundation for Alcohol Education and Research. The Australian Fetal Alcohol Spectrum Disorders Action Plan 2013-2016. <https://www.fare.org.au/wp-content/uploads/research/FARE-FASD-Plan.pdf> (2013, accessed 5 February 2018).
- [34] Adnams CM. Fetal alcohol spectrum disorder in Africa. *Curr Opin Psychiatry* 2017; 30: 108–112.
- [35] Public Health Agency of Canada. *Fetal alcohol spectrum disorder (FASD) : a framework for action*. Health Canada. <https://www.canada.ca/en/public-health/services/reports-publications/fetal-alcohol-spectrum-disorder-fasd-framework-action.html> (2003, accessed 8 August 2018).
- [36] Australian Government. *Title: National Fetal Alcohol Spectrum Disorder Strategic Action Plan*.

<http://www.dpmc.gov.au/government/commonwealth-coat-arms> (2018, accessed 22 February 2019).

- [37] Adebiyi BO, Mukumbang FC, Okop KJ, et al. A modified Delphi study towards developing a guideline to inform policy on fetal alcohol spectrum disorders in South Africa: A study protocol. *BMJ Open* 2018; 8(4): DOI: 10.1136/bmjopen-2017-019907.
- [38] Blas E, Koller T, Magar V, et al. WHO library cataloguing-in-publication data WHO Handbook for guideline development. *Peer Rev Evidence-based Med World Heal Organ* 2014; 1: 179.
- [39] World Health Organisation. *WHO Handbook for guideline development*. World Health Organisation. [http://apps.who.int/iris/bitstream/10665/75146/1/9789241548441\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/75146/1/9789241548441_eng.pdf) (2012, accessed 1 March 2018).
- [40] Gardner J. South African journal of bioethics and law. *South African J Bioeth Law* 2016; 9: 26.
- [41] Sanders J, Currie CL. Looking further upstream to prevent fetal alcohol spectrum disorder in canada. *Can J Public Heal* 2014; 105: e450–e452.
- [42] Van Schalkwyk I, Marais S. Educators' relational experiences with learners identified with fetal alcohol spectrum disorder. *South African J Educ* 2017; 37: 1–9.
- [43] Millians MN. Educational Needs and Care of Children with FASD. *Curr Dev Disord Reports* 2015; 2: 210–218.
- [44] Blackburn C, Whitehurst T. Fetal alcohol spectrum disorders (FASD): raising awareness in early years settings. *Br J Spec Educ* 2010; 37: 122–129.
- [45] Poole N, Schmidt RA, Green C, et al. Prevention of fetal alcohol spectrum disorder: current Canadian efforts and analysis of gaps. *Subst Abuse* 2016; 10: 1–11.

- [46] Watkins RE, Elliott EJ, Wilkins A, et al. Recommendations from a consensus development workshop on the diagnosis of fetal alcohol spectrum disorders in Australia. *BMC Pediatr* 2013; 13: 156.
- [47] Coons KD, Watson SL, Yantzi NM, et al. Health Care Students' Attitudes About Alcohol Consumption During Pregnancy: Responses to Narrative Vignettes. *Glob Qual Nurs Res* 2017; 4: 2333393617740463.
- [48] Payne J, France K, Henley N, et al. Changes in health professionals' knowledge, attitudes and practice following provision of educational resources about prevention of Prenatal Alcohol Exposure and Fetal Alcohol Spectrum Disorder. *Paediatr Perinat Epidemiol* 2011; 25: 316–327.
- [49] Payne JM, Watkins RE, Jones HM, et al. Midwives' knowledge, attitudes and practice about alcohol exposure and the risk of fetal alcohol spectrum disorder. *BMC Pregnancy Childbirth* 2014; 14: 377.
- [50] Mutch RC, Jones HM, Bower C, et al. Fetal Alcohol Spectrum Disorders: Using Knowledge, Attitudes and Practice of Justice Professionals to Support their Educational Needs. *J Popul Ther Clin Pharmacol* 2016; 23: e77-89.
- [51] Passmore HM, Mutch RC, Burns S, et al. Fetal Alcohol Spectrum Disorder (FASD): Knowledge, attitudes, experiences and practices of the Western Australian youth custodial workforce. *Int J Law Psychiatry* 2018; 59: 44–52.
- [52] Cox LV, Clairmont D, Cox S. Knowledge and attitudes of criminal justice professionals in relation to Fetal Alcohol Spectrum Disorder. *Can J Clin Pharmacol* 2008; 15: e306-13.
- [53] Centers for Disease Control and Prevention (CDC). Fetal Alcohol Spectrum Disorders (FASDs)

| NCBDDD | CDC. <https://www.cdc.gov/ncbddd/fasd/index.html> (2018, accessed 7 May 2018).

- [54] Coons KD, Watson SL, Schinke RJ, et al. Adaptation in families raising children with fetal alcohol spectrum disorder. Part I: What has helped. *J Intellect Dev Disabil* 2016; 41: 150–165.
- [55] Hanlon-Dearman A, Green CR, Andrew G, et al. Anticipatory guidance for children and adolescents with fetal alcohol spectrum disorder (FASD): practice points for primary health care providers. [https://www.researchgate.net/profile/Ana\\_Hanlon-Dearman/publication/271140236\\_Anticipatory\\_Guidance\\_for\\_Children\\_and\\_Adolescents\\_with\\_Fetal\\_Alcohol\\_Spectrum\\_Disorder\\_FASD\\_Practice\\_Points\\_for\\_Primary\\_Health\\_Care\\_Providers/links/5504684b0cf2d60c0e677bc9/Ant](https://www.researchgate.net/profile/Ana_Hanlon-Dearman/publication/271140236_Anticipatory_Guidance_for_Children_and_Adolescents_with_Fetal_Alcohol_Spectrum_Disorder_FASD_Practice_Points_for_Primary_Health_Care_Providers/links/5504684b0cf2d60c0e677bc9/Ant) (accessed 7 June 2017).
- [56] Kapasi A. *'Caregivers' Experiences Raising a Child with Fetal Alcohol Spectrum Disorder'*. Other Psychology Commons. <https://ir.lib.uwo.ca/etd/2713> (2015, accessed 22 February 2019).





# SECTION IV

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In this section, summary and recommendation and conclusion was written in form a policy brief.

This was done in line with the aim of the study.



# CHAPTER SEVEN

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Policy requirements for the prevention and management of fetal alcohol spectrum disorder in South Africa. *International Perspectives in Psychology: Research, Practice, Consultation (Under review)*

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## **Executive summary**

This policy brief emanated from a Ph.D. study designed to develop a guideline for the prevention and management of fetal alcohol spectrum disorder (FASD) to guide policymakers in developing a comprehensive and multi-sectoral policy. FASD is a leading source of non-genetic developmental and intellectual disability and is usually associated with primary and secondary disabilities. South Africa has been identified to have the highest prevalence of FASD in the world. Nevertheless, evidence shows that there is no specific policy for FASD, albeit there are clauses that could be attributed to its prevention and management in other existing policies. This brief is to inform policymakers about a guideline to tackle the FASD problem and other relevant contexts through developing a policy to guide the design and implementation of FASD interventions and programmes in South Africa.

