

© 2012

Joelle Marie Zabotka

ALL RIGHTS RESERVED

“HOW COULD I HAVE DONE THIS?": A QUALITATIVE STUDY OF  
BIRTH MOTHERS WHO HAVE CHILDREN DIAGNOSED  
WITH FETAL ALCOHOL SYNDROME

By

JOELLE MARIE ZABOTKA

A Dissertation submitted to the  
Graduate School-New Brunswick  
Rutgers, The State University of New Jersey  
in partial fulfillment of the requirements

for the degree of

Doctor of Philosophy

Graduate Program in Social Work

written under the direction of

Michael LaSala, Ph.D.

and approved by

---

---

---

---

New Brunswick, New Jersey

May 2012

ABSTRACT OF THE DISSERTATION

“How Could I Have Done This?": A Qualitative Study of  
Birth Mothers Who Have Children Diagnosed  
With Fetal Alcohol Syndrome

by JOELLE MARIE ZABOTKA

Dissertation Director:  
Professor Michael LaSala, Ph.D.

The National Organization of Fetal Alcohol Syndrome (2007) estimates that 20% of U.S. children with FAS are raised by their birth families. The purpose of this study was to describe and understand the feelings, coping behaviors, and thoughts of biological mothers who have given birth to and are parenting children diagnosed with Fetal Alcohol Syndrome (FAS). Qualitative interviews were conducted by telephone with 11 biological mothers of children with FAS. Participants were gathered through contact with the National Organization of Fetal Alcohol Syndrome. Results of the study revealed that almost all of the mothers reported experiences of abuse during their childhoods. Several detailed witnessing domestic violence as children as well as violence in their adult relationships. Feelings of guilt regarding the etiology of their child's FAS were prevalent. These feelings of guilt were continuous no matter the age of the child or the length of time since diagnosis. This group of mothers found ways to understand their use of alcohol during pregnancy through reliance on: the disease model, inaccurate or incomplete knowledge of the consequences of drinking during pregnancy, the advice of others, and a lack of awareness of the pregnancy. Additionally, several themes

emerged to explain how these mothers were able to cope and move forward with their lives including: spirituality, devotion to a cause/giving back, knowledge that their children needed them, and relying on support from others. Professionals in the fields of mental health, healthcare, and addictions are key in treating children with FAS and their biological mothers and in preventing future cases of FAS. Policy implications in the areas of medical education, public/societal education and ongoing funding of services are offered.

## ACKNOWLEDGEMENTS

I have reached this point due to the tremendous amount of support, encouragement and faith of so many people.

First, I would like to thank Dr. Michael LaSala who I feel privileged to have had as my chairperson and mentor. Not only did he provide invaluable guidance throughout this entire process, I am appreciative of his patience and understanding, his consistent help and feedback and his time as he read and re-read this dissertation. I would like to express my sincere gratitude to Dr. Susan Aduato, Dr. Yvonne Johnson and Dr. Shari Munch. They provided support, insightful feedback and also gave generously of their time.

I would like to acknowledge Dr. Rose Anne Turiano for her support, encouragement and assistance with data coding. She too was generous with her time (often times without notice and at late hours!). My parents provided constant support, company for car rides to Rutgers, babysitting, and always encouragement. My mother always knew I would get to this point, even when I waivered. I am also thankful for the support of the rest of my family, especially the Steinberg family and Aunts Anne and Irene who in the early days of this pursuit kept me company during car rides to New Brunswick and sat in the library during my classes.

My children, James, Caitlin and Caroline bring me great joy. I am so proud of them. They always displayed a great deal of love and patience as I completed this process—never complaining, always inspiring and motivating me!

There is simply no way to truly express my gratitude to my husband, Christopher Cevasco. Simply put—I would not be here without him. Throughout every minute of this very long process he has given me the confidence and motivation to go on. He has never hesitated to make my goals his goals and has endless faith in my academic and

professional pursuits. He allowed me to have a life and a family while pursuing this degree.

Finally, I owe a great debt to the eleven women who participated in this study. They willingly opened their lives and hearts in order to help others. They are an inspiration.

## TABLE OF CONTENTS

ABSTRACT .....	ii
ACKNOWLEDGEMENTS .....	iv
LIST OF TABLES .....	vii
LIST OF FIGURES .....	viii
CHAPTER I. INTRODUCTION-PROBLEM STATEMENT .....	1
CHAPTER II. LITERATURE REVIEW AND THEORETICAL FRAMEWORK .....	4
What Is Fetal Alcohol Syndrome? .....	4
How Is Fetal Alcohol Syndrome Diagnosed? .....	5
Presentation of Fetal Alcohol Syndrome in Infants and Children .....	9
Children With Fetal Alcohol Syndrome and the Family .....	12
Tobacco Use During Pregnancy .....	28
Mothers and Guilt.....	34
Theoretical Framework .....	38
Summary of Literature Review .....	41
Research Questions .....	42
CHAPTER III. METHODOLOGY .....	43
Design .....	43
Sample and Data Collection.....	45
Data Analysis.....	46
Validity and Reliability .....	47
CHAPTER IV. RESULTS.....	50
Traumatic Experiences .....	50
Feelings of Guilt.....	59
Summary of Results.....	84
CHAPTER V. DISCUSSION.....	87
Overview.....	87
Implications for Practice .....	90
Implications for Policy .....	99
Implications for Cognitive Dissonance Theory.....	101
Limitations and Areas for Further Research .....	102
APPENDIX A. STUDY FLIER.....	110
APPENDIX B. INTERVIEW STRUCTURE.....	111
REFERENCES.....	116

## LIST OF TABLES

Table	Page
1. Participants .....	46
2. Participants' Experiences of Abuse .....	51



## LIST OF FIGURES

Figure	Page
1. The relationship between and amongst drinking during pregnancy, FAS diagnosis, understanding prenatal alcohol exposure and moving on.....	84

## CHAPTER I

### INTRODUCTION-PROBLEM STATEMENT

This research examines biological mothers whose children are diagnosed with Fetal Alcohol Syndrome (FAS). Specifically, this study sought information on the feelings, coping behaviors, thoughts and parenting experiences of biological mothers who have given birth to, and are parenting, children diagnosed with FAS. Increasing our understanding in this area not only has the potential to benefit members of this population through uncovering unaddressed needs, but also to provide information on potential prevention efforts for any woman who drinks during pregnancy. FAS refers to a group of physical abnormalities (most discernable in certain characteristics of the face), reduced height and weight, (prenatally and postnatally), and problems of behavior and cognition (Astley & Clarren, 2000; Jones, Smith, Ulleland, & Streissguth, 1973). FAS is caused by prenatal exposure to alcohol. While the physical attributes of FAS often attenuate as the individual reaches adolescence and adulthood, the behavioral and cognitive effects never completely disappear. FAS results in high costs for the individual, the family, and society (Popova, Stade, Bekmuradov, Lange, & Rehm, 2011; Institute of Medicine [IOM], 1996).

Given the set of neurobehavioral characteristics of individuals with FAS, it is reasonable to conclude that individuals parenting children with FAS are challenged on a daily basis. The literature reveals much information about these challenges; however, the vast majority of information in the literature has been obtained from foster parents, and not from birth mothers themselves. For birth mothers who have retained custody of their children, the stress of parenting may be compounded by feelings regarding the origin of the syndrome, namely their alcohol use during the pregnancy.

The literature further reveals needs, some met and others not, of parents raising children with FAS. Again, this information is gathered mainly from foster parents. There

is a paucity of research focused on birth mothers. It is reasonable to assume that biological mothers raising children with FAS may have many of the same needs as the foster parents described in the literature. However, this population of birth mothers is not adequately understood and gaps in service availability may exist given that the syndrome is caused by biological mothers' alcohol consumption. It is not unreasonable to think that biological mothers may have additional/more complex needs (possibly including mental health treatment needs) that are left unaddressed. Gaining increased understanding of thoughts, feelings, and impressions of parenting, and uncovering unaddressed needs and deficiencies in the support structures for this special population of mothers will help not only these mothers, but also their children.

