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# FETAL ALCOHOL SPECTRUM DISORDER: HOW CHILDREN ARE IMPACTED THROUGHOUT THEIR LIVES

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FETAL ALCOHOL SPECTRUM DISORDER: HOW CHILDREN ARE IMPACTED  
THROUGHOUT THEIR LIVES

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A Research Paper  
Submitted in Partial Fulfillment of the Requirements for the  
Master of Science Degree

Rehabilitation Counselor Training Program  
In the Graduate School  
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RESEARCH PAPER APPROVAL  
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A Research Paper Submitted in Partial

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For the Degree of

Master of Science

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Approved by:

Dr. Thomas Upton

Graduate School  
Southern Illinois University Carbondale  
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## AN ABSTRACT OF THE RESEARCH PAPER

Tytiana Davis, for the Master of Science degree in Rehabilitation Counseling, presented on November 7, 2014, at Southern Illinois University Carbondale.

TITLE: FETAL ALCOHOL SPECTRUM DISORDER: HOW CHILDREN ARE IMPACTED THROUGHOUT THEIR LIVES

MAJOR PROFESSOR: Thomas D. Upton

The following research paper will be completed on the importance of Fetal Alcohol Spectrum -Disorder, and how children are possibly affected later in life and the impact it has on society. Fetal Alcohol Spectrum Disorder includes Full Blown Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (pFAS), Alcohol related neurodevelopmental disorder (ARND), Alcohol Related Birth Defects (ARBD). According to CDC.org, the rate of Fetal Alcohol Spectrum Disorder has been estimated to be between 0.5 to 2.0 cases per 1,000 live births. Information from more than thirty sources will be used to provide an overview of the etiology of the condition, number of individuals in the US affected by this condition, and the impact of society on the cause of the condition. I will also provide a detailed description of the condition and how the condition affects changes that may take place in the body. Medical management of this condition will also be discussed as well as physical, psychological, and social challenges an individual may face related to this condition. The conclusion of this research paper will describe treatment methods specific to this condition.

## **ACKNOWLEDGEMENTS**

First, I would like to dedicate this research paper to my sons, Antonio Jr. and Aston Brown. They are the reason I work so hard to achieve every goal I set for myself. They are my biggest inspiration. Secondly, I would like to dedicate this research paper to my husband, Antonio Brown Sr. without your love and support, I would not be the woman I am today. Thank you! Lastly, I would like to dedicate this research paper to one of the best professors I have had the pleasure of knowing throughout my years enrolled at Southern Illinois University Carbondale, Dr. Thomas Upton. He has motivated and encouraged me to work hard and strive to be the best student I am capable of being.

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## CHAPTER 1

### INTRODUCTION

According to reports from the Centers for Disease Control and Prevention (CDC), studies have shown that 0.2 to 1.5 cases of fetal alcohol syndrome (FAS) occur for every 1,000 live births in certain areas of the United States. Other studies using different methods have estimated the rate of FAS at 0.5 to 2.0 cases per 1,000 live births

<http://www.cdc.gov/ncbddd/fasd/data.html>. In 2002, the lifetime cost for an individual who suffered from Fetal Alcohol Syndrome was estimated to be around 2 million dollars.

Each year, more than 500, 000 fetuses (about 13% of all births) in the United States are exposed to alcohol during pregnancy (CDC, 2002). The prevalence of alcohol use decreases during pregnancy (Stratton, et. al., 1996). There is still a small percent of women that consume alcohol throughout their pregnancy. Some women will drink frequently and others will participate in binge drinking. However, there are a large number of pregnant women in the United States that expose their fetuses to large amounts of alcohol consumption. Annually, about 130, 000 pregnant women consume alcohol and place their fetuses at risk for Fetal Alcohol Syndrome or other impairments resulting from prenatal alcohol exposure (i.e. fetal alcohol effects (FAE)). (Stratton, et. al., 1996).

The diagnosis of FAS and some related conditions requires a documented history of prenatal alcohol exposure. There have not been any conclusive data on the dose, timing, or duration of exposure that is likely or necessary to cause FAS or other related impairments (Stratton, et. al., 1996). Prenatal alcohol exposure is a necessary cause of FAS and FAE, but it cannot stand alone and be the sole cause of FAS.

## Background

The phrase FAS was announced to the mainstream in 1973, and by the mid-1980s, FAS was believed to be the leading identifiable cause of mental retardation and neurological deficit in the Western world (Stratton, et. al., 1996). In February 1973, a Professor of Pediatrics and the University of Washington along with his fellow were asked to evaluate eight infants who were born to alcoholic mothers. A physician by the name of Dr. Ulleland, was informed by an Obstetric Resident that an alcoholic woman was in labor and that delivery was imminent. She used much urgency to get to the library to find out everything she could about the effects of alcohol on fetal development and discovered she found there was no information. Based on her being unable to locate any data, she spent time learning everything she could about the topic. Over a one year period, she found records of eleven babies had been born to alcoholic mothers (Stratton, et. al., 1996).

Eight children who were born to alcoholic mothers were examined and four of the children had very defined patterns of malformation that included: microcephaly, short palpebral fissures, and a smooth philtrum. (Jones, et. al., 1973). Dr. Smith was a physician who had been unable to diagnose his patients in the past, decided to review his medical records after the discovery of FAS. After careful review of his medical records, Dr. Smith identified two children who had the same three patterns of malformation and after further research was conducted, it was concluded that the mothers were also alcoholics (Jones, et. al., 1973).