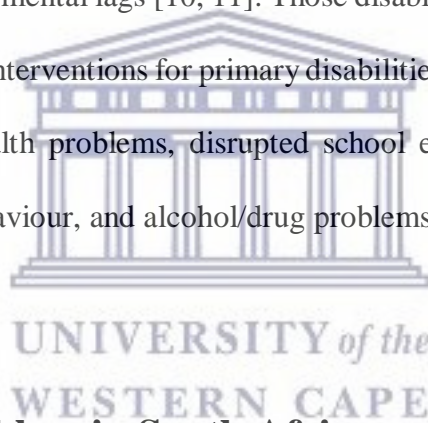


## Key Points

- Alcohol consumption (especially during pregnancy) is a complex public health issue in South Africa, with various adverse outcomes including fetal alcohol spectrum disorder (FASD), which is the leading source of non-genetic developmental and intellectual disabilities.
- The national prevalence of FASD in South Africa ranges from 29 to 290 per 1 000 live births, which is the highest in the world.
- Research shows the lack of a harmonised approach and specific policy to address FASD in South Africa while government programmes remain limited and fragmented across relevant departments. Therefore, there is a need for streamlined programmes within the integrated health system to address FASD.
- Research indicates the need to develop a comprehensive and multi-sectoral policy for the prevention and management of FASD.
- Evidence suggests having a policy that is culturally diverse and sensitive, collaborative, holistic, evidence-based, multi-sectoral and that considers needs across the lifespan and address social determinants of health could address FASD.
- Finding indicates awareness and education of the dangers of drinking alcohol, access to treatment for alcohol problems, training of service providers, capacity building related to diagnosis and support for parents and individuals with FASD as the essential components of an FASD policy.
- More research is needed on how to successfully implement a comprehensive and multi-sectoral policy for FASD.
- There are no safe limits of alcohol during pregnancy.

## **An overview of FASD**

Fetal alcohol spectrum disorder is a diagnostic term used to describe a range of conditions affecting persons exposed to alcohol during pregnancy [1–3]. These conditions can be classified under four groups, i.e. fetal alcohol syndrome (FAS), partial FAS, alcohol-related neurodevelopmental disorders and alcohol-related birth defects [4, 5]. No amount of alcohol is safe, and there is no safe time to drink during pregnancy which will not lead to FASD [6, 7]. FASD may lead to primary and secondary disabilities [8]. Primary disabilities are those with which these individuals are born [9]. They may include intellectual disability, learning difficulties, poor impulse control, problems with attention, memory loss, social perception, reasoning and using judgement, cognitive processing, mathematics and language deficits, and developmental lags [10, 11]. Those disabilities that have developed because of a lack of early and appropriate interventions for primary disabilities are called secondary disabilities. They could comprise mental health problems, disrupted school experience, trouble with the law, custody, inappropriate sexual behaviour, and alcohol/drug problems [12].



## **Contextualising the problem in South Africa**

South Africa is considered to have the highest prevalence of FASD in the world, which ranges from 29 to 290 per 1 000 live births [13]. Alcohol drinking is a complex public health issue in the country, with various adverse outcomes including FASD [13, 14]. The rate of alcohol consumption in South Africa is said to be the highest in Africa and among the highest in the world [15]. The levels of lifetime consumption of alcohol are 49% and 22% for men and women, respectively [16]. Although the rate of alcohol consumption for women seems low, it is important to know that those who drink, do so in excess and binge drinking is widespread [17–19]. Alcohol consumption during pregnancy is also rampant with a rate ranging from 2.5% to 45% [20]. Drinking is used by many women to cope with their socio-economic and socio-political realities [21].

The root cause of excessive alcohol consumption in South Africa could be linked to the ‘dop’ system – a practice where farmers compensated for work either in part or in full using alcoholic beverages [22]. Although this system has been abolished, its lingering effects remain and still influences the drinking patterns for men and women, especially those in wine-producing areas [23]. The ‘dop’ system contributes to a persistent increase in the prevalence of FASD along with the presence of many illegal liquor stores, e.g. shebeens which make alcohol accessible to all groups of people [24].

The endemic nature of maternal risk factors causes the FASD problem to be severe in South Africa [25]. These factors include low socio-economic status, unemployment, low educational status, sexual and intimate partner violence, substance abuse, living conditions, family structure (single parent), an unhealthy lifestyle, low religiosity, and unhealthy patterns of alcohol consumption [25]. The National Department of Health and Western Cape Government have recognised FASD as one of ten focal genetic conditions and priority birth defects [26]. However, services and interventions to address FASD are fragmental across relevant departments at national and provincial level [27–29]. Most efforts to address FASD in South Africa have been made by non-profit organisations whose services have been hindered by a shortage of capital and human resources [28].

## **Summary of the findings from the study**

Our study confirmed that there is no specific policy document addressing FASD in South Africa [27, 28, 30]. However, clauses that possibly attribute to the prevention and management of FASD exist in other related policy documents, although these do not address FASD in a holistic manner. We conducted a document review of several related policy documents. This review indicated that more policy-related documents mentioned the terms FAS and FASD in comparison to another one conducted in 2008 [29, 31]. Even with the availability of effective interventions in preventing and managing

FASD, this finding cannot be construed that the increase in the number of policy documents mentioning these terms has translated to a systematic approach in addressing FASD. Herein, we explored the policymakers and service providers re approaches to policy development and policy requirements for the prevention and management of FASD. Then, we engaged the experts on FASD through the Delphi approach to formulating measures for the prevention and management of FASD in South Africa.

### **The proposed measures for the prevention and management of FASD in South Africa**

#### **Overall guiding principles of the policy**

- Be holistic, considering the prevention, diagnosing and management of FASD.
- Consider the individual with FASD and their caregivers.
- Involve all relevant government departments such as the departments of health, education, justice, social development, trade and industry, labour.
- Consider the needs of individuals with FASD throughout their lifespan.
- Involve the collaborative action of various professionals (social service, justice and healthcare); healthcare professionals from the doctors, midwives, nurses, to the community healthcare workers.
- Adopt a human rights-based approach, which protects and promotes the rights of women, children, families and communities affected by FASD and recognises the principles of non-discrimination, participation, inclusion, equity and access.
- Adopt a public health framework, which acknowledges drinking during pregnancy and FASD are part of a complex interplay of biological, social, psychological, environmental and economic factors.
- Be culturally diverse and culturally sensitive, acknowledging the importance and strength of cultural values and norms.
- Use relevant and current evidence to inform practice and interventions to strengthen the knowledge base to effectively prevent and manage FASD.
- Establish clear referral pathways for the effectiveness of the prevention and management FASD
- Avoid victim blaming that is placing women at the centre of the FASD problem, which will not consider them as the perpetrators of the problem.
- Consider cost-effective interventions, which encourages a population-wide approach and enhances a wider coverage.
- Be family-centred, service providers must acknowledge and value the need for individuals within the family structure.
- Address social determinants of health contributing to FASD.
- Consider input from individuals with FASD and their families in developing a policy for the prevention and management of FASD.