Streissguth, Barr, Kogan, and Bookstein (1997) defined primary disabilities related to FAS as deficits that reflect central nervous system dysfunction, and identified secondary disabilities as potential negative outcomes for children with FAS, such as mental health or substance problems, trouble with the law, disruptive school experience or institutionalization. In their studies of children with FAS, Streissguth, Barr, Kogan, and Bookstein (1997) and Streissguth, Bookstein, Sampson, O'Malley, and Young (2004) identified protective factors which they found reduced the likelihood of these secondary disabilities: the stability, safety, and quality of the family environment, and the provision of basic needs (food, clothing, shelter, education). If we can assist parents in providing a stable and nurturing home for their children, we will greatly affect the children's lives.

With increased knowledge and understanding of this vulnerable population come increased opportunities for prevention of future cases of FAS. The Centers for Disease Control (CDC) have recognized the importance of preventing FAS and related disorders (Gerberding, Cordero, & Floyd, 2004). As a result of the research carried out in this study, ideas about helpful services, including mental healthcare for mothers, coping

mechanisms and social support for the mother and family, and/or public educational and services emerged.

Chapter II defines Fetal Alcohol Syndrome, its diagnosis and presentation. I also examine the available literature on FAS as it relates to adoptive/foster parents and biological mothers. Other populations of mothers who have harmed their children and mothers who experience guilt elucidate the relationship between mothers of children with FAS and guilt. The theory of Cognitive Dissonance is used to further understand the relationship between the action of drinking alcohol during pregnancy and feeling about the cause of FAS.

## CHAPTER II

### LITERATURE REVIEW AND THEORETICAL FRAMEWORK

#### **What Is Fetal Alcohol Syndrome?**

FAS describes a constellation of symptoms or characteristics found in individuals resulting from a woman's use of alcohol during pregnancy. FAS is the leading cause of nongenetic, preventable intellectual disability in the United States (IOM, 1996; Office of the United States Surgeon General Press Office, 2005). The incidence of FAS according to the CDC is 0.5 to 2.0 cases per 1000 live births (Office of the United States Surgeon General Press Office, 2005). The CDC reports that persons of color and other disadvantaged groups experience rates as high as three to five cases per 1,000 births (Gerberding et al., 2004).

The only way children can acquire FAS is if their biological mothers drink alcohol during pregnancy. As of this writing, according to the United States Surgeon General, there is no known safe amount of alcohol consumption during pregnancy (United States Department of Health & Human Services Press Office, 2005). Alcohol is the necessary component for the development of FAS and related disorders (i.e. alcohol-related birth defects, alcohol-related neurodevelopmental disorder), but not all children exposed to heavy alcohol consumption during pregnancy are affected or are affected to the same degree. Socio-behavioral risk factors, the quantity and timing of alcohol consumption and the stage of fetal development at the time of exposure may influence the development of FAS (O'Leary, 2004). In addition, not all women with alcoholism appear to have equal risk for having a child with FAS (Abel, 1995; Astley, 2000a). It is not known why some women with high levels of consumption during pregnancy bear an unaffected child, while women with more moderate to lower levels of consumption have children diagnosed with FAS. The search for a greater understanding of this population is justified as Astley, Bailey, Talbot, and Clarren (2000a) report that once a woman has

given birth to a child with FAS and continues to drink alcohol, each subsequent pregnancy will bear a progressively more severely affected child.

FAS is broadly characterized by growth deficiency, a characteristic set of minor facial anomalies, central nervous system (CNS) dysfunction (varied from slight to severe learning disabilities, brain abnormalities, distortion in executive functioning) and prenatal alcohol exposure (Astley & Clarren, 2000). I will define these features before moving forward. Growth deficiency includes prenatal growth deficiency (defined as decreased birth weight for gestational age), postnatal growth deficiency (defined as lack of catch-up growth in spite of adequate nutrition) and low weight to height ratio. Some characteristic facial features include: short palpebral fissures (separation between the upper and lower eyelids), maxillary hypoplasia (under-development of the upper jaw), epicanthal folds (skin folds of the upper eyelids in individuals whose ancestry make epicanthal folds unlikely to occur), thin upper lip, and flattened philtrum (the thin vertical groove in the upper lip under the nose). Central nervous system dysfunction may take several forms including: microcephaly (decreased head circumference for age and gender), or other structural brain abnormalities (with no significant catch-up through early childhood), developmental delays, intellectual disability and/or neonatal problems including irritability and feeding difficulties (O'Leary, 2004).

### **How Is Fetal Alcohol Syndrome Diagnosed?**

The Institute of Medicine (IOM) of the National Academy of Sciences, under mandate from the United States Congress, conducted a study of FAS and related birth defects. In 1996, the committee delineated five diagnostic categories for the identification of FAS: Category 1—FAS with a history of maternal alcohol exposure, Category 2—FAS without a known history of maternal alcohol exposure (instances when maternal history is unavailable), Category 3—partial FAS with a history of maternal alcohol exposure, Category 4—alcohol-related birth defects (ARBD) with a history of

maternal alcohol exposure; physical anomalies only), Category 5—alcohol-related neurodevelopmental disorder (ARND) with a history of maternal alcohol exposure; evidence of CNS abnormalities and/or evidence of behavioral or cognitive impairment. The FAS diagnoses require evidence of growth retardation, evidence of the characteristic pattern of facial anomalies, and evidence of CNS neurodevelopmental abnormalities. Diagnosis of partial FAS requires evidence of some components of the characteristic pattern of facial anomalies, evidence of growth retardation and evidence of CNS abnormalities. The diagnosis of partial FAS also encompasses the diagnosis of adults whose facial characteristics may have attenuated after childhood or may be used as a deferred diagnosis in a child while more evaluations or data are gathered. Categories 4 and 5 are intended to encompass some uncertainty whether prenatal alcohol exposure can definitively account for the individual's effects (IOM, 1996).

Prior to the late 1990's, a more subjective, instinctual approach for diagnosis was utilized, derived from the work of Clarren and Smith (1978). In 1997, a potentially more objective and comprehensive diagnostic model of FAS was created (Astley & Clarren, 1997, 1999, 2000, 2001). The expressed purpose of this diagnostic model—entitled the 4-Digit Diagnostic Code—was to define the key diagnostic features of FAS as presented throughout several published FAS diagnostic guidelines (Astley & Clarren, 2000). The 4-Digit Diagnostic Code is considered the preeminent model and is the model in use in the six Regional Fetal Alcohol Syndrome Diagnostic Centers throughout the state of New Jersey. However, the American Academy of Pediatrics (AAP), the American College of Obstetricians and Gynecologists (ACOG), and the Substance Abuse and Mental Health Services Administration (SAMHSA) does not recommend a particular diagnostic criterion.

The 4-Digit Diagnostic Code provides assessment of the four key diagnostic features of FAS: growth deficiency, facial characteristics of FAS, CNS

damage/dysfunction and prenatal alcohol exposure. These features are assessed on a scale ranging from (1) denoting the absence or unlikelihood of these features and abnormalities to (4) denoting significant/severe findings.

Astley and Clarren (1997, 1999, 2000, 2001) define growth deficiency according to the 4-Digit Diagnostic Code as having been at any given point in time at or below the 10<sup>th</sup> percentile in height and weight for one's age. They define and describe the measurement of the facial phenotype diagnostic category (of the 4-Digit Diagnostic Code) through the assessment of three key facial features: small palpebral fissures, a smooth philtrum, and a thin upper lip. These features are measured to document the magnitude of expression of the FAS facial phenotype (Astley & Clarren, 2001). Palpebral fissure length (PFL) is a measurement of the eye, from the endocanthion to the exocanthion (one corner of the eye to the other). The measurement is made in millimeters and transformed to a standardized score. The philtrum furrow is defined as the vertical groove extending from the upper lip to under the nose (Astley & Clarren, 2001). The philtrum smoothness and upper lip thinness are measured on a five point Likert Scale using the University of Washington pictorial lip-philtrum guide. This guide shows a series of five pictures of lips and philtrums (for either Caucasians or African Americans) with progressively thinner upper lips and increasingly flatter philtrums (Astley & Clarren, 2001). The upper lip is assessed for its width or thickness using the pictures on the lip-philtrum guide (Astley & Clarren, 2000). A formula is used to combine the ratings of the palpebral fissure length, upper lip thinness and philtrum to achieve a score of 1-4.