Out of the original eight children, seven of them were evaluated by a psychologist at the University of Washington. All of the children's social and motor skills were delayed. "Fine motor dysfunction, including tremulousness, weak grasp, and/or poor hand eye coordination was present in the majority; most were delayed in gross motor performance. Their IQ scores and

motor development index ranged from < 50 to 83.” (Jones et al., p.375). In 1974, three doctors took a trip to Washington D. C to access a large national data base from the Collaborative Perinatal Project of the National Institute on Neurologic Diseases and Stroke. This was the first comprehensive study that had been conducted on the etiology of neurological impairment in children. (Jones, et. al., 1973).

Women, who were reported to come into clinician’s offices that appeared to have issues with alcohol and sobriety, were chosen for the focus of the study. Even though only 23 alcoholic mothers were initially identified, children of 55,000 women from twelve states in the United States were examined during the first seven years of their lives. (Jones, et. al., 1973). In comparison to nonalcoholic mothers from very similar backgrounds, the children of alcoholic mothers outcomes were much worse. “Perinatal mortality of 17% compared to 2% for the controls and a 32% rate of FAS compared to none for controls. In the survivors, borderline to moderate mental deficiency at 7 years of age was the most frequent problem, at 44% for children of alcoholic mothers vs. 8% for controls.” (Jones et al., p.377).

One year after the first paper focusing on Fetal Alcohol Syndrome was published, the results of this case/comparison group study was published (Jones, et. al., 1974). The paper focused its research on more than one topic and was able to choose possible effects of socioeconomic background, maternal education, race, maternal age, parity, marital status, and regional affiliation. This research was very important because it was concluded that Fetal Alcohol Spectrum Disorder was not solely linked to mothers from poor backgrounds and lifestyles (Jones, et. al., 1974).

It has been reported that Fetal Alcohol Spectrum Disorder has been underestimated because of several different factors such as physical features, doctors not having enough

knowledge in the field, and mothers underreporting their alcohol consumption during pregnancy, for fear of rejection from society (Jones, et. al., 1974). An International Collaborative Initiative on Fetal Alcohol Spectrum Disorders was funded in 2003 by the National Institute of Alcohol Abuse and Alcoholism (Jones, et. al., 1974). This chain was created to provide a better understanding as well as more knowledge of mechanisms, diagnostic approaches, prevention, treatment, and the overall effects alcohol exposure has on a fetus (Jones, et. al., 1974).

### Purpose

There is no amount of alcohol that is truly considered safe for consumption while a mother is pregnant. Fetal Alcohol Spectrum Disorder is preventable as long as the mother does not consume any alcohol while she is pregnant. The objective of this research is to discover more information concerning Fetal Alcohol Spectrum Disorder and the negative effects a child may experience throughout their lives that are a direct result of mother's consuming large quantities of alcohol while pregnant. I would also like to inform the readers of my research paper as well as myself, about other disabilities that could have possibly been prevented but are direct causes of Fetal Alcohol Spectrum Disorder.

There are several factors that may come into play when a mother chooses to consume large quantities of alcohol while she is pregnant. I would like to discover information on how environmental factors may or may not play an important role on the mother's decision making while pregnant as well as personal factors including but not limited to social support, race, marital status and education level.

Any amount of alcohol consumed by a mother while she is pregnant is immediately carried to her fetus through the umbilical cord. According to the CDC, if a mother chooses to consume alcohol during her pregnancy, not only is she exposing the child to the possibility of

having FASD, but she is also risking the chances of miscarriages, still births, and a host of other disabilities that can negatively affect a child throughout their lives, such as physical issues, behavioral issues as well as Intellectual Disabilities. To locate the information for my research paper, I used peer reviewed academic articles from PsychInfo, PubMed, and Academic Search Premiere.

### Definition of Terms

Throughout this research paper, there are terms that I find to be very important for the reader to know and understand.

**Fetal Alcohol Syndrome (FAS):** FAS represents the severe end of the FASD spectrum. Fetal death is the most extreme outcome from drinking alcohol during pregnancy. People with FAS might have abnormal facial features, growth problems, and central nervous system (CNS) problems. People with FAS can have problems with learning, memory, attention span, communication, vision, or hearing. They might have a mix of these problems. People with FAS often have a hard time in school and trouble getting along with others.

**Alcohol-Related Neurodevelopmental Disorder (ARND):** People with ARND might have intellectual disabilities and problems with behavior and learning. They might do poorly in school and have difficulties with math, memory, attention, judgment, and poor impulse control.

**Alcohol-Related Birth Defects (ARBD):** People with ARBD might have problems with the heart, kidneys, or bones or with hearing. They might have a mix of these.

**Fetal Alcohol Effects:** a term introduced in 1978 that was used to describe abnormalities seen in individuals that were compatible with those caused by prenatal alcohol exposure.

(Source <http://www.cdc.gov/ncbddd/fasd/facts.html>)

**Mortality:** the state or condition of being subject to death

**Philtrum:** the vertical groove on the surface of the upper lip, below the septum of the nose.

**Malformation:** faulty or anomalous formation or structure, especially in a living body.

**Microcephaly:** having a head with a small braincase.

**Necropsy:** the examination of a body after death; autopsy

**Etiology:** pathology; the study of the cause of disease; the cause or origin of a disease

(Source: dictionary.com)

## CHAPTER 2

### REVIEW OF LITERATURE

The literature that I will be providing for Fetal Alcohol Spectrum Disorder (FASD) contains information regarding various sources. I will focus on the potential long-term effect FASD has on a person throughout their lives and how FASD and possible prevention methods. I will focus on prevention programs and what pregnant women could do to ensure they are healthy throughout their entire pregnancies. This research paper will also focus on physical symptoms, data and statistics, the estimated lifetime cost of a person with FAS, legal, screening, and diagnostic issues, prevention methods, and interventions.