- Promote responsible parenting, which recognises human values and enhance the development of individuals with FASD.

## **FASD prevention measures**

### **Education-related prevention measures for FASD**

- Increase awareness of the dangers of drinking alcoholic beverages during pregnancy in educational settings.
- Assist individuals with alcohol-use problems in educational settings to access treatment.
- Address the barriers to access treatment for alcohol-related problems in educational settings.
- Address stigma associated with alcohol abuse in educational settings.
- Improve training of teachers on FASD prevention/awareness programme.
- Facilitate the development and implementation of FASD awareness programmes in educational settings.
- Facilitate the use of peer education for FASD awareness programme in educational settings.
- Promote healthy lifestyle in schools through sport and other extra-curricular activities.
- Discourage the establishment of the liquor stores in the proximity of educational settings.
- Promote the education of young individuals about healthy pregnancy in educational settings.
- Facilitate the teaching of responsible parenthood in educational settings.
- Improve the teaching of safe sex practices in educational settings.

### **Health-related prevention measures for FASD**

- Improve the screening of alcohol use in clinics and hospitals.
- Improve documentation on the alcohol history for women, especially pregnant women.
- Facilitate the inclusion of FASD prevention as a part of health promotion activities in clinics and hospitals.
- Improve the education of individuals and couples on the dangers of drinking alcoholic beverages during pregnancy in the pre-conception clinic.
- Improve the education of individuals and couples on the dangers of drinking alcoholic beverages during pregnancy in the reproductive clinic.
- Encourage the use of visible posters and pamphlets for FASD prevention campaigns in all clinics and hospitals.
- Improve the training of healthcare professionals on FASD prevention.
- Improve early and appropriate referral to treatment for individuals (including women) with alcohol misuse issues.
- Empower health professionals with the skills to counsel and ask questions about alcohol use in a safe and appropriate way.
- Promote the use of contraceptives to avoid unplanned pregnancy.
- Improve assistance to parents of individuals with FASD to avoid having another child with FASD.

### **Community/social-related prevention measures for FASD**

- Improve education and public awareness of the dangers of alcohol abuse.
- Improve the education of all people in the community on the dangers of drinking alcohol during pregnancy.
- Improve the education of individuals and couples on the dangers of drinking alcohol during pregnancy in the community.



- Encourage the use of community groups for FASD prevention (education and awareness).
- Improve the training of the community health /community-based workers and youth care/social workers on FASD prevention.
- Facilitate early intervention and assistance for individuals with alcohol-use problems in the community.
- Facilitate the creation of social programmes such as skills training and empowerment programmes for women in the community.
- Improve awareness and education on FASD in the workplace, rural and urban areas and farming communities.
- Promote the use of multimedia such as posters, adverts, pamphlets, TV, social media and road shows for FASD awareness in the communities.
- Improve enforcement of liquor laws and regulation of shebeens to control accessibility and availability of alcohol in the community.
- Improve access to treatment for people with alcohol use problems in the community.
- Improve smooth aftercare and community reintegration for people who have attended alcohol rehab.
- Promote afterschool activities in the community to prevent early exposure of adolescents to alcohol.
- Mandate labels on alcohol containers to contain information on the dangers of drinking alcoholic beverages during pregnancy.
- Mandate that liquor stores have warning signs regarding alcohol and pregnancy.
- Enable the creation of support groups for individuals with alcohol misuse issues in the community.
- Facilitate the training of the community and religious leaders on FASD prevention.
- Promote collaboration and the use of non-profit organisation (NPO) for FASD prevention.
- Utilise the community and religious leaders to increase FASD awareness among their communities.
- Promote the expansion and adoption of NPO evidence-based interventions for prevention in the community.
- Improve assistance to families to support individuals with alcohol use problems.
- Improve interventions services for mothers who have a child with FASD in the community.

## **FASD management measures**

### **Education-related management measures for FASD**

- Facilitate the development of a curriculum that accommodates individuals with FASD.
- Improve the training of teachers on classroom management for individuals with FASD.
- Promote skill schools for learners with learning disabilities (including individuals with FASD) that are not benefiting from formal education.
- Provide special assistance for individuals with FASD within mainstream schools.
- Facilitate the creation of the special schools for learners with a learning disability (including individuals with FASD) that are not benefiting from mainstream schooling.
- Facilitate the education of parents on the needs and management of individuals with FASD.

### **Health-related management measures for FASD**

- Increase capacity building re diagnosis among health professionals.
- Facilitate FASD screening for all children that are known to have been prenatally exposed to alcohol.

- Provide diagnostic services for individuals.
- Promote diagnosis for school children, adolescents and adults to reduce rates of people who are left undiagnosed or misdiagnosed.
- Promote appropriate referral pathways to services after diagnosis.
- Facilitate the creation of diagnostic centres in clinics, hospitals and communities.
- Facilitate the creation of national surveillance for FASD via reports from health professionals.
- Encourage routine consideration of FASD re the diagnosis and management of mental illness and developmental disorders.
- Provide integrated medical services for individuals with FASD.

#### **Community/social-related management measures for FASD**

- Provide skills training and empowerment programmes for those who need it among individuals with FASD.
- Facilitate appropriate employment opportunities for individuals with FASD.
- Facilitate the training of community health workers/community-based workers/ youth care workers/ social workers and professionals within the judiciary system re FASD management.
- Improve the training of the biological and foster parents/caregivers regarding the management of FASD.
- Promote the empowerment of the parents/caregivers of individuals with FASD in the community.
- Promote the establishment of support systems for biological and foster parents/caregivers and individuals with FASD in the community.
- Promote the referral of parents and individuals with FASD to appropriate services.
- Provide effective counselling services for parents and individuals with FASD.
- Encourage family/community support for individuals with FASD.
- Provide support for individuals with FASD in child protection/foster care and the criminal justice system.
- Facilitate the creation of structure and supportive environment at home, school and beyond.
- Facilitate the provision of adequate information about individuals with for the adoptive parents.