It is important to note that these determinants may vary among ethnic populations (Abel, 1995; O'Leary, 2004). Some facial features can be attributed to ethnicity, for example, epicanthic folds are more common among Native American, Asian and Hispanic populations (Abel, 1995). Furthermore, as children with FAS enter



adolescence, the facial characteristics of FAS often become less distinct, and the disparity between their weight and the mean weight for their age begins to diminish.

Unlike the facial features and growth deficiency, the central nervous system abnormalities and brain damage do not attenuate but are pervasive throughout the lifespan (O'Leary, 2004). The most significant disability resulting from prenatal alcohol exposure is brain damage/dysfunction (Astley & Clarren, 2000). The effects of alcohol on the developing brain can vary from structural abnormalities to more mild changes in neurochemical levels (Astley & Clarren, 2000). However, the assessment of brain damage within the 4-Digit Diagnostic Code does not assess the severity of structural, neurological or functional problems of the individual, but rather the strength of evidence supporting an organic origin for brain dysfunction; in other words, the likelihood that the dysfunction is attributable to brain damage due to alcohol consumption (Astley & Clarren, 2000). The final category within the 4-Digit Diagnostic Code, prenatal alcohol exposure, provides assessment according to the quantity, timing, frequency, and certainty of the fetus's exposure to alcohol (Astley & Clarren, 2000).

In 2002, also under a mandate from the United States Congress, the CDC also developed diagnostic criteria for FAS. However, in the current literature, this criterion is not being utilized. Taking racial norms into account, the individual must exhibit all of the following facial characteristics: smooth philtrum and thin upper lip (both utilizing the University of Washington Lip-Philtrum Guide Rank 4 or 5), and small palpebral fissures (at or below the 10<sup>th</sup> percentile). Growth measurements (height or weight or both) must be documented at any one point in time, at or below the 10<sup>th</sup> percentile (adjusted for age, sex, gestational age, race, or ethnicity). The individual must exhibit CNS abnormalities including: 1) structural abnormalities (head circumference at or below the 10<sup>th</sup> percentile adjusted for age and sex and/or clinically significant brain abnormalities observable through imaging), 2) neurological problems or soft neurological signs outside normal

limits (not attributed to postnatal insult or fever), and 3) functional abnormalities (performance substantially below expected as evidenced by: global cognitive or intellectual deficits (below the 3<sup>rd</sup> percentile) across multiple domains of functioning or functional deficits (below the 16<sup>th</sup> percentile) in at least three of the following domains: cognitive or developmental deficits or discrepancies, executive functioning, motor functioning, difficulties with attention or hyperactivity, social skills, and other issues (for example: sensory problems, pragmatic language problems, memory deficits). Documentation of all three facial features, growth deficits and CNS abnormalities is required to meet the criteria for FAS (Gerberding et al., 2004).

### **Presentation of Fetal Alcohol Syndrome in Infants and Children**

Upon cognitive testing, a wide range of IQ scores are found in children with FAS ranging from average scores to scores indicative of severe intellectual disability. Many individuals with FAS have an average IQ score between 60 and 70, within the mildly mentally handicapped range (O'Leary, 2004). Generally speaking, impairments in cognition in adolescents and young adults with FAS are prominent in the areas of mathematics, particularly in calculation, estimation, and higher order processes. Memory deficits are also noted in children with FAS (Kerns, Don, Mateer, & Streissguth, 1997). Deficits in attention, verbal learning and executive function (cognitive system responsible for organizing, prioritizing, abstract thought and rule acquisition) are reported in young adults with FAS whose IQ scores are within the normal range. These deficits are more severe than is suggested by the IQ score alone (O'Leary, 2004).

The literature and research on the history, characteristics, and diagnosis of the disorder originated with the medical community and focuses on neurological and physical characteristics. Fewer studies discussed the emotional/psychological characteristics and the challenging behaviors of children suffering the effects of prenatal alcohol exposure. O'Leary (2004) noted the possibility that the behavioral and

developmental abnormalities can be exacerbated by environmental factors including family instability and dysfunction. Broadly defined, children with FAS tend to have the following set of behavioral challenges: impulsivity, attention deficits, hyperactivity, intrusiveness, insensitivity to social cues, poor social judgment, and difficulty connecting actions to outcomes (Coles, 2001; Gardner, 2000, O'Leary, 2004). O'Leary (2004) stated that infants with prenatal alcohol exposure, but not meeting the full diagnostic criteria for FAS, may show mood regulation and self-soothing problems, hypersensitivity to sensory stimuli, irritability, and hyperactivity. Infants and toddlers with FAS have been reported to have a weak suck, feeding and sleeping difficulties, and failure to thrive (Giunta & Streissguth, 1988; O'Leary, 2004). Young children with FAS tend to be impulsive, uninhibited, overly friendly, excessively demanding for affection and physical contact, intrusive, insensitive to social cues, and lacking in social judgment. Approximately 33% of children prenatally exposed to moderate or heavy levels of alcohol have been found to exhibit significant aggressive behavior as compared with 4 to 5% of the general population (O'Leary, 2004). The adolescent with FAS is also described as curious about sex, yet often lacking the understanding of socially appropriate sexual behavior leading to increased risk for sexual victimization due to impulsivity and poor social judgment (Giunta & Streissguth, 1988). The authors noted the likelihood that many individuals with FAS will require a supervised and structured living environment throughout their lives (Giunta & Streissguth, 1988).

A link between FAS and attention-deficit hyperactivity disorder (ADHD) has been suggested in the literature, however, there are reports that the neurocognitive and behavioral characteristics differ between children with FAS and those with a primary diagnosis of ADHD. Children with both FAS and ADHD are sometimes mistakenly diagnosed with Oppositional Defiant Disorder. The children lack cognitive understanding, respond to interpersonal communication inappropriately or off topic and

often do not perceive or understand a link between cause and effect in their or others' actions. In addition, children with FAS often do not respond well to commonly prescribed behavior management techniques (O'Leary, 2004).

As stated earlier, Streissguth and her colleagues discerned primary and secondary disabilities in individuals with FAS (Streissguth et al., 1997). Primary disabilities are caused by organic brain damage/neurological effects, including: low IQ/learning difficulties, eating and sleep disturbance, and neurobehavioral effects. Secondary disabilities lack an organic etiology and can be influenced by factors in the family and environment. The authors studied a group of 661 children and adults diagnosed between 1973 and 1995 with FAS, Possible or Probable Fetal Alcohol Syndrome (patient was on the borderline of meeting diagnostic criteria—this category is not currently in use), Fetal Alcohol Effects or Possible or Probable Fetal Alcohol Effects (this term is not currently in use, but is consistent with the category now termed Alcohol Related Neurodevelopmental Disability (ARND)).

Out of the 661 patients, 403 (61%) were diagnosed in 1993 or after at the University of Washington FAS Clinic. Out of the 661 patients, 473 were sampled for analysis of primary disabilities and 415 were sampled for analysis of secondary disabilities. Some patients were included in both samples, although the exact number is not reported. The primary disabilities subsample was administered a Weschler IQ Test and the Wide Range Achievement Test-Revised. The Vineland Adaptive Behavior Scale was administered to a caregiver or other person very familiar with the patient. The secondary disabilities subsample was administered the Life History Interview, which was developed by the authors for this study. The Life History Interview is a structured interview, administered by telephone to the caregivers to evaluate ten major areas of functional impairment characteristic of patients diagnosed with FAS and Fetal Alcohol Effects. The sample had a median age of 14 years and a median age of 10 year at

diagnosis. Sixty-seven percent of the group had been victims of physical abuse, sexual abuse or domestic violence. The authors state that lack of an early diagnosis around prenatal alcohol exposure was strongly correlated with adverse outcomes (Streissguth et al., 2004).