#### Brief History

##### FAS in Western Cape Province of South Africa

In South Africa, AIDS has been a highly publicized and very well documented illness, but there has been something underreported and developing for hundreds of years, Fetal Alcohol Syndrome (FAS). The highest rates of Fetal Alcohol Syndrome (FAS) have been found to be in The Western Cape Province of South Africa (McKinstry, 2005). FAS is caused by mothers consuming alcohol at some point during her pregnancy. FAS is preventable and if a mother chooses to drink during her pregnancy, she may cause mental and physical retardation to her infant, which is a leading cause worldwide (McKinstry, 2005). Statistics regarding FAS in Western Cape Province is reported below.

"...The most recent statistics on FAS rates in the Western Cape Province, reported by the National Institute of Alcoholism and Alcohol Abuse, show that 40.5 to 46.4 per 1000 children are found by screening to have FAS.' Compare this rate with a FAS frequency of 0.5 to 2.0 per

1000 children in the United States or the average rate of 0.97 per 1000 children in the developed world, and the difference is staggering (McKinstry, p.1097)."

A population based study was completed, "Maternal Risk Factors for Fetal Alcohol Syndrome in the West Cape Province of South Africa" was conducted and the participants were mothers who were from various different socioeconomic backgrounds. These participants were chosen to explore different factors related to children being born with FAS (McKinstry, 2005). Results from this study concluded that two important details were consistent. Mothers who came from low socioeconomic statuses had a higher risk of having a child with FAS because of very limited knowledge surrounding the consumption of alcohol while pregnant along with the negative effects it may have on the child (McKinstry, 2005).

The study uses the Western Cape Province "dop" system to measure drinking and it finds that prevention needs to take place in order to stop the FAS epidemic (McKinstry, 2005). The "dop" system needs to be thoroughly understood in order to get a clear understanding as to why FAS rates are so high in a geographical area that is so small (McKinstry, 2005).

In the 1700s, European colonists used the fertile land of South Africa to create an agricultural economy. Grape and wine production started in Western Cape Province. Farmers worked long hours on the farms, and instead of them being paid in cash, they were paid using a new system that was referred to as the "dop" system (McKinstry, 2005). Payments the farmers received included bread, wine, and tobacco. One thing that made the "dop" system unique was that it allowed other farmers to get rid of excess wine that could not be sold (McKinstry, 2005). This system was made illegal after 300 years, but the negative work was already done.

"The dop system promoted and sustained a culture of alcohol intake that not only ensured that local communities stayed impoverished, but also had negative biological, psychological, and

social consequences for the population. Nowhere is this more evident than in the effect the system has had on the mothers and children of the Western Cape Province (McKinstry, 2005 p.)"

There are still concerns regarding FASD and the fact it is under recognized and undertreated, specifically in certain areas that are considered "high risk", including hospitals for psychiatric patients, the child welfare system, and correctional/juvenile detention facilities (McKinstry, 2005). Since the diagnosis for FASD happens so late in life, the child is usually already experiencing behavioral and emotional problems, performing poorly in school, and already having established negative relationships with their families (O'Connor et al., 2011).

### Physical Symptoms

Infants suffering from FAS often have low birthweights; physical dysmorphology, most notably in the face and head; and developmental difficulties (McKinstry, 2005). FAS is characterized by very distinct facial anomalies, growth retardation, and central nervous system dysfunction (O'Connor, et. al., 2011). People who have been diagnosed with FASD are often diagnosed with intellectual and learning disabilities, executive dysfunction, speech and language delays, difficulty controlling behavioral and emotional situations, little to no social skills and poor motor skills (O'Connor et al., 2011).

A study was conducted using mothers who consumed alcohol while they were pregnant, showed increased abnormalities with their children. Children who were products of mothers who were binge drinkers showed a significant "increased dysmorphology, decreased head circumference, short palpebral fissures, and indistinct vermilion boarder" (Blankenship, et. al., p.508). Within the first trimester, those physical traits are able to assist clinicians with clues determining whether or not a fetus has been exposed to alcohol (May, et. al., 2011).

Similar to what has been done in past studies, it has been identified that prenatal alcohol use is linked to negative physical effects on children (May, et. al., 2011) than its effect on neurobehavioral. Prenatal drinking exposure affects neurobehavioral based on environmental conditions that a child experiences such as, the education level of their mother as well as whether or not she received proper healthcare and the families socioeconomic status (May, et. al., 2013b). However, it is possible for the brain of a child with FASD to improve in areas such as verbal acuity and the ability to focus as long as the primary caregiver follows up with adequate postnatal care (May, et. al., 2013b). When a person has been exposed to and diagnosed with FASD, there are several other consequences they are faced with, including but not limited to, performing poorly in school, delinquency, and various substance abuse issues (May, et. al., 2011).

#### Data and Statistics

According to reports from the Centers for Disease Control and Prevention (CDC), studies have shown that 0.2 to 1.5 cases of fetal alcohol syndrome (FAS) occur for every 1,000 live births in certain areas of the United States. Other studies using different methods have estimated the rate of FAS at 0.5 to 2.0 cases per 1,000 live births.

<http://www.cdc.gov/ncbddd/fasd/data.html> In 2002, the lifetime cost for an individual who suffered from Fetal Alcohol Syndrome was estimated to be around 2 million dollars.

Each year, more than 500, 000 fetuses (about 13% of all births) in the United States are exposed to alcohol during pregnancy (CDC, 2002). The prevalence of alcohol use decreases during pregnancy (Stratton, et. al., 1996).