## **Conclusions**

FASD is recognised as a public health problem in South Africa. However, there is no specific policy to guide efforts to address the condition. There has been a persistent increase in FASD prevalence despite current prevention efforts. This increase calls for the decolonisation of the current approach to policy and intervention. FASD is a lifelong disability that affects individuals, families and

communities, preventing people from actualising their potentials. Therefore, to achieve Vision 2030 (National Development Plan), strategies for FASD should be streamlined within the current integrated services.

A policy should be developed to facilitate awareness and education programmes in the communities, health facilities and schools and the training of service professionals re FASD prevention strategies. The policy should also encourage the training of relevant service providers regarding the diagnosis and management of individuals with FASD. Furthermore, it should support individuals with FASD and their families along with skills development for these individuals.

## Recommendations

In developing this policy, we recommend the following:

- (1) The policy should be developed in a way that incorporates most of the guiding principles that we have mentioned above. Collaboration between different sectors (departments) to prevent and manage FASD requires policy development to take a multi-sectoral approach. The many consequences that may arise from prenatal alcohol exposure usually encompassing medical, educational and social problems warrant the collaboration of the relevant departments, which currently work in silos. Therefore, to address FASD holistically, departments such as Education, Health, Social Development, Labour, Trade and Industry, Justice and Correctional Services should collaboratively work together. Working in this manner will ensure information sharing and promote interventions across the lifespan.
- (2) There are many factors such as income, living conditions, educational status (social determinant of health) contributing to the increase in the prevalence of FASD. There is a need to address these factors for interventions to be effective in addressing FASD. Furthermore,

interventions for prevention and management must be based on current evidence and culturally diverse and sensitive. Additionally, a family-centred approach should be considered in the development of the policy. This approach encourages input from individuals with FASD and their families and ensures their human rights are protected. Moreover, there is a need to decolonise the current policy approach; women should be seen as victims and not perpetrators of the problem to avoid victim-blaming.

- (3) FASD is preventable, therefore there is a need to develop holistic prevention strategies for FASD to reduce the prevalence of FASD and the number of individuals who will require management services. There is a need for awareness and education on the danger of drinking alcohol during pregnancy in the communities, health facilities and schools targeting young adolescents. The importance of awareness and education is to promote abstinence and responsible drinking before adolescents reach childbearing age. Awareness and education should also target the general population, and could be part of the current integrated services. However, these strategies need to be streamlined within the integrated services for them to be effective in addressing FASD.
- (4) Because unplanned pregnancies contribute to the increase in the prevalence of FASD, there should be a promotion of the use of contraceptives to couples. Furthermore, individuals with an alcohol problem should be assisted to access and complete treatment and be supported to integrate into society after treatment. Promoting skills development and a social programme is also necessary for the communities to engage individuals, and may reduce drinking. Also, relevant service providers should be trained to be able to document and counsel individuals appropriately as well as pregnant women with alcohol problems.
- (5) There is a need to develop a comprehensive strategy to manage FASD. The consequences of prenatal alcohol exposure may lead to both primaries and secondary disabilities. These consequences must be managed timeously to improve the quality of life for individuals with

FASD. FASD-related screening of babies confirmed to have been exposed to alcohol during pregnancy should be routinised. Routinised screening can promote early diagnosis and intervention to prevent secondary disabilities. Relevant service providers to support the routine screening of diagnosis and management is necessary as it requires a multidisciplinary team of professionals to diagnose FASD. Early diagnosis and the establishment of national surveillance for FASD are encouraged to create a mechanism for managing FASD. Training of teachers should also be included in an FASD policy for classroom management of FASD, as individuals with this condition may find the classroom challenging and require additional support to cope.

- (6) Policymakers should consider enacting an FASD policy that promotes a school of skills and special schools for individuals with FASD who are not benefiting from the mainstream schools because of their low intellectual abilities. When designing FASD programmes and interventions, support for individuals with the disorder and their biological and foster parents should also be considered. This support can enable individuals with FASD to maximise their potential.

- (7) An enacted FASD policy must consider viable and reliable pathways for sharing information on a diagnosis across departments, especially departments such as Education, Health and Social Development. For example, if a child is diagnosed by the Department of Health, this information must be shared with the Department of Education, so that the child can be assisted and channelled to an appropriate school. The information should also be shared with the Department of Social Development to assist the child and parents in the communities, and with the Department of Justice and Labour.

## References

- [1] Burns L, Breen C, Bower C, et al. Counting fetal alcohol spectrum disorder in Australia: the evidence and the challenges. *Drug and Alcohol Review* 2013; 32: 461–467.
- [2] Cook JL, Green CR, Lilley CM, et al. Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *CMAJ* 2016; 188: 191–197.
- [3] Mutch RC, Watkins R, Bower C. Fetal alcohol spectrum disorders: notifications to the Western Australian register of developmental anomalies. *J Paediatr Child Health* 2015; 51: 433–436.
- [4] Chudley AE, Conry J, Cook JL, et al. Fetal Alcohol Spectrum Disorder: Canadian guidelines for diagnosis. *CMAJ* 2005; 172: S1–S21.
- [5] Blackburn C, Whitehurst T. Fetal alcohol spectrum disorders (FASD): raising awareness in early years settings. *Br J Spec Educ* 2010; 37: 122–129.
- [6] Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities D of BD and DD. Alcohol Use in Pregnancy | FASD | NCBDDD | CDC. *Centers for Disease Control and Prevention*, <https://www.cdc.gov/ncbddd/fasd/alcohol-use.html> (2018, accessed 16 July 2018).
- [7] National Organization on Fetal Alcohol Syndrome. National Organization of Fetal Alcohol Syndrome, <https://www.nofas.org/> (2018, accessed 16 July 2018).
- [8] Warren KR. A review of the history of attitudes toward drinking in pregnancy. *Alcohol Clin Exp Res* 2015; 39: 1110–1117.
- [9] Ann P. Streissguth, Helen M. Barr, Julia Kogan et al. Understanding the occurrence of secondary disabilities in clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE).



*Centers for Disease Control and Prevention* 1996; 96–06.

- [10] Riley EP, McGee CL. Fetal Alcohol Spectrum Disorders: an overview with emphasis on changes in brain and behavior. *Exp Biol Med (Maywood)* 2005; 230: 357–65.
- [11] Riley EP, Infante MA, Warren KR. Fetal Alcohol Spectrum Disorders: an overview. *Neuropsychol Rev* 2011; 21: 73–80.
- [12] Clark E, Lutke J, Minnes P, et al. Secondary disabilities among adults with Fetal Alcohol Spectrum Disorder in British Columbia. *J FAS Int* 2004; 2: 1–12.
- [13] Olivier L, Curfs LMG, Viljoen DL. Fetal alcohol spectrum disorders: prevalence rates in South Africa. *South African Med J* 2016; 106: 103–106.
- [14] Jacobs, L., Steyn, N., & Labadarios D. 'Mind the gap': observations in the absence of guidelines for alcohol abstinence among expectant women in South Africa, <http://repository.hsra.ac.za/bitstream/handle/20.500.11910/3008/7682.pdf?sequence=1> (2013, accessed 12 January 2018).
- [15] WHO. Global status report on alcohol and health. *World Heal Organ* 2014; 1–100.
- [16] Statistics South Africa. Media release: South Africa Demographic and Health Survey | Statistics South Africa. *Statistics South Africa*, <http://www.statssa.gov.za/?p=9836> (2016, accessed 12 January 2018).
- [17] Vellios NG, Van Walbeek CP. Self-reported alcohol use and binge drinking in South Africa: Evidence from the National Income Dynamics Study, 2014 - 2015. *South African Med J* 2017; 108: 33.
- [18] Peltzer K, Davids A, Njuho P. Alcohol use and problem drinking in South Africa: findings from



a national population-based survey. *Afr J Psychiatry* 2011; 14: 30–7.