Streissguth and her colleagues discussed the presence and prevalence of secondary disabilities in adults and adolescents including 5 adverse life outcomes: mental health problems (90%), disrupted school experience (61%), involvement with criminal justice system (60%), confinement in a health, addictions or criminal justice facility (50%), repeated problems with inappropriate sexual behaviors (49%), and drug/alcohol problems (35%) (Streissguth et al., 2004). Their work illuminated 8 protective factors found to significantly reduce the likelihood of secondary disabilities in individuals with FAS. Four factors are closely related to family environment: living in a stable and nurturing home for 72% of the individual's life, staying in a living situation for an average of 2.8 years, experiencing a good quality home from the ages of 8 through 12 and having basic needs (such as food, clothing, shelter, education, safety) met for at least 13% of the individual's life (Streissguth et al., 1997, 2004). Olson, Oti, Gelo, and Beck (2009) point out that despite the recognized need, environmental stability is not common for this group.

### **Children With Fetal Alcohol Syndrome and the Family**

A small body of literature is available on parenting children with FAS. The studies focused mainly on adoptive or foster parents, with few of the studies making reference to birth mothers. Overall, the questions posed in each study focused on the needs of the families/parents in relation to maintaining a stable home environment for the child. After an overview, I will go on to discuss literature specific to adoptive and foster parents of children with FAS and finally, biological mothers of children with FAS.

In their article “Fetal alcohol syndrome through the eyes of parents” (2004), authors Jocie Devries and Ann Waller provided a description of the “core disability traits” through describing five main aspects of the common behavioral profile found in children with FAS. The authors developed these descriptions and assertions through their own experiences of parenting children with Fetal Alcohol Spectrum Disorders and their contacts with other parents. Though not describing an empirical study, the authors provide informal validation of other research as well as a more personal perspective on the struggles of families dealing with FAS. The five main aspects of the behavioral profile they described include: 1) exaggerated vulnerability to peer pressure and the environment--the “moral chameleon”; these individuals’ values change to reflect the values of the people they are with at the moment, 2) behavioral volatility— however, it is important to note the lack of intent to harm others (the authors use the presence of intent to identify possible co-occurring mental health conditions), 3) impairment in understanding the need for social rules and cooperative living—often the individuals can name the rules and consequences for breaking the rules, yet cannot adhere to the rules possibly due to the inability to remember, process or generalize the rules or they believe the rules do not apply to them, 4) childlike innocence extending into adolescence and adulthood --lack of interpersonal sophistication, 5) exaggerated need for immediate gratification—inability to delay gratification; for example, engaging in irresponsible sexual activity.

The authors proposed the establishment of a lead agency in each state to provide a point of entry for services and encouraged further development of diagnostic and training services. The authors suggested an easily accessible mentoring system. A mentoring system would allow experienced parents to share their wisdom, successes and failures with families of newly diagnosed children thus providing social and parenting support as recommended by Giunta and Streissguth (1988). This is in keeping with

Devries and Waller's (2004) suggestion of "Intervention Touchpoint Systems" for children with FAS including child welfare, healthcare, education, disability, vocational rehabilitation, criminal justice, chemical dependency, and mental health.

Giunta and Streissguth (1988) underscored the needs of the family and recognized that the caretaker of a child with FAS accepts responsibility in excess of the typically perceived parenting responsibility. The child with FAS was stated to require constant supervision, an extraordinary amount of time, energy, love, and consistency, and a strong advocate. The authors concluded that the caretakers require education about FAS, reasonable and realistic expectations for the child and social support. In addition, many caregivers require financial assistance due to the specialized medical and educational needs of children with FAS.

### **Adoptive and Foster Parents and Fetal Alcohol Syndrome**

Closely linked with this study's focus are the identified experiences and needs of non biological parents raising children diagnosed with FAS. The experiences of adoptive/foster parents of children with FAS are potentially different from those of biological parents whereas they do not have the additional complications of maternal guilt regarding the origin of the children's syndrome. Nevertheless, adoptive/foster parents can provide insight into the experience of parenting children with FAS.

These families and parents are familiar with the stresses and struggles of parenting, but bear no responsibility for the damage to the children. Granitsas (2004) utilized a qualitative, phenomenological approach to describe the experiences of adoptive parents of children with FAS. An open ended question was posed to each participant: "What has it been like for you to parent a child with Fetal Alcohol Syndrome?" The author contacted six prospective participants by telephone. Five parents agreed to participate. The author discussed neither how she located the six

potential participants nor why the sixth parent refused participation. Ultimately, Granitsas conducted four interviews.

Six essential themes were identified that described the parenting experience: 1) feeling delighted upon the adoption, 2) not knowing—the parents received no or incomplete information about the child’s diagnosis and/or the feeling of not knowing about the child’s future, 3) identifying problems, concerns and difficulties—developmental, medical, behavioral, educational problems, 4) feeling frustrated—frustrations with the manifestations of the child’s diagnosis, 5) feeling devoted—devotion and love for the child and 6) feeling pride—pride in the child’s accomplishments. The author believed that the six themes identified confirmed her own personal experiences as an adoptive parent of a child with FAS. Although the sample size is small, this study offered the first attempt to capture the parenting experiences of adoptive parents raising children with FAS. This research holds importance for this study as similar research questions were outlined.

Gardner’s (2000) qualitative research study described the challenges inherent in parenting children with FAS. The author conducted in depth, unstructured interviews with eight foster mothers who collectively parented 17 children with FAS. The children were placed in their homes for at least one year allowing for an adequate length of time for foster parent observation. The author posed open ended questions to participants such as “Tell me what it is like raising a child with FAS.”

The content analysis yielded two distinct/main categories of content: effects of FAS on the child and effects on the foster parent. The main category of effects on the child was further divided into the categories of cognitive concerns and behavioral management. The foster mothers reported cognitive concerns including: diminished memory/comprehension, lack of understanding consequences, and absence of fear/judgment. The foster mothers reported behavioral management concerns including:



hyperactivity, aggressiveness, destructiveness, and high pain tolerance. The main category of effects on the foster parent focused on coping with daily realities and included: necessity of providing consistency, coping strategies, and fears for the child's future. The foster mothers reported placing high priority on consistency and structured scheduling in the home and noted difficulties resulting from any break in routine or any unpredictability. Coping strategies were very individualized and included having a support system in place during times of stress, taking a break from the child and increasing the foster parents' education around parenting and FAS. Of particular interest was the foster parents' realization of the necessity to alter their expectations for the child and to realistically view the child's potential (Gardner, 2000).

Strengths of this study included its description of challenges facing both children and parents, in both realms of cognition and behavior. Limitations included: the small sample size ( $N = 8$ ), and the recruitment strategies—in this case, word of mouth and through parent support group meetings. As the foster mothers were recruited in this way, it is reasonable to assume that they already had a social support network in place which may have aided in their abilities to parent effectively. The foster parents may have thus been able to procure parenting and social/emotional support and/or have an outlet for their emotions as a result of their social connectedness. Therefore, generalizability of these findings is called into question because these foster parents may have had a somewhat easier time than the general population of foster parents of children with FAS.

Brown and Bednar (2003) posed the research question "What do you need to be a good parent to a child with Fetal Alcohol Spectrum Disorder(s)?" to a group of nineteen birth, foster or adoptive parents. Participants were recruited through two Canadian newsletters. Nineteen parents called for further information and all enrolled in the study. The sample included 12 females and 7 males, from 14 families. Only two participants

were birth parents (gender unspecified), highlighting the need for more information on this population and also the difficulty recruiting birth parents who are willing to participate in a study. The participants parented a total of 25 children between the ages of 2 and 12 years with Fetal Alcohol Spectrum Disorders.