A mother that drinks throughout her pregnancy, (no matter which trimester she starts), increases her chances of having a child with FASD by 65 times compared to mothers who do not

consume any alcohol during their pregnancies. Even though mothers who consume alcohol during the first trimester of their pregnancies increase their chances by 12 times, there is still a good chance that if the mother stops consuming alcohol early in the first trimester, she can decrease the chances of her child being born with FASD (May, et. al., 2011). It has been reported that approximately 90% of persons with FASD also suffer from comorbid mental health problems such as depression, substance abuse, and psychotic disorders (Douglas, et. al., 2013).

According to Brownell, in the western society, Fetal Alcohol Spectrum Disorder (FASD) has been a leading cause of intellectual disability, which leads to a significant increase in health risks, education and social services. Disabilities such as depression, substance abuse and anxiety are often found in conjunction with people who have been exposed to FASD. As a result, the person may have poor social skills and become products of the court system earlier than usual (Brownell, et. al., 2013). A study was completed and the specific objective was to take a closer look into the related health risks, education level, and whether the available social service opportunities were being utilized and this would be used to determine how much of a burden a person born with FASD would cause society (Brownell, et. al., 2013).

The search that specifically measures the level of alcohol consumption during pregnancy which is a direct cause of Fetal Alcohol Syndrome as well as other terms that fall under the Fetal Alcohol Spectrum Disorders category have been obtained through clinical settings, drinking surveys, various methods studies and concluded from data in previous studies (Brownell, et. al., 2013). The amount of alcohol a woman consumes while she is pregnant varies among different populations throughout the world. It was estimated that 20-32% percent of pregnant women drank in the United States, England, and Canada and the percent of women who drank alcohol during pregnancy was estimated at around 50% in other European countries (Brownell et. al.,

2013). The percentage in South Africa was 34-51% (Brownell et. al., 2013). Even though a mother may consume alcohol while she is pregnant, the child may not be born with Fetal Alcohol Spectrum Disorder (Brownell et. al., 2013). The risk a mother places on her fetus involves several different factors. The interaction between biological, familial, historical, social, and psychological influences (Gomberg, 1993), are all very important when attempting to diagnose Fetal Alcohol Syndrome. In this particular study population, alcohol is the sole drug used. Alcohol is the teratogen and other predisposing conditions are secondary (Abel and Hannigan, 1995 and May and Gossage, 2011).

The mothers of the participants in this study were all provided the same questionnaires to answer as well as complimentary grocery store gift cards for being a part of the study (May, et. al., 2005). Questions that were not harmful on general health and childbearing were the first questions that were asked, nutrition followed, and it was found that questions asked in this particular way were more accurate (King, 1994).

#### Estimated Cost

Previous estimates surrounding the annual cost of FAS also has changed over the years, ranging anywhere from \$75 million to \$4 billion per year. Several factors were taken into consideration, including the various costs, the age range that was covered, as well as the population and the prevalence rates (Lupton, et. al., 2004). In the United States, it has been estimated that the total lifetime cost for a person born with FASD is approximately \$2 million dollars, majority of the cost being used for special education programs, medical expenses, and mental health treatments (Lupton, et. al., 2004). Research that was completed in countries other than the United States has shown similar high costs surrounding FASD (Lupton, et. al., 2004)

### Adaptive Behaviors Related to Fetal Alcohol Spectrum Disorder

The term adaptive behavior originated from literature surrounding animal research but it is used in clinical psychology, special education, and criminal law for diagnosis of Intellectual Disabilities, but it has been used to diagnosis FASD as of lately (Edwards, et. al., 2010). One of the diagnostic protocol methods that was used to measure the adaptive behavior associated with FASD was the Vineland Adaptive Behavior Scales (VABS). Literature surrounding FASD can be found in the Fetal Alcohol Behavior Scale (FABS), which is an inventory (Edwards, et. al., 2010).

The FABS inventory is not considered to be an instrument that measures adaptive behavior, it possess many of the same qualities of any other type of adaptive behavior rating measure (Edwards, et. al., 2010). The FABS is considered to be important because it pin points specific symptoms that are specifically associated with FASD (Edwards, et. al., 2010). A detection study was taken and the FABS was filled out by correction staff for 81 male inmates that were placed in a unit of the Washington state prison system for inmates who were developmentally and emotionally disturbed, but who were not psychotic (Edwards, et. al., 2010). The data collected from the FABS was used to determine whether or not the mothers of these particular inmates had consumed alcohol while pregnant. Results of the study concluded that the four individuals with the highest FABS scores, three of them were reportedly born to mothers who consumed alcohol during her pregnancy and the normative sample had similar results (Edwards, et. al., 2010).

### Psychologists' Knowledge of FASD

Many practicing psychologists have dealt with patients who have been affected by mother's who have consumed alcohol while she is pregnant (Braddock, et. al., 2007). Most

women will stop drinking or significantly reduce the amount of alcohol intake once they find out they are pregnant, but the knowledge of pregnancy may not be revealed until 6-7 weeks after conception. If your patients are adult women, there is a good chance you would be able to reduce alcohol consumption while pregnant as long as you are informed about the potential dangers of consuming alcohol while pregnant (Braddock, et. al.,2007). Most psychologists that have studied are uniformed about issues related to FAS and FASD and this causes issues and concerns about dangers to the fetus (Braddock, et. al.,).

In the United States, FAS has been determined to be the most preventable cause of birth defects (Braddock, et. al., 2007). According to Braddock and colleagues, “FAS is estimated to occur in as many as 500 births and for every child born with FAS, 10 more suffer from alcohol-related problems (Braddock, et. al., 2009 p. 209).” According to the CDC and other groups, FASD does not consist of one deficit, but also includes hyperactivity and learning difficulties (Braddock, et. al., 2007).