- [19] Chambers D. Binge-drinking is a huge problem in SA — but we can't admit it | UCT News, <https://www.news.uct.ac.za/article/-2018-01-04-binge-drinking-is-a-huge-problem-in-sa-but-we-cant-admit-it> (2018, accessed 1 February 2019).
- [20] Culley CL, Ramsey TD, Mugenyi G, et al. Alcohol exposure among pregnant women in sub-saharan Africa: a systematic review. *J Popul Ther Clin Pharmacol* 2013; 20: e321-33.
- [21] Cloete L, Ramugondo E. 'I drink': mothers' alcohol consumption as both individualised and imposed occupation. *South African J Occup Ther* 2015; 45: 34–40.
- [22] London L. The 'dop' system, alcohol abuse and social control amongst farm workers in South Africa: a public health challenge. *Soc Sci Med* 1999; 48: 1407–1414.
- [23] Phillip Gossage J, Snell CL, Parry CDH, et al. Alcohol use, working conditions, job benefits, and the legacy of the 'dop' system among farm workers in the Western Cape Province, South Africa: Hope despite high levels of risky drinking. *Int J Environ Res Public Health* 2014; 11: 7406–7424.
- [24] Bowers Y, Rendall-Mkosi K, Davids A, et al. Liquor outlet density, deprivation and implications for foetal alcohol syndrome prevention in the Bergriver municipality in the Western Cape, South Africa. *South African Geogr J* 2014; 96: 153–165.
- [25] Esper LH, Furtado EF. Identifying maternal risk factors associated with Fetal Alcohol Spectrum Disorders: a systematic review. *Eur Child Adolesc Psychiatry* 2014; 23: 877–889.
- [26] London leslie. South Africa fails to tackle its high foetal alcohol syndrome rate, <http://theconversation.com/south-africa-fails-to-tackle-its-high-foetal-alcohol-syndrome-rate-46791> (2015, accessed 18 December 2018).

- [27] Adebiyi BO, Mukumbang FC, Cloete LG, et al. Policymakers' Perspectives Towards Developing a Guideline to Inform Policy on Fetal Alcohol Spectrum Disorder: A Qualitative Study. *Int J Environ Res Public Health* 2019; 16: 945.
- [28] Adebiyi BO, Mukumbang FC, Cloete LG, et al. Exploring service providers' perspectives on the prevention and management of fetal alcohol spectrum disorders in South Africa: A qualitative study. *BMC Public Health*; 18. Epub ahead of print 2018. DOI: 10.1186/s12889-018-6126-x.
- [29] Rendall-Mkosi K, London L, Adnams C, et al. Fetal alcohol spectrum disorder in South Africa: situational and gap analysis. *UNICEF, Pretoria*, [https://www.unicef.org/southafrica/SAF\\_resources\\_fetalalcohol.pdf](https://www.unicef.org/southafrica/SAF_resources_fetalalcohol.pdf) (2008, accessed 14 September 2017).
- [30] Adebiyi BO, Mukumbang FC, Okop KJ, et al. A modified Delphi study towards developing a guideline to inform policy on fetal alcohol spectrum disorders in South Africa: a study protocol. *BMJ Open* 2018; 8: e019907.
- [31] Adebiyi BO, Mukumbang FC, Beytell A-M. To what extent is Fetal Alcohol Spectrum Disorder considered in policy-related documents in South Africa? A document review. *Heal Res Policy Syst* 2019; 17: 46.

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# APPENDIX

## Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No. Item	Guide questions/description	Reported on Page #
<b>Domain 1: Research team and reflexivity</b>		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Results (8) Babatope O. Adebisi
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Babatope O. Adebisi PhD Student  Ferdinand C. Mukumbang PhD  Lizahn G. Cloete PhD  Anna-Marie Beytell PhD
3. Occupation	What was their occupation at the time of the study?	Student; Post-Doctoral researcher Lecturer, Lecturer
4. Gender	Was the researcher male or female?	Male, Male, Female, Female
5. Experience and training	What experience or training did the researcher have?	Methods (1) They all have extensive experience in conducting qualitative study
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	(8) Yes
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	(8) Participant information sheet and Consent form
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Methods (9) The participants know that the primary researcher is a student
<b>Domain 2: study design</b>		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Methods (8,10) - Exploratory qualitative design - Framework Method
<i>Participant selection</i>		

10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Methods (8) Purposive sampling
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Methods (8) face-to-face, telephone, email
12. Sample size	How many participants were in the study?	Results (9) 65
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Methods (8) 3 (It was because of the work load)
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Methods (9) Clinic, workplace
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Results (9) No
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Results (9) Profession, Gender and Working experience
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Methods (9) No
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Methods (9) Yes
20. Field notes	Were field notes made during and/or after the interview or focus group?	Methods (9) Yes
21. Duration	What was the duration of the inter views or focus group?	Methods (9) 30 – 60 minutes
22. Data saturation	Was data saturation discussed?	Methods Yes
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A No
<b>Domain 3: analysis and findings</b>		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	Methods (10) 2
25. Description of the coding tree	Did authors provide a description of the coding tree?	No
26. Derivation of themes	Were themes identified in advance or derived from the data?	Methods (10) Derived from the data?
27. Software	What software, if applicable, was used to manage the data?	N/A
28. Participant checking	Did participants provide feedback on the findings?	Strengths and limitations No
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Results (11-22) Yes
30. Data and findings consistent	Was there consistency between the data presented and the findings?	(22-27)

		Relationship to existing knowledge Yes
31. Clarity of major themes	Were major themes clearly presented in the findings?	Results (11-22) Yes
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Discussion (22-27) Yes



Open Access

Protocol

## BMJ Open A modified Delphi study towards developing a guideline to inform policy on fetal alcohol spectrum disorders in South Africa: a study protocol

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### ABSTRACT

**Introduction** Maternal alcohol consumption during pregnancy can result in mental and physical birth defects in individuals. These birth defects are usually described as fetal alcohol spectrum disorders (FASDs). With an estimated 183–259 per 1000 children born with FASDs, South Africa is identified to have the highest prevalence of FASDs in the world. Nevertheless, there is a lack of appropriate policies, guidelines and interventions addressing the issues around FASDs. This protocol outlines a proposed process for developing a guideline to inform policies on FASDs.