The interview question was open-ended, which allowed the parents to provide information and insights on any number of topics from their own perspectives. Results produced seven clusters of needs including: 1) need for support of family and friends, 2) need for trained professionals, 3) need to collaborate with the school, 4) need for health and social services, 5) need to see the child as an individual with unique needs, 6) need for specific child management (skills), and 7) optimal personality characteristics of the foster parents including: calm demeanor, sense of humor, patience, tolerance, composure and sensitivity, among others. Several needs noted by Brown and Bednar not previously reported in the literature included the need to be treated with respect by professionals and others with whom their children are involved, the need for a broad continuum of public services, and the need for the internet as a source of information.

A weakness of this study, similar to that of the previous study, lies in the recruitment method. The authors advertised in two Canadian province-wide family association newsletters and at an urban clinic for parents of children diagnosed with Fetal Alcohol Spectrum Disorders. Therefore, the respondents may have been better connected with clinical services and support networks by virtue of subscribing to a family association newsletter. Therefore, external validity of the findings is called into question because the respondents' experiences may not necessarily reflect those of the typical parent of a child with FASD. A strength of this study was the researchers' separation of responses by gender leading to the conclusion that the responses of females and males did not appear to be different. The Brown and Bednar (2003) study supports the previously discussed conclusions of Giunta and Streissguth (1988) and Devries and

Waller (2004) regarding the importance of social support and mentoring for foster parents.

Brown, Sigvaldason and Bednar (2004) posed a similar research question: “What do you need for a successful (foster care) placement for a child who has a fetal alcohol spectrum disorder?” This study included a larger sample ( $N = 63$ ) than Brown and Bednar’s (2003) previous work, but specifically targeted foster parents. Participants were gathered through a randomized list of the telephone numbers of licensed foster homes in a Canadian province. Of the 137 foster parents contacted, 72.9% (100) agreed to participate and 63% ( $N = 63$ ) of these had fostered a child with a diagnosis within the Fetal Alcohol Spectrum including: FAS, Fetal Alcohol Effects (FAE) (confirmed prenatal alcohol exposure, behavioral and cognitive effects without facial characteristics), Partial FAS (confirmed prenatal alcohol exposure, some facial characteristics and one of the following: CNS abnormalities, growth retardation, or behavioral or cognitive disabilities) ARND (alcohol-related neurodevelopmental disorder—neurodevelopmental effects are present, but no facial or physical characteristics are noted) or ARBD (alcohol-related birth defects—indicates adverse physical outcomes related to prenatal alcohol exposure potentially including: cardiac, skeletal, renal or ocular abnormalities).

The study’s findings were similar to and corresponded with the clusters of needs identified in Brown and Bednar’s 2003 study including the need for social support, material support, a structured home environment, professionals, other foster parents, understanding of fetal alcohol spectrum disorders, the right kind of personality (including endurance, love, patience, and flexibility) and organizational skills (including maintaining clear behavioral limits, structure, and reasonable expectations). Compared to the 2003 study, new findings included the disparity between the economic/financial costs of caring for a child with a fetal alcohol spectrum disorder as compared to caring for a child

without a disability are noted, as well as the importance of accessibility of information and professional advice on an on-call basis (Brown et al., 2004).

The authors acknowledged limitations of the study including the small, voluntary sample ( $N = 63$ ) which may not be representative of foster parents of children with FASD in the Canadian province. Furthermore, the children were not only diagnosed with FAS, but also included those in the range of diagnoses under Fetal Alcohol Spectrum Disorders. The placement needs for children diagnosed with different alcohol related disabilities may be different, and therefore the failure to identify the distinctive needs of children with each diagnosis is a limitation of this study. It is reasonable to assume that a more severely affected child, or child with a diagnosis of FAS, may require more intensive services and have greater placement needs.

Nevertheless, from the aforementioned study, we can deduce that raising a child with FAS is a stressful experience and that parents require a great deal of support. In addition, similarly to Devries and Waller (2004), these findings underscored the need for responsive professionals.

### **Biological Mothers and Fetal Alcohol Syndrome**

Biological mothers who parent their children with FAS face unique challenges. Not only must they face the daily struggles of parenting a special needs child, but they must also face these challenges with the knowledge that their children's problems are due to their own actions during pregnancy. While some children diagnosed with FAS are parented by extended family members, adoptive families and/or foster families, many are being raised by their biological parent(s). The National Organization of Fetal Alcohol Syndrome (2007) estimates that 20% of U.S. children with FAS are raised by their birth families.

Giunta and Streissguth's study (1988), discussed above, briefly discussed the needs of biological mothers parenting children with FAS. The authors defined these

women as a “special group of caretakers” as they face the challenges of remaining sober and at the same time parenting a child with special needs. These challenges resulted in this special group of caretakers having additional needs including: parenting classes, public health nurses for one-on-one additional support, nutritional counseling, and counseling potentially to work through feelings of guilt (Giunta & Streissguth, 1988).

However, not every biological mother parenting a child with FAS is an alcoholic. It is important to note, as previously stated, that the U.S. Surgeon General's report emphasizes that there is no known safe amount of alcohol consumed during pregnancy (United States Department of Health & Human Services Press Office, 2005). A mother who is not an alcoholic, might drink alcohol before she knows she is pregnant, and a fetus exposed to even small amounts of maternal alcohol can develop FAS while an individual exposed to greater amounts of alcohol during pregnancy is not affected, or is affected to a lesser degree. Binge drinking has been identified as the most damaging pattern of alcohol consumption to a developing fetus as it produces the highest peak in blood alcohol level. It is the peak in blood alcohol level that is the most damaging to a developing fetus (Abel, 1998).

The neurobehavioral challenges confronting children with FAS are a source of stress for any parent. Although no research to date has directly examined the thoughts and feelings of biological mothers, it is reasonable to assume that these mothers may experience feelings of guilt. Questions remain such as: What are the parenting and emotional experiences of mothers raising their biological children with Fetal Alcohol Syndrome? What sources of support have enabled these mothers to deal with their (presumed) feelings of guilt? With increased knowledge of the challenges facing this specific population of mothers, clinicians will be better able to provide support, understanding and services to assist parents which in turn will improve the outcomes for children with FAS.

One study that has focused on biological mothers, though not their thoughts and feelings, is the Fetal Alcohol Syndrome Prevention Study (Astley et al., 2000a). This study was conducted over five years in the U.S. state of Washington and had 3 goals: 1) to assess the feasibility of using a diagnostic and prevention center for identifying and targeting primary prevention to women who had given birth to a child with FAS (considered at high risk for delivering another alcohol effected child), 2) to generate a lifetime profile of the women, 3) to identify factors that have enabled or hindered the women's ability to achieve sobriety and/or practice effective birth control if they are using alcohol (Astley et al., 2000a, Astley, Bailey, Talbot, & Clarren, 2000b).

Two sources of patients were used by the researchers: mothers of patients diagnosed at the FAS clinic at the University of Washington and patients diagnosed through other University of Washington or Children's Hospital and Regional Medical Center neurodevelopmental and genetic clinics. The study targeted the birth mothers of all children exposed to alcohol in utero and whose diagnosis demonstrated strong evidence of brain damage. This distinction is pertinent as the study included not only birth mothers whose children were diagnosed with FAS, but in addition, birth mothers whose children did not meet the full criteria for FAS, but did demonstrate evidence of brain damage as a result of the alcohol exposure.

Over a 36-month period, 257 women were identified as potentially eligible. Each had given birth to one or more children with confirmed alcohol exposure and a diagnosis of FAS (either utilizing the 4-Digit Diagnostic Code or, prior to its creation, through diagnostic confirmation by Clarren, one of the study coauthors) or diagnosis of static encephalopathy/alcohol exposed (instances in which the child shows evidence of brain damage without evidence of growth deficiency or characteristic facial features). One hundred forty seven were identified through the FAS clinic at the University of Washington and 110 through other clinics. Of the 257, 92 women were confirmed as

eligible as their names and locations were known, 58 were deemed ineligible (31 no longer lived in Washington State and 27 were deceased) and 107 women's eligibility could not be determined (none could be located, although 97 women were identified by name). Outreach efforts were conducted via telephone or letter of invitation. Of the 92 eligible women, six women declined and six women were identified by name and location, but could not be reached directly. This resulted in the sample of 80 women (87%) who participated in a four hour structured interview.