Even though FASD is preventable, the number of women continuing to consume alcohol while they are pregnant, is significantly high (Braddock, et. al., 2007). If psychologists received the appropriate training, knowledge, and skills, they would be able to they could possibly be very important in recognizing, the treatment, and the diagnosis of FASD early enough so that they can receive the best possible treatment (Braddock, et. al., 2007). The following quote is based on surveys that were taken concerning physicians and other healthcare professionals knowledge and attitudes of FASD.

“recent survey conducted by investigators at the CDC of over 1,000 obstetricians and gynecologists in a national random sample revealed a troubling lack of knowledge about FAS as well as

clinical practices that did not conform to published practice guidelines, illustrating the characteristic gap between science and practice...(Braddock, et. al., 2007 p. 209).”

There has never been a safe amount of alcohol established for a woman to consume while she is pregnant, 50% of the participants involved in the study thought consuming one or less drinks per week would not expose the unborn fetus to any danger, while 16%-28% were not sure the safety net existed (Braddock, et. al., 2007). The Midwest Regional Fetal Alcohol Syndrome Training Center (MRFASSTC) was established in 2002 the Saint Louis University along with other universities in Missouri (Braddock, et. al., 2007). The group worked closely with the American Psychological Association (APA) Research Office to develop a survey and educate health care providers in the six states that were in their region (Missouri, Arkansas, Oklahoma, Nebraska, Iowa, Kansas) to determine what knowledge, skills, resources, and barriers existed (Braddock, et. al., 2007).

71% of psychologist revealed they had a lack of training associated with barriers to diagnosing FAS. 39% also revealed that they felt like they were unprepared when asked whether or not they would be able to diagnose children with FAS (Braddock, et. al., 2007). According to Braddock and colleagues 2007, most of the responses toward whether or not they would be prepared to diagnose children with FAS stemmed from legal, ethical and professional issues they were faced with. The current study suggests psychologists have general knowledge surrounding FAS, but some do not feel prepared to diagnose children. With the appropriate training and knowledge, psychologist would be able to provide patients with information that could possibly reduce the amount of children born to FAS (Braddock, et. al., 2007).

### Limitations to Studies

The data collected is from one specific population which also has the highest rates of FASD in the world and alcohol is the primary drug of choice. Factors such as social, economic and cultural conditions are significantly connected to FASD. Up to 40% of women in this population choose to binge drink on weekends while drinking in moderation and during weekdays is uncommon. This suggests that patterns of mothers who consume alcohol are more easily visible whereas mothers who consume alcohol exist with lower prevalence, kept a secret from doctors and family members or accompanies other illicit drugs. The results would be different if more children were assessed or if the participants came from a random sample (Buckley, et. al., 2011).

One particular question that this study placed emphasis on was what would be the differences or similarities if the mothers were from backgrounds with high and middle class socioeconomic status populations or if they were from countries with different drinking, nutrition, and prenatal care was different (Eriksson, 2007)?

### Legal Issues

In a group of offenders that were considered to be vulnerable offenders, persons with Fetal Alcohol Spectrum Disorder (FASD) were identified (Douglas, et. al., 2013). According to the resolutions passed by the American Bar Association (2012) and Canadian Bar Association (2011), in North America, FASD is hoarding the justice policy (Douglas, et. al., 2013). Each resolution focused on how offenders with FASD needed to be responded to and assisted with their needs (Douglas, et. al., 2013). There is not a significant amount of research available related to the number of persons with FASD in the correction system but findings from

limited sources reveal that persons with FASD (especially ARND) are overrepresented in the correction system with an estimated 10%-23% making up incarceration (Douglas, et. al., 2013)

According to some research that has been completed, adolescents who suffer from a decline in their cognitive abilities, show higher rates of impairments regarding legal issues such as interrogation and adjudication (Douglas, et. al., 2013). Different types of psychopathology have also been linked to a decline in their cognitive abilities such as learning disabilities, attention problems, psychosis, and externalizing behaviors (Douglas et. al., 2013). There has not been any research completed that explains the psycholegal abilities of offenders with FASD which makes it unclear whether or not offenders with FASD psycholegal abilities are at a greater risk of being compromised than offenders who do not have FASD (Douglas, et. al., 2013).

Approximately 60% of individuals with FASD have substance abuse issues and some type of involvement with the correction system (Burd, et. al., 2010). FASD has continued to be incorrectly diagnosed since it was discovered thirty years ago. Since diagnosis of FASD is either incorrect or not diagnosed at all, future problems becoming problematic increases and the possibility for interventions throughout life is decreased because many people believe that impairments related to FASD will not affect individuals for long periods of time (Burd, et. al., 2010).

Accurately identifying individuals with FASD in the correction system has been very difficult, with three issues being the leading cause of the difficulties; changes in FASD phenotype throughout the years, lack of adequate documentation concerning PAE, and high rates of postnatal activities that makes the condition more difficult to diagnose (Burd, et. al., 2010). A survey was conducted of correction facilities in the United States, and out of 3.08 million inmates, there was only one confirmed diagnoses of FASD (Burd, et. al., 2010). If accurately

screening offenders once they entered correction systems was performed and diagnoses were made, the number of individuals with FASD entering correction systems would decrease and since the individuals have been identified, they would possibly be able to receive interventions and possibly reduce recidivism rates (Burd, et. al., 2010).