**Methods and analysis** This process will have three phases. Phase I will be carried out in three steps: we plan to conduct a document review of available policies on the prevention and management of FASDs and update the existing systematic review on FASDs interventions. The aim of the two reviews is to explore the availability and content of existing policies and global interventions on FASDs. In addition, we will conduct two exploratory qualitative studies to obtain the perspectives of various stakeholders on the existing or possible guidelines and policies for the management of FASDs and available interventions and services. In phase II, we will aggregate the findings of the previous phase to develop a prototype guideline. In phase III, using the developed prototype, we will apply the Delphi approach with experts on FASDs, soliciting their opinions on the nature and content of the proposed guidelines for policies. The information gathered will be used to modify the prototype to formulate a policy guideline on FASDs. The data will be analysed using thematic analysis and narrative synthesis.

**Ethics and dissemination** Ethical clearance has been obtained from the ethics committee of the university and governmental departments. The findings will be disseminated through publications and the guideline will be submitted to relevant departments.

### INTRODUCTION

Fetal alcohol spectrum disorders (FASDs) refer to an array of birth disorders related to fetal exposure to alcohol during pregnancy. FASDs are classified under four broad groups: fetal alcohol syndrome (FAS), partial FAS,

### Strengths and limitations of this study

- The study proposes the use of multiple sources for data collection towards developing a guideline to inform policy on fetal alcohol spectrum disorders (FASDs).
- It also proposes a proven methodology—the Delphi technique to develop the guideline.
- A potential limitation of this study is that it will not include individuals with FASDs.
- This study is expected to inform policy on FASDs nationally; however, it will be conducted in only one province out of nine provinces of South Africa.

alcohol-related neurodevelopment disorders (ARNDs) and alcohol-related birth defects.<sup>1</sup> Of these four groups, FAS is identified as having the most serious anomalies.<sup>2,3</sup>

FASDs may lead to primary and secondary disabilities.<sup>4</sup> Primary disabilities are those that the child is born with,<sup>5</sup> usually associated with damages to the brain domains that are responsible for physical motor skills, sensory processing skills, cognition, communication skills, academic achievement, memory skills, executive functioning and abstract reasoning, attention and adaptive skills.<sup>6,7</sup> The brain damages could also result in physical abnormalities such as antenatal and postnatal growth retardation, eye and ear malformations, mouth and jaw deformation, skeletal defects, organ pathology, sensory deficits and impaired immune system.<sup>1</sup>

Secondary disabilities relate to those disabilities that develop because of untimely and inappropriate interventions to primary disabilities—consequences of unaddressed primary disabilities. These include fatigue, frustration, anxiety, fearfulness, rigid, resistant, argumentative behaviour, becoming overwhelmed, shut down (withdrawn), a poor self-concept, feelings of failure, low

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BMJ

Adebisi BO, et al. *BMJ Open* 2018;8:e019907. doi:10.1136/bmjopen-2017-019907

1



RESEARCH ARTICLE

Open Access



# Exploring service providers' perspectives on the prevention and management of fetal alcohol spectrum disorders in South Africa: a qualitative study

Babatope O. Adebiyi<sup>1\*</sup>, Ferdinand C. Mukumbang<sup>1</sup>, Lizahn G. Cloete<sup>1</sup> and Anna-Marie Beyteli<sup>2</sup>

## Abstract

**Background:** Fetal alcohol spectrum disorder (FASD) is among the leading causes of developmental and intellectual disabilities in individuals. Although efforts are being made toward the prevention and management of FASD in South Africa, the prevalence remains high. The sustained high prevalence could be attributed to several factors, including the lack of policy for a coordinated effort to prevent, diagnose and manage FASD nationally. In this study, our aim was to explore the perspectives of service providers (health and allied professionals, teachers, social workers) on the prevention and management of FASD towards developing a guideline to inform policy.

**Method:** Guided by the exploratory qualitative research design, we purposively sampled relevant service providers in the field of FASD prevention and management for focus group discussions. Nine of these discussions were conducted with to eight participants per discussion session. The discussants were asked various questions on the current and required interventions and practices for the prevention and management of FASD. Following the Framework Method, data were transcribed verbatim and analysed using the thematic content analysis approach.

**Results:** Our findings show that aspects of the prevention and management of alcohol-related conditions are present in various policies. However, there is no clear focus on coordinated, multi-sectoral efforts for a more comprehensive approach to the prevention and management of FASD. The participants recognised the need for specific requirements on broad-based preventive awareness programs, training and support for parents and caregivers, inclusive education in mainstream schools and training of relevant professionals.

**Conclusions:** Comprehensive and coordinated prevention and management programs guided by a specific policy could improve the prevention and management of FASD. Policy formulation demonstrates commitment from the government, highlights the importance of the condition, and elaborates on context-specific prevention and management protocols.

**Keywords:** Policies, Guidelines, Fetal alcohol Spectrum disorders, Service providers, Interventions, Services, Women, Development disabilities, Prevention, Management

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Full list of author information is available at the end of the article







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Article

# Policymakers' Perspectives Towards Developing a Guideline to Inform Policy on Fetal Alcohol Spectrum Disorder: A Qualitative Study

Babatope O. Adebisi <sup>1,\*</sup> , Ferdinand C. Mukumbang <sup>1</sup> , Lizahn G. Cloete <sup>2</sup>  and Anna-Marie Beytell <sup>3</sup> 

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Received: 5 February 2019; Accepted: 11 March 2019; Published: 15 March 2019



**Abstract:** Fetal alcohol spectrum disorder (FASD) has a high prevalence in South Africa, especially among the poor socioeconomic communities. However, there is no specific policy to address FASD. Using a qualitative study design, we explored the perspectives of policymakers on guidelines/policies for FASD, current practices and interventions, and what practices and interventions could be included in a policy for FASD. The data analysis was done using the Framework Method. Applying a working analytical framework to the data, we found that there is no specific policy for FASD in South Africa, however, clauses of FASD policy exist in other policy documents. Preventive services for women and screening, identification, assessment, and support for children are some of the current practices. Nevertheless, a multi-sectoral collaboration and streamlined program for the prevention and management of FASD are aspects that should be included in the policy. While there are generic clauses in existing relevant policy documents, which could be attributed to the prevention and management of FASD, these clauses have not been effective in preventing and managing the disorder. Therefore, a specific policy to foster a holistic and coordinated approach to prevent and manage FASD needs to be developed.