At the time of the interview, the 80 women had given birth to 272 children. It is important to note, that more than half of the participants did not live with their children at the time of the child's diagnosis. The lifetime profile documents the sociodemographics, social and healthcare utilization patterns, adverse social experiences, and mental health of the 80 participants. Several instruments were used including: standardized instruments such as the Social Support Questionnaire (Short Version), the Quick Diagnostic Interview Schedule III R, and the Shipley-Hartford Institute of Living Scale. In addition, three other, non-standardized instruments were constructed by the researchers including: Sociodemographic and Lifetime Social/Health Care Utilization Questionnaire, Reproductive and Family Planning History Questionnaire, and Alcohol Use and Treatment History Questionnaire. The researchers did not indicate if tests of validity and reliability were carried out on these instruments, which makes it difficult to fully evaluate the study.

Forty nine (61%) of respondents did not complete high school; twenty (25%) women attended some college education. Forty seven (59%) women had a household gross annual income of less than \$10,000. The authors reported on lifetime alcohol use and treatment history. Two important findings were noted: 76 (95%) of the mothers had been physically or sexually abused during their lifetime and 77 (96%) had between one and ten mental health disorders (Astley et al., 2000b). Diagnoses of post traumatic

stress disorder and simple phobia were the most common with (61 women) 77% and (35 women) 44%, respectively. When examined in detail, 46 (57.5%) of the mothers reported being sexually abused as a child, 37 (46.2%) reported being physically abused as a child, and 79 (98.8%) reported histories of childhood emotional abuse (Astley, et al., 2000b).

The authors noted that in this population, the prevalence of mental health disorders, as measured by administering the National Institute of Mental Health Quick Diagnostic Interview Schedule IIIR, appeared to be greater and more likely to precede the onset of alcohol abuse as compared to findings reported by Kessler, Crum, Warner, Nelson, Schulenberg, and Anthony (1997). Kessler et al. (1997) examined co occurrence of diagnosed alcohol abuse and alcohol dependence with other diagnosed psychiatric disorders utilizing the National Comorbidity Survey, a nationally representative household survey. Participants were household members between the ages of 15 and 54, not necessarily mothers or parents. The researchers also studied the order of onset between the psychiatric disorders and alcohol disorders. Kessler et al. (1997) reported a lifetime prevalence of Post Traumatic Stress Disorder of 10.5% of the sample of 299 women with diagnoses of alcohol abuse as compared with 77.2% reported by Astley et al. (2000b). Kessler et al. (1997) reported occurrence of depression (30.1%), simple phobia (28.2%), social phobia (24.1%), antisocial personality (2.1%), agoraphobia (9.3%), generalized anxiety disorder (8.4%), mania (3.8%) and panic disorder (7.3%). Comparatively, Astley and her colleagues (2000b) reported rates of occurrence of depression--59.5%, simple phobia--44.3%, social phobia--43.0%, antisocial personality--39.2%, agoraphobia--36.7%, generalized anxiety disorder—34.2%, mania—21.5% and panic disorder—20.3%.

Fifty (63%) women in the Astley study had achieved abstinence by the time of the study and 25 (31%) had not. The authors did not report on the 5 remaining subjects.



Abstinence was defined as consuming no alcohol or consuming minimal amounts of alcohol on special occasions only. On average, the 50 women who were abstinent had higher IQ's, higher incomes, larger social support networks, were more likely to hold a religious affiliation and were more likely to have parents who had a problem with alcohol use. This group was more likely (52.2% vs. 26.1% in the group who continued to use alcohol) to have received mental health treatment, although they were equally likely to have mental disorders. However, the two groups were comparable in race, level of education, employment, adverse experiences (for example, history of abuse), and age at interview, first attempt at abstinence, age during first pregnancy, birth of index child and age when drinking began (Astley et al., 2000b).

Astley and her colleagues' (2000a, 2000b) studies are significant but are not without limitations. Not all children of mothers sampled were diagnosed with FAS (Astley et al. 2000a, 2000b). Eleven percent had diagnosis of static encephalopathy alcohol exposed without the full FAS facial phenotype. Similarly, as previously stated, Astley and her colleagues reported that less than 50% of participants lived with their children. In addition, over 40% (107) of the women identified as potentially eligible (257) were not located. The possibility of different outcomes exists if more women could have been located and recruited.

However, even with these weaknesses this study's findings are compelling. It provided the first detailed examination of mothers who have given birth to babies diagnosed with FAS. The authors offered a profile inclusive of demographics, such as access to social and health care services, mental health history, reproductive and family planning history, alcohol, drug and tobacco use and history of adverse experiences. In addition, the findings underscored the importance of carrying out this study and learning more about the emotions and challenges for these birth mothers from a prevention standpoint as an additional 61 children were born to 35 of the women during the course

of the study. Forty seven (75%) of those children were exposed to alcohol in utero (Astley et al., 2000b). This finding highlights the need for intervention and prevention and also suggests the importance of a comprehensive service delivery system.

In 2010, Astley profiled the first 1400 individuals evaluated at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network (Astley, 2010). Comprised of seven clinics throughout Washington State, Astley's study included both birth mother and birth father characteristics: whether each attended the child's FASD evaluation, mean ages for mother and father at the time of the child's birth and at the time of the child's diagnosis, highest grade completed in school and the presence of learning disabilities in both parents.

Three studies have examined characteristics of mothers of children with FASD in Western Cape Province, South Africa. Viljoen, Croxford, Gossage, Kodituwakku and May (2002), May, Gossage, Brooke, Snell, Marais and Hendricks (2005) and May, Gossage, Marais, Hendricks, Snell, Tabachnick, Stellavato, Buckley, Brooke and Viljoen (2008) identified characteristics of mothers of children with FASD. Thirty-five and 54 mothers of children in first grade with FASD were interviewed and compared to a control group for the 2002 and 2005 studies, respectively. Seventy-two mothers of children in 1<sup>st</sup> grade were compared to a control group of 134 mothers randomly selected from the same schools in the 2008 study. The authors identified several risk factors including: heavy drinking, drinking among members of the extended family and social network, more years of drinking, smoking, previous treatment for alcohol and/or drug abuse, older age, high gravidity, lower educational attainment, lower income, lower IQ, sexual and/or physical abuse and mental illness. (May et al., 2005, 2008; Viljoen et al., 2002). It is unclear if a study focused on an international population may compare to groups within the United States, however, many of the characteristics identified are the same as those identified by Astley et al. (2000a, 2000b).

Most recently, Cannon, Dominique, O'Leary, Sniezek, and Floyd (2012) examined a group of 353 biological mothers of children with FAS to discern characteristics and drinking behaviors. As with the previously reviewed studies, this study did not focus on the thoughts and feelings of biological mothers. The study utilized data from the Fetal Alcohol Syndrome Surveillance Network (FASSNet) which is a CDC sponsored method for identifying FAS cases through passive reporting and record review from various sources including hospitals, Medicaid, private physicians, early intervention programs, etc. The FASSNet surveillance gathered information from Alaska, Arizona, Colorado, New York and Wisconsin, although information from Wisconsin was not utilized for purposes of this study as it used only birth certificates as a data source for children that might meet the criteria of the FAS case definition, thus it was insufficient. To meet the FAS case definition criteria the child must possess: 1) abnormal facial features consistent with FAS as reported by a physician or have two of the following: short palpebral fissures, abnormal philtrum, and thin upper lip, 2) at least one CNS structural or functional abnormality, and 3) intrauterine or postnatal growth delay. To meet the criteria for probable FAS the child was required to meet the same criteria for facial features and possess either the CNS abnormality or the growth delay. The study included children born between 1/1/1995 and 12/31/1997. Mothers of children who met criteria for either the case definition of FAS or the probable FAS definition were included in the study. The authors note that as they were reliant on existing reported data, there were instances of missing information.