#### Screening Issues

There are currently no valid screening tools being used in the correction systems to diagnose potential offenders with FASD but Asante Centre for Fetal Alcohol Syndrome Probation Officer Screening & Referral Form was selected as a screening tool for youth in the juvenile justice system (Burd, et. al., 2010). This is a form used by probation officers that is not difficult to use and is composed of information that includes social, personal, and mental factors. The information does not come from the offender but comes from the probation officer (Burd, et. al., 2010).

#### Diagnostic Issues

According to Burd, et. al., 2010, the United States and Canada both created multidisciplinary teams comprised of pediatricians/physicians, psychiatrists, geneticists, psychologists, speech language pathologists, social workers, and other health professionals to be the people who diagnosed FASD. This medical diagnosis involves taking into consideration other developmental disabilities, genetic syndromes, mental health disorders, and effects the child may experience after birth that could potentially cause physical and cognitive impairments (Burd, et. al., 2010).

There is currently no lab test for the diagnosis of FAS but it is usually diagnosed from the abnormalities that are found to be similar in majority of FAS patients (O'Leary, 2004). Abnormalities in three categories include growth retardation, characteristic facial features, and

central nervous system (CNS) dysfunction (O'Leary, 2004). Even though diagnosis of FAS needs confirmation of the amount of alcohol a mother consumes while pregnant, the physical abnormalities can be used to exclude other diagnosis. Facial features and growth retardation changes throughout life and can vary throughout ethnic populations (O'Leary, 2004).

Longitudinal studies have taken place and discovered difficulties in the diagnosis of FAS in adolescence because facial features change throughout life. The abnormalities of the CNS do not change, but are recognizable throughout life (O'Leary, 2004). IQ's of children diagnosed with FAS is usually in the 60-70 range (mildly mentally handicapped) but there are people who are severally handicapped but have IQ scores in the normal range (O'Leary, 2004).

#### Epidemiology of FAS

“Alcohol is clearly the necessary factor for the development of FAS and related disorders, but as not all children exposed to heavy alcohol consumption during pregnancy are affected or are affected to the same degree, expression of anomalies appears to require component causes (O'Leary, 2004 p. 3).”

Embryos that had been aborted in the first trimester of mothers who were considered to be chronic alcoholics were examined and determined to have brain malformations and disorders such as microcephaly, hydrocephaly, hydraencephaly, and other disorders (O'Leary, 2004).

Studies have shown correlation between prenatal growth delays and alcohol consumption in the first 8 weeks of pregnancy. Alcohol later in pregnancy may cause post natal growth, and factors such as a mothers age and whether or not she smokes are also determining factors (O'Leary, 2004).

Patients of mothers who had a history of daily, severe, heavy alcohol use or frequent and heavy alcohol use, demonstrated the full FAS phenotype (O'Leary, 2004). In order for the fetus

to potentially be in danger, it has to be reported that the mother is chronically consuming alcohol on a daily basis with a monthly alcohol consumption rate being 45 drinks per month (O'Leary, 2004). There has not been an exact amount of alcohol used to diagnose FAS/FAE (O'Leary, 2004).

## CHAPTER 3

### INTERVENTIONS

#### Community Based Interventions

An intervention was put into place for mothers who were participants in a program titled, First Steps. This program followed the outcome of high-risk mothers and their children for 3 years (Badry, et. al., 2012). The Alberta First Steps intervention program was established in Canada in 1999 and is similar to a federally funded program that was started in 1991 at the University of Washington called the Parent-Child Assistance Program (PCAP) (Badry, et. al., 2012). The focus of PCAP was to prevent future exposure to mothers who had previously delivered children who had been exposed to drugs and alcohol (Badry, et. al., 2012).

#### Behavioral Interventions

People, who have been diagnosed with FASD, may experience negative effects even after birth such as their mother and/or father continuing to abuse substances after the child is born, abuse, neglect, domestic violence, and their parents dealing with mental issues (O'Connor, et. al., 2011). Studies have shown that children who have been diagnosed with FASD have often experienced foster care placement, being placed up for adoption, or being institutionalized (see Stratton, et. al., 1996). According to Astley and colleagues (2002), the percent of children living in foster care was found to be significantly higher than those who were raised in the general population.

Though it is beneficial for children to be removed from homes where the parents are abusing alcohol, the children still suffer from negative environmental interactions as well as caregiving relationships being negatively affected (O'Connor et al., 2011). Accompanying the risks of the

children born with FASD, creating effective interventions will be challenging (O'Connor et al., 2011).

“Interventions that seek to both remediate primary deficits as well as mitigate the various environmental liabilities that often accompany a history of prenatal alcohol exposure may yield the most positive outcomes (O'Connor, et. al., p.66).”

Different intervention techniques such as taking steps toward improving parenting skills, providing parents and caregivers with training to enable them to better advocate for services as well as connecting with the available community resources, and strengthening the level of care giving altogether. Other approaches include working closely with parents to ensure they are working with their children while they are home to ensure they are maximizing the treatment experience (O'Connor, et. al., 2011).

There is also certain stigmatization correlated with FASD that could potentially cause obstacles in receiving specific information on if and when a child had been exposed to FASD (O'Connor, et. al., 2011). Physicians may not feel comfortable enough to ask their pregnant female patients whether or not she consumed alcohol during her pregnancy. Mothers may downplay their alcohol use during pregnancy altogether for fear of being blamed, judged, or the thought of potential future legal repercussions (O'Connor, et. al., 2011). Due to physicians and mothers being uncomfortable to discuss the potential alcohol use during pregnancy, FASD is usually diagnosed later in life and this causes the child who has been exposed to miss the chance of early intervention (O'Connor, et. al., 2011). According to findings from a Washington State FAS Diagnostic and Prevention Network study, the average age of children diagnosed with FASD was 9.5 (Olson, et. al. 2007).