**Keywords:** policies; guidelines; fetal alcohol spectrum disorder; policymakers; interventions; services; women; developmental disabilities; alcohol; children

RESEARCH

Open Access

# To what extent is Fetal Alcohol Spectrum Disorder considered in policy-related documents in South Africa? A document review



Babatope O. Adebisi<sup>1\*</sup>, Ferdinand C. Mukumbang<sup>1</sup> and Anna-Marie Beytell<sup>2</sup>

## Abstract

**Background:** South Africa is considered to have the highest prevalence of fetal alcohol spectrum disorder (FASD) globally. Nevertheless, the extent to which the South African government has responded to the high FASD prevalence at the policy level is unclear. Herein, we aimed to identify targeted and generic clauses that could be attributed to the prevention and management of FASD in relevant South African policy documents.

**Methods:** We conducted a search of two search engines (PubMed and Google) and the websites of South African national and provincial departments from January to April 2018. A total of 33 policy documents were included in this review. Using content analysis, we sought documents that mention the terms 'fetal alcohol syndrome' and 'fetal alcohol spectrum disorder'. The Framework method was also used to thematically identify specific and generic clauses attributed to the prevention and management of FASD in South Africa.

**Results:** The content analysis indicated that 12 policy documents contained the searched terms. Findings from the thematic analysis showed that targeted and generic clauses for FASD exist in various policy documents. Some of the generic clauses focused on the regulation of liquor outlets, enforcement of liquor laws, and the general management of persons with mental and educational challenges. Specific clauses focused on creating platforms to improve the awareness, screening, identification and support for individuals with FASD.

**Conclusions:** There is a noticeable increase in the number of policy documents that considered elements of FASD enacted in the last decade. Although this study revealed the existence of targeted and generic clauses that could be attributed to the prevention and management of FASD, the sustained high prevalence of FASD in South Africa, as reported in the literature, calls for more holistic and comprehensive approaches to tackle this FASD problem in South Africa.

**Keywords:** Fetal alcohol spectrum disorder, policy, guidelines, clauses, South Africa, prevention, management, development disabilities, pregnancy, alcohol

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# The Distribution of Available Prevention and Management Interventions for Fetal Alcohol Spectrum Disorder (2007 to 2017): Implications for Collaborative Actions

Babatope O. Adebisi<sup>1,\*</sup> , Ferdinand C. Mukumbang<sup>1</sup>  and Charlene Erasmus<sup>2</sup> 

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(This article belongs to the Special Issue Fetal Alcohol Spectrum Disorder (FASD))

 Full-Text |  PDF [1627 KB, uploaded 25 June 2019] |  Figures |  Review Reports

## Abstract

The global prevalence of Fetal Alcohol Spectrum Disorder (FASD) remains high despite the various preventive and management interventions that have been designed and implemented to tackle the issue in various settings. The aim of the scoping review is to identify and classify prevention and management interventions of FASD reported globally across the life span and to map the concentration of these interventions across the globe. We searched some selected databases with predefined terms. Framework and narrative approaches were used to synthesize and report on the findings. Thirty-two prevention intervention studies and 41 management interventions studies were identified. All the interventions were reported to be effective or showed promising outcomes for the prevention and management of FASD, except four. Although Europe and Africa have a relatively higher prevalence of FASD, the lowest number of interventions to address FASD were identified in these regions. Most of the interventions for FASD were reported in North America with comparatively lower FASD prevalence. The uneven distribution of interventions designed for FASD vis-à-vis the burden of FASD in the different regions calls for a concerted effort for knowledge and intervention sharing to enhance the design of contextually sensitive preventive and management policy in the different regions. [View Full-Text](#)

**Keywords:** fetal alcohol spectrum disorder; perinatal alcohol exposure; prevention; management; interventions; scoping review; pregnant women; children; adults; development disabilities

## ▼ Figures



# SUBMITTED ARTICLES



Health Services Research

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## 2nd Australasian FASD Conference 2018 Our Science Our Stories

Dear Babatope,

We look forward to meeting you at the Pan Pacific Hotel in November 2018 for the **2nd Australasian FASD Conference: Our Science Our Stories**.

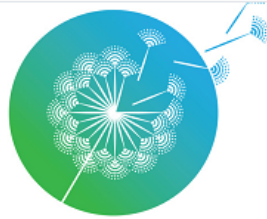
Please find below details of all your presentation/s. This information will be printed in the program and your biography will be provided to the session chairs for a brief introduction.

Should there be any discrepancies in your biography, presentation title, author or organisation, please contact our office by COB on **Monday 10 September 2018**.

### Speaker Presentations

Title	Exploring policymakers' perspectives on the available policies and interventions for FASDs. A qualitative study
Session Details	5B - Advocacy and Policy Nov 22, 2018 11:30 AM - 1:05 PM GB Centre
Presentation Time	12:20 PM - 12:35 PM
Presentation Order	4
Presenting Author	Mr. Babatope Adebisi Affiliations: University Of the Western Cape
Biography	Mr. Babatope Oluwadamilare Adebisi is a doctoral researcher of the School of Public Health, University of the Western Cape, Bellville, South Africa. His Ph.D. study focuses on the development of guidelines to inform policy for the prevention and management of FASDs in South Africa. He has started publishing articles in peer review journal from his Ph.D. study. His research interests include development and evaluation of interventions, FASDs, HIV/AIDS, qualitative inquiry, systematic review among others





## 2nd Australasian FASD Conference 2018

### Our Science Our Stories

Dear Babatope,

We look forward to meeting you at the Pan Pacific Hotel in November 2018 for the **2nd Australasian FASD Conference: Our Science Our Stories**.

Please find below details of your accepted poster/s. This information will be printed in the program so should there be any discrepancies please contact our office by COB on **Monday 10 September 2018**.

### Speaker Presentations

Title	Exploring service providers' perspectives on the Prevention and Management of Foetal Alcohol Spectrum Disorders.
Presenting Author	Mr. Babatope Adebiyi Affiliations: University Of the Western Cape

### Posters

**Production of Poster**  
AO size (portrait)  
841mm wide x 1189mm high

Each poster board is 2400mm wide, therefore 2 posters will be allocated per side. Please ensure that your poster is produced in the correct dimensions and is **portrait** to ensure that 2 posters are able to be accommodated on the one side.

### Poster Set Up and Pull Down

Please place your poster on your allocated poster board by the morning tea break on Wednesday 21 November. We will provide you with poster board numbers in due course.