The authors reported results grouped by state and also as compared to national data information. Overall, in each of the four states as compared to other women from that state who had recently given birth, mothers of children with FAS were more likely to be: older, non-Hispanic, unmarried, unemployed, lack prenatal care, smoke during pregnancy, have a lower educational level and have a greater number of live born

children. The sample included 74 women from Alaska, 118 women from Arizona, 67 women from Colorado and 94 women from New York. A relatively high proportion of mothers had a child other than the identified child with suspected alcohol effects (Alaska 29%, Arizona 15%, Colorado 13% and New York 9%.

When examining the results in comparison to women in national surveys, the authors reported that mothers in the four states combined were more likely: to have a history of mental illness, to be on public assistance, to be on Medicaid at the time of her child's birth, to have received treatment for alcohol abuse, to have a diagnosis of alcoholism, to have used marijuana or cocaine during the pregnancy and to have her child screen positive for alcohol or drugs at birth.

Cannon et al. (2012) discerned similar characteristics for mothers of children with FAS as compared to results reported by Astley et al. (2000b) and May et al. (2008) including: lower educational attainment, lower socioeconomic status and severe drinking. Although the authors do note that pieces of data were not available for all members of the sample, the sample was identified through population based surveillance. This is a contribution noted by the authors as the samples in aforementioned studies were gathered from a more narrowed population.

Drinking behavior, mental health history, educational and socioeconomic status, among other characteristics, has been examined and identified in mothers of children with prenatal alcohol exposure. The aforementioned studies provide valuable information on the characteristics and drinking behavior of mothers who have given birth to children with FASD. However, the mothers' thoughts and feelings on the cause of their children's FASD were not captured in this previous research and is the focus of this study.

### **Tobacco Use During Pregnancy**

Due to the paucity of research focusing directly on biological mothers and FAS, it is useful to examine other populations of women whose behavior may have had negative effects on their children or placed their children at risk. Studies of mothers who smoke cigarettes either during or after pregnancy provide some insight and offer some degree of transferability to mothers who drink alcohol during pregnancy. Like alcohol, cigarettes are legal, but discouraged during pregnancy. Cigarettes also possess an addictive quality. Tobacco use during pregnancy can decrease oxygen delivery to the fetus, reduce uterine and placental blood flow, cause placental problems, and decrease birth weight. Smoking is also linked to perinatal mortality and Sudden Infant Death Syndrome (SIDS). In addition, in utero exposure to tobacco appears to increase the risk of cognitive deficits, attention deficit hyperactivity disorder, conduct disorder, criminality in adulthood and a predisposition in the offspring towards smoking and alcohol abuse (Jauniaux & Greenough, 2007). However, using tobacco during pregnancy does not have the same effects as alcohol specifically in the areas of facial characteristics, and reduced height and weight beyond birth, and brain abnormalities.

Ludman, McBride, Nelson, Curry, Grothaus, Lando, and Pirie (2000) explored the potential relationship between stress, depression, and addictive behavior during pregnancy and established a link between pregnancy and failure to cease smoking. The authors examined perceived stress and depressive symptoms as correlates and predictors of continued smoking during pregnancy. They hypothesized that women who report less stress and have fewer symptoms of depression were more likely to quit smoking early in pregnancy; and among women who smoke in early pregnancy, lower baseline levels of stress and symptoms of depression would be associated with quitting later in pregnancy. The authors utilized data previously collected to evaluate smoking cessation and relapse prevention interventions among 897 women recruited from two

managed care organizations, who were either pregnant and smoking or who stopped smoking during or immediately prior to pregnancy. Women were surveyed between their 4<sup>th</sup> and 12<sup>th</sup> weeks of pregnancy (baseline) and surveyed again at 28 weeks of pregnancy (follow-up).

The researchers defined smoking status in terms of frequency and quantity of cigarettes and use of the Heavy Smoking Index (HSI) (Heatherton, Kozlowski, Frecker, Rickert, & Robinson, 1989). At baseline, they completed a health behaviors survey and reported being a current smoker or a recent quitter. At the 28 week follow up, respondents were asked “Do you happen to have smoked any cigarettes in the prior 7 days?” Stress was assessed at baseline and follow up with a four item measure drawn from the Perceived Stress Scale (PSS; Cohen, Karmack, & Mermelstein, 1983). The scale measured the extent to which respondents felt their lives were unpredictable, uncontrollable and overwhelming. Researchers also utilized an eight item self-report instrument derived from the RAND Screening instrument for depressive disorders (Burnam, Wells, Leake, & Landsverk, 1988) to assess depressive symptoms at baseline and follow-up.

The researchers found a statistically significant association between lower levels of perceived stress and depression and smoking cessation in early pregnancy, but lower levels of perceived stress were not predictive of cessation in late pregnancy. An inverse, weak though non-significant association was found between depressive symptoms and smoking cessation. In the absence of a relationship between stress, depression, and smoking cessation for those who continued to smoke during early and late pregnancy, the authors postulated that these women were more highly addicted smokers prior to becoming pregnant than those who quit smoking during early or late pregnancy. However, they related that the results suggest that stress, higher levels of addiction, and potentially depression, may be barriers to smoking cessation during early pregnancy.

Furthermore, Ludman and her colleagues (Ludman, et al., 2000) questioned whether the quitters' lower levels of stress may reflect that quitting itself reduces perceived stress. Additionally, they proposed that addiction may be a bigger barrier to cessation than stress and depression for women who continue smoking beyond early pregnancy (Ludman et al., 2000). The authors suggested that women of lower socioeconomic status may experience life circumstances that compound stress, depression, and continued smoking (Ludman et al., 2000).

A parallel may be drawn between these findings and the profile findings of Astley et al. (2000) discussed previously. While Ludman et al. (2000) noted a possible relationship between stress, depressive symptoms and smoking, Astley et al. (2000b) noted that 96% of their sample had at least one mental health disorder (not specifically depression) and had experienced stressful life circumstances (i.e. 59% of participants with income less than \$10,000 and 95% of participants had been physically or sexually abused during their lifetime). Mental health symptoms along with insufficient financial resources could be indicative of stress as well as sources of stress. Given these findings, it may be reasonable to look at stress and environmental factors in relation to continued alcohol consumption during pregnancy.

In another study, focus group methodology was used to provide insight into barriers to "quitting" smoking during pregnancy, pregnant women's attitudes about the use of nicotine patches and their perceptions of counseling by care providers in North Adelaide, Australia (Hotham, Atkinson, & Gilbert, 2002). An estimated 250 women (the researcher did not keep an exact record of how many) were approached by the principal investigator to participate in the study. Those women interested signed a consent form for follow up (number not noted by the researcher), but several refused participation when contacted by telephone (number not noted by the researcher). Thirty-six women agreed to participate in the study, however only 19 members attended the focus group.

Explanation of the loss of seventeen participants was not offered by the authors.

However, it is reasonable to wonder if the women had re-considered their participation as the study examined an aspect of their behavior that was socially stigmatized.

Generalizability is called into question due to this small sample size, the difference between the sample size and the number of women approached for the study and the unexplained loss of women recruited (17 participants). The 19 respondents were divided into three groups: five women (all smokers) experiencing a low risk pregnancy, four women (all smokers) experiencing a high risk pregnancy, and ten women who had quit smoking either before this pregnancy or early in this pregnancy. Six barriers to smoking cessation were common to both pregnant women and those known for smokers in general including: addiction, reliance on smoking for stress relief, smoking behavior of others, lack of willpower, fear of weight gain, and doubt about ability to maintain abstinence. Three pregnancy-specific barriers to smoking cessation were also noted including: skepticism that smoking harms, stress about harm leading to increased smoking, and societal attitudes. The first pregnancy-specific barrier appeared to the researchers to originate and be reinforced by anecdotal experiences (i.e. another woman known to the respondent, smoked and “her baby’s fine”). The second barrier to cessation, related to the opposite scenario, the mothers were aware of the harmful effects of smoking, which led to stress and an increase in smoking. Finally, the third barrier was negative societal attitudes towards smoking during pregnancy. Respondents expressed feeling pressure to quit, even from strangers. While some respondents reported this to be an incentive, others viewed this as a trigger that increased stress levels which resulted in a continuation of smoking.