### Parent Focused Intervention

Children who have been diagnosed with FASD can often time be too difficult for parents to care for properly. According to a study conducted by Paley and associates, parents raising children with FASD experienced high levels of stress. In a study of a middle class family was conducted by (O'Connor, et. al., 1992), mothers who only drank for a short period of time during their pregnancy had better relationships with their children than mothers who consumed large amounts of alcohol during her pregnancy. A sample of preschool aged children was taken and results concluded that children who had been exposed to alcohol for a longer period of time were had more negative relationship with their mothers than children who were only exposed for a short period of time (O'Connor, et. al., 2006).

### Behavioral Consultation

Families Moving Forward (FMF) is an intervention that was designed by Olsen and colleagues to help support families raising children with FASD. This intervention was established in order to raise awareness and cause a reduction in behaviors from children with FASD and providing parents with guidance and information they may need to successfully raise children with FASD (O'Connor, et. al., 2011). Not only does FMF provide families with the resources they may need raising children with FASD, but they also offer education and support to school personnel working with the families of children with FASD.

### Educational and Cognitive Interventions

Children who are diagnosed with FASD usually have difficulties with verbal and spatial learning, memory, making plans, their ability to think in more ways than one, and problem solving. However, children diagnosed with FASD often have difficulties in skills such as reading, spelling, and math (O'Connor, et. al., 2011). Children with FASD are faced with

challenges such as not performing appropriately in school (dropping out, being suspended and/or expelled) due to learning disabilities and behaving poorly in classrooms (O'Connor et. al., 2011). According to Kalberg and Buckley (2007),

“It is helpful to think of the environment as an external nervous system of the child, a place where external (environmental) supports can be implemented to bolster the deficit areas of the child” (p. 282).

#### Cognitive Control Therapy

Cognitive Control Therapy (CCT), is type of intervention that is used to assist children who have been diagnosed with FASD in enhancing their ability to organize information (O'Connor et. al., 2007). This intervention was used in Western Cape Region of South Africa on a group of 10 children (May et. al., 2009). This study helped identify the children's strengths as well as their weaknesses.

#### Fetal Alcohol Spectrum Disorder: Training, Resource, and Evaluation Project

The lives of children who have been diagnosed with FASD would benefit greatly from receiving school-based supports (Koren, et. al., 2013). In an assessment conducted in Toronto, in 2010, it was found that there was a lack of knowledge in public school systems. With the lack of knowledge being publicized, 829 schools in Ontario received appropriate training and resources to staff in the 2011-2012 school year (Koren, et. al., 2013). There were several recommendations made in the assessment completed in 2010, but there was an urgency to bring more awareness to children diagnosed with FASD in the school systems as well as advocacy (Koren, et. al., 2013).

There was a resource and training conducted to provide better support to individuals with FASD with support from clinicians and it was also put into place to provide the education that

was missing regarding FASD (Koren, et. al., 2013). There has been certain Canadian areas that have adopted and provides citizens with training and resource programs regarding patients with FASD, but there are other areas that are not willing to provide the same supports due to a lack of evidence (Koren, et. al., 2013). The following quote comes from an article that believes there should be some support and interventions for FASD.

“while no evidence-based and externally peer- reviewed resources are currently available that specifically target educators, this project aims to contribute to the cultivation of a much need- ed evidence-based culture in the field of FASD support and intervention (Koren, et. al., 2013 p.52).”

The Motherisk FASD Clinic has been accepted as the “gold standard of resources for educators (p. 53)” because it focused on adding more information to the literature that already existed and focused on the Healthy Child Manitoba document for educators which was closely related to the clinical practices currently being used (Koren, et. al., 2013). The total cost of the training was \$11,200, which averages to \$13.56/per participant (Koren, et. al., 2013). The results of the study concluded that majority of the participants would be interested if their school board offered future training and whether they felt the training would positively impact their job performance (Koren, et. al., 2013).

#### Language and Literacy Training

A study took place in South Africa that focused on language and literacy of 9 year old children (O’Connor, et. al., 2007). This particular study aimed to enhance the children phonics skills as well as target pre and early literacy skills such as knowledge, reading real words, and semantic skills (O’Connor, et. al., 2007). This study focused on 40 children who were randomly assigned to intervention condition or FASD control group who received Language and Literacy Training (LLT) from a speech language pathologist for one hour weekly

for a period of 9 months. Results of the use of LLT showed significant improvements in the recognition of letter knowledge, reading, and spelling (O'Connor, et. al., 2007).

### Social Skills Interventions

Children who have been diagnosed with FASD typically have deficits in their social functions, including but not limited to difficulties understanding knowledge, socialization, processing information, and carrying on conversations (O'Connor, et. al., 2007). It has been shown that negative relationships with peers is related to performing poorly in school, anxiety, and symptoms of depression (O'Connor, et. al., 2007). An evidence-based social skills intervention was created for children who were diagnosed with FASD titled, Children's Friendship Training (CFT).

The focus of the group based intervention, CFT was developed to teach children social skills and encourage participation with their parents and peers (O'Connor, et. al., 2007). A study took place that monitored the social progress of 100 children between the ages of 6-12, who had been diagnosed with FASD, and had an IQ score of 70 or higher (O'Connor, et. al., 2007). All participants were randomly assigned to the CFT group or to a delayed treatment condition (DTC) (O'Connor, et. al., 2007). This was a 12 week long study and the participants had weekly 90 minute sessions while their parents were assigned to group settings (O'Connor, et. al., 2007). Results of the study showed the CFT group had better improvement of knowledge and their parents reported they had better social skills (O'Connor, et. al., 2007).