There will be limited supply of velcro, therefore we suggest you bring some with you. Your poster can be pulled down during the Farewell Refreshments on Thursday 22 November. Any posters remaining in place at 5.30pm on the Thursday will be regarded as rubbish. The organisers are unable to collect/post/store/pull down or place any posters on

Thank you for submitting your abstracts for the 8<sup>th</sup> International Conference on FASD: Research: Results and Relevance 2019, Integrating Research, Policy, and Promising Practice Around the World, to be held from March 6-9, 2019, in Vancouver, BC, Canada. I am pleased to advise you that your abstracts titled "*Policy Makers' Perspectives on Available Policies and Interventions for FASD*" and "*A Scoping Review on Global Distribution of the Prevention and Management Interventions for FASD Across the Life Span (2007-2017)*" have been selected as Posters. Your abstract "*Service Providers' Perspectives on Available Policies and Interventions for FASD*" has been selected as a 15-minute oral paper session (+ Q&A).

As the primary presenter, all correspondence will be directed to you. Please ensure that any co-presenters are forwarded all information as well.

To confirm your participation in the conference please respond to this email by Tuesday, November 13. Please also ensure you review your session information below, and complete any missing information (highlighted in yellow). Please take careful note of this, as some of the details may have changed from your original submission. Should you have any changes, please let me know by Tuesday, November 13. When you send back your confirmation and adjustments, please ensure all session information and affiliations are written as you would like them to be printed in the conference brochure.

## POSTER #1 INFORMATION

### Presentation Title

*Policy Makers' Perspectives on Available Policies and Interventions for FASD*

### Presenter Affiliations & Contact

Primary Presenter:

Babtope Adebiyi, PhD Student, Researcher, School of Public Health, University of the Western Cape, Western Cape, South Africa

## POSTER #2 INFORMATION

### Presentation Title

*A Scoping Review on Global Distribution of the Prevention and Management Interventions for FASD Across the Life Span (2007-2017)*

### Presenter Affiliations & Contact

Primary Presenter:

Babtope Adebiyi, PhD Student, Researcher, School of Public Health, University of the Western Cape, Western Cape, South Africa

## PRESENTATION INFORMATION

### Presentation Title

*Service Providers' Perspectives on Available Policies and Interventions for FASD*



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Dear Babatope Adebisi

On behalf of the upcoming QHR Congress, 12 - 15 March 2018, Sun City, South Africa, we are pleased to advise that the below listed abstract has been accepted for **Oral Presentation**.

Title	Foetal alcohol spectrum disorder: Exploring service providers' perspectives on interventions and policies
Paper Number	73
Paper Status	Accepted   Oral Presentation
Presentation Type	Oral Abstract Presentation
Theme	Qualitative Health Research: Health Policy and Practice
Presenting Author	Mr Babatope Adebisi Affiliations: University Of the Western Cape, South Africa

Presenters will be allocated 20 minutes (15 min + 5 min discussion), please note the exact time slot allocated to your presentation will be advised shortly. Kindly visit the Congress website, for programme and congress updates.

Abstracts will be judged throughout the congress and the Best Presentation Award will be announced before the close of Congress on Thursday 15 March.

**Kindly confirm with the Congress Office by return email before 17 January 2018, whether you accept this presentation, as well as confirm who the presenting author will be.**

**Please note**, all abstract presenters are required to register for the Congress by **Sunday, 17th January 2018**. Kindly follow the below link in order to register online and select the Accepted Abstract Submission Delegates registration category.

[QHR Online Registration](#) **UNIVERSITY of the**

***Should your acceptance and registration not be received by Sunday, 17th January, the scientific committee reserves the right to remove your presentation from the programme.***

# 70<sup>TH</sup>

Anniversary of the  
World Health  
Organization (WHO)



## PHASA

### Annual Conference 2018

Khaya iBhubesi, Parys 10 - 12 Sep



Health for All, Thinking Globally Acting Locally

Dear Mr Babatope Adebisi,

We are pleased to inform you that your abstract/s as detailed below has been accepted as a POSTER presentation and will be included in the provisional program for the PHASA Conference 2018 to be held at Khaya iBhubesi, Parys from 10th - 12th September 2018.

#### Poster Presentations

Title	Exploring service providers' perspectives on the Prevention and Management of Foetal Alcohol Spectrum Disorders.
Paper Number	115
Presentation Type	Converted to poster
Theme	2. Health Systems as a Determinant of Health
Sub Theme	Health Care Services
Presenting Author	Mr Babatope Adebisi Affiliations: University Of The Western Cape
Co-Author	Dr Ferdinand Mukumbang Affiliations: University Of The Western Cape
Co-Author	Dr Anna-marie Beytell Affiliations: University Of The Western Cape
Title	Exploring policymakers' perspectives on available policies and interventions for FASDs. A qualitative study
Paper Number	114
	Converted to poster

**70<sup>TH</sup>**  
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Organization (WHO)



**PHASA**

**Annual Conference 2018**

**Khaya iBhubesi, Parys 10 - 12 Sep**



**Health for All, Thinking Globally Acting Locally**

Dear Mr Babatope Adebisi,

We are pleased to inform you that your abstract/s as detailed below has been accepted and will be included in the provisional program for the PHASA Conference 2018 to be held at Khaya iBhubesi, Parys from 10th - 12th September 2018.

### **Presentations**

<b>Title</b>	Prevention and management interventions for Foetal Alcohol Spectrum Disorders across the lifespan: A systematic review
<b>Paper Number</b>	123
<b>Presentation Type</b>	Poster
<b>Theme</b>	3. Addressing the Burden of Disease
<b>Sub Theme</b>	Maternal and Child Health
<b>Presenting Author</b>	Mr Babatope Adebisi Affiliations: University Of The Western Cape
<b>Co-Author</b>	Dr Ferdinand Mukumbang Affiliations: University Of The Western Cape
<b>Co-Author</b>	Dr Anna-marie Beytell Affiliations: University Of The Western Cape

Specific information for your presentation(s) will follow in due course.

**For the Organising Committee to finalise your participation, please ensure that you have registered and paid for your attendance by 25th June 2018.**



Dear Mr Babatope Adebisi,

We are pleased to inform you that your abstract/s as detailed below has been accepted and be included in the provisional programme for the PHASA Conference 2019 to be held at College of Cape Town, Cape Town from 16th - 18th September 2019.

## Presentations

Title	To what extent is Fetal Alcohol Spectrum Disorder considered in policy-related documents in South Africa? , document review
Paper Number	178
Presentation Type	Oral
Theme	4. Multi-sectoral action for improved health outcomes - Health in All Policies
Presenting Author	Mr Babatope Adebisi Affiliations: University of the Western Cape
Co-Author	DR Ferdinand Mukumbang Affiliations: University of the Western Cape
Co-Author	Dr Anna-marie Beytell Affiliations: University of the Western Cape

Specific information for your presentation(s) will follow in due course.

**For the Organising Committee to finalise your participation, please ensure that you have registered and paid for your attendance by 22nd July.**

In order to register please click on the link below and login with your email address and password and follow the prompts. The conference fees and the cancellation policy are listed on the registration page.

<https://confco.eventsair.com/phasa-conference-2019/individual-registration>