### The Spectrum of FAS Prevention Approaches

It has been proven that Fetal Alcohol Syndrome is 100% preventable as long as the mother does not consume any alcohol while she is pregnant. An intervention spectrum for FAS was described by The Committee to Study Fetal Alcohol Syndrome of the Institute of Medicine

of the National Academy of Sciences and included three stages of prevention (Hankin, 2002). The first prevention method mentioned was the universal prevention method. The purpose of this method was for public service announcements i.e. billboards, advertisements in the media, and information posted in doctor's offices so expectant mothers would have easy access to this information (Hankin, 2002). Selective prevention is the second target and was established for any woman who is old enough to have a child (Hankin, 2002). An example of this target is screening all pregnant women for potential alcohol use, counseling, and referral's as needed (Hankin, 2002). The last prevention method targets pregnant women who have abused alcohol and offers treatment services to them (Hankin, 2002).

#### Evidence that Knowledge of FAS has increased over time

Data from the National Health Interview Surveys kept track of a study over a five year period. The first study focused on 19,000 people whose aged ranged from 18 to 44 in 1985 and the second study surveyed 23,000 people in 1990 (Hankin, 2002). Over the five year period, the participants women's knowledge of FAS increased from 62 to 73 percent and 49 to 55 percent in men (Hankin, 2002). Concerning the topic of correctly identifying FAS as a birth defect, knowledge in men increased fro 25 to 39 percent from 1985 to 1990 (Hankin, 2002).

There have been several programs developed to inform women about FAS and the potential effects that could be caused to a fetus (Hankin, 2002). Centers for Disease Control and Prevention (CDC), funds a selective prevention project, project CHOICES (Changing High-Risk AlcOhol Use ad Increasing Contraception Effectiveness Study) and the target is to provide women of childbearing age with information to prevent alcohol exposure during pregnancy (Hankin, 2002). This project targets women from different populations i.e. incarcerated women,

women who are attend meetings at drug and alcohol facilities, or women in clinics (Hankin, 2002).

There is also a recent study that focuses on informing college students on the importance of not consuming alcohol or using contraception if they choose to consume alcohol (Hankin, 2002). The overall goal of this program is to decrease alcohol consumption rates among college students as well as inform women about the importance of using contraception (Hankin, 2002). Women, Infant, and Children (WIC) programs are available to provide expectant mothers with screenings to identify and define what a high risk drinker consists of (Hankin, 2002). NIAAA has provided funding to various different studies, but the NIAAA has plans to fund a study that focuses on the environment and FAS prevention methods (Hankin, 2002). There is still research being conducted on all of the programs (Hankin, 2002).

### Conclusion

The objective of this research paper is to bring awareness and inform women who consume alcohol during their pregnancy of the potential dangers that may be caused to the fetus. Fetal Alcohol Spectrum Disorder is a 100% preventable disease if the mother abstains from alcohol consumption or seeks treatment from a substance abuse facility early during her pregnancy. According the Center for Disease Control and Prevention, 0.2 to 1.5 cases of fetal alcohol syndrome (FAS) occur for every 1,000 live births in certain areas of the United States. Annually, more than 500, 000 fetuses (about 13% of all births) in the United States are exposed to alcohol during pregnancy (CDC, 2002). This places a hefty financial burden on the United States. In 2002, the lifetime cost for an individual who suffered from Fetal Alcohol Syndrome was estimated to be around 2 million dollars.

Any amount of alcohol consumed by a mother while she is pregnant, is immediately carried to her fetus through the umbilical cord. According to the CDC, if a mother chooses to consume alcohol during her pregnancy, not only is she exposing the child to the possibility of having FASD, but she is also risking the chances of miscarriages, still births, and a host of other disabilities that can negatively affect a child throughout their lives, such as physical issues, behavioral issues as well as Intellectual Disabilities.

Infants suffering from FAS often have low birthweights; physical dysmorphology, most notably in the face and head; and developmental difficulties (McKinstry, 2005). FAS is characterized by very distinct facial anomalies, growth retardation, and central nervous system dysfunction (O'Connor, et. al., 2011). People who have been diagnosed with FASD are often diagnosed with intellectual and learning disabilities, executive dysfunction, speech and language delays, difficulty controlling behavioral and emotional situations, little to no social skills and poor motor skills (O'Connor et al., 2011).

The highest rates of Fetal Alcohol Syndrome (FAS) have been found to be in The Western Cape Province of South Africa (McKinstry, 2005). Statistics concerning FAS in South Africa, is provided below:

"...The most recent statistics on FAS rates in the Western Cape Province, reported by the National Institute of Alcoholism and Alcohol Abuse, show that 40.5 to 46.4 per 1000 children are found by screening to have FAS.' Compare this rate with a FAS frequency of 0.5 to 2.0 per 1000 children in the United States or the average rate of 0.97 per 1000 children in the developed world, and the difference is staggering (McKinstry, p.1097)."

Limitations concerning FAS are the lack of research that is currently available to better inform people of the potential dangers associated with consuming alcohol while pregnant. Factors such as social, economic and cultural conditions are significantly connected to FASD. Legal issues, screening issues, and diagnostic issues are also factors that should be taken into consideration when dealing with individuals who have been diagnosed with FAS. There are several Interventions and prevention methods are discussed in this research paper that are found to be helpful to people diagnosed with FAS, but there is still research being done to provide more helpful information about FAS to women of childbearing ages.

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FETAL ALCOHOL SPECTRUM DISORDER: HOW CHILDREN ARE IMPACTED  
THROUGHOUT THEIR LIVES

Major Professor: Dr. Thomas D. Upton