Generally, the participants did not have positive perceptions of the health care providers. Respondents reported that care providers did not suggest “ideas” about how to stop smoking and that when they stated they “cut back” there was no further



questioning. The participants reported surprise that their pregnancy care providers did not follow up and question their smoking status. This response was consistent with previous findings that pregnant smokers hold care providers responsible if the issue of smoking is not discussed (Hotham, Atkinson, & Gilbert, 2002). Could these findings provide insight into why some women drink during pregnancy? Is there a relationship between stress and drinking? Are the women waiting for their care providers to tell them to stop drinking? As stated previously, a significant weakness of this study was not only the small sample size, but also the rate of drop out without explanation. In addition, although the participant's perceptions of care provider counseling was a main theme reported by the respondents, a direct question on care providers was not included in the questioning path published with the article. Thus, it appears that this was a compelling issue for the respondents in that they raised it without prompting.

Even though the limitations are substantial, this study provided insight into the perceptions of pregnant women who smoke, particularly into barriers to cessation specifically related to pregnancy. Particularly alarming was the women's skepticism about smoking's harms. This related directly to the ineffectiveness of public education about the dangers of smoking during pregnancy. The authors suggested that these same pregnancy-related barriers to smoking cessation could provide insight into why women drink during pregnancy. The same three pregnancy specific barriers: Skepticism about smoking's harms, stress about harm leading to increased smoking and societal attitudes are quite possibly at work with pregnant women who take alcohol. It might also be possible that, as has been reported by the smokers, health care providers might not be sufficiently addressing the dangers of alcohol use with their pregnant patients.

Irwin, Johnson, and Bottorff (2005) drew on qualitative interviews ( $N = 36$ ) of two previous studies (Bottorff, Johnson, Irwin, & Ratner, 2000; Secord, 2000) to look at the internalization of discourses by women to account for and justify their decisions around

tobacco use. It is important to point out that the women in the overall sample were not pregnant at the time of either previous study. The current study examined a subsample of 27 women who had stopped smoking during pregnancy and then relapsed during the postpartum period and a subsample of 9 women (4 former smokers and 5 regular smokers) who shared their experiences about smoking and the ways they protected their children from second hand smoke. In their research the concept of discourse was referred to as a “dominant and accepted view, perpetuated by continued use, that organizes the way people in society think and act” (Irwin, Johnson, & Bottorff, 2005, p. 577). The discourse of a “good mother” who is selfless, strong, and confident, always placing her child’s needs first and accepting responsibility for the child’s health contrasts with the discourse of smoking tobacco as a bad habit that causes cancer and also inflicts harm on the “innocent” (Irwin et al., 2005).

The findings revealed five ways the mothers framed their tobacco use and maintained the discourse of a “good mother”: 1) demonstrated knowledge of the health risks of tobacco use (seemingly used to curtail any offers of advice; i.e. reciting public health messages about the harm of tobacco to preempt the interviewer from offering advice or information), 2) confessing guilt and shame (seemingly to elicit a sympathetic response), 3) deflecting accusations of neglect (explanations of efforts to minimize the effects of tobacco; i.e. “I go out to the carport” ), 4) smoking for the sake of the child (smoking provides a necessary break to help them be better mothers), and 5) taking an antismoking stance (indicating their disapproval of smoking supports the image of a good mother). The authors noted that in this study, the women did not discuss the problem of addiction, as has been the case in other studies (Irwin, Johnson, & Bottorff, 2005).

As in the previously discussed study (Hotham et al., 2002), this study, provides some clues about what woman who drink during pregnancy are thinking. The mothers in

this study are also subjected to the social discourses around drinking and being a “good mother.” It is likely that women who drink during pregnancy also somehow frame their drinking to maintain the discourse of a “good mother.” In addition, this study lends clinical understanding of these populations of mothers and assists clinicians to have greater empathy and be more aware of the rationales women use.

### **Mothers and Guilt**

In addition to examining the literature on other populations of women whose behavior may have had negative effects on their children or placed their children at risk, it is pertinent to examine the literature on other mothers who experience guilt. It is particularly significant to note that the literature suggests that maternal guilt is universal and experienced by mothers regardless of the ages of the mothers or the children (Rich, 1986; Rotkirch & Janhunen, 2009). Maternal guilt begins in pregnancy when women are cautioned to “make themselves perfect vessels for the gestation of their offspring” and continues throughout the years of motherhood (Seagram & Daniluk, 2002, p. 62). Seagram and Daniluk (2002) recruited participants by posting notices in various community settings in an urban area frequented by women. Women who were mothers of at least one child between the ages of two and 12 years, were parenting with a male partner, and who had experienced feelings of guilt relative to the role of mothering without being debilitated by these feelings were potentially eligible for the study. The study excluded mothers who are solely supporting their children and mothers who are lesbians as the authors explain that these mothers may experience unique stressors that may fortify feelings of maternal guilt. Approximately 75 women responded over a two month period of time inquiring about participation. Of the 75, only twelve women met the criteria for participation. The majority of interested women were sole support mothers who were therefore ineligible for the study. The children of other interested women were either too young or too old.

The authors qualitatively interviewed a final sample of 12 mothers and reported on the first 8 participants (the authors determined that they had reached a point of saturation). Although not stated within the article's text, it is inferred that the women had no reason to feel guilt and that their children were typically developing with no special needs. Even so, the authors sought to understand the participants' experiences of maternal guilt. These researchers, along with others (Hare-Mustin & Broderick, 1979; McBride, 1973; Oakley, 1992; Rich, 1986) attributed the origin of maternal guilt to our North American cultural notion which holds mothers completely responsible and accountable for the health and well being of their children. The analysis yielded six themes representing the participants' experience of maternal guilt: 1) sense of complete responsibility, 2) strong desire to have a positive impact on their children's lives and development, 3) sense of profound connection to their children, 4) fear that their children might come to harm, 5) sense of depletion and 6) sense of inadequacy (Seagram & Daniluk, 2002). Results indicated that the mothers expected their guilt to be a part of their mothering experience for the rest of their lives (Seagram & Daniluk, 2002).

Jackson and Mannix (2004) presented a feminist-based, exploratory-descriptive, qualitative study of mothers' experiences of mother blaming. Twenty mothers were interviewed with conversation-style interviewing, with three goals: 1) to gain insight into the nature of mother blaming as it has been experienced by women, 2) to explore the issue of mother blaming as it affects women in their attempts to seek health care for their children and 3) to develop understandings that will assist nurses and other health professionals to provide a supportive milieu for mothers. Initially, three participants were recruited through a women's email network. Next, a snowball method, by which participants recruit new participants from those they know, was used to recruit 17 more women with children ages 17 years and older. The participants were asked the interview question of "Can you think back over your years as a mother and tell me some

stories about the most challenging, as well as the most positive aspects, of your mothering journey?”

The authors' findings included a clear discussion of mother blaming in 18 of the 20 interviews. Blame was experienced as a burden that was given to them by others and, at times one that they placed on themselves. One participant stated, “Poor little thing, he cried all the time.....he got it (atopic allergies) in the first place because I mucked up on the breast feeding” (Jackson and Mannix, 2004, p 153). Jackson and Mannix (2004) discerned that some subjects internalized the mother blaming attitudes of others and blamed themselves for “things that were often outside their control and that could not be reasonably linked to actions or omissions on their part” (p. 153). The sampling method was a limitation in this research as the vast majority (17) of the sample was collected through a snowball method; thus it is not representative and therefore not generalizable to the larger general population of mothers. However, the research is relevant to this study. If mothers perceive blame and guilt without a clear cause, it was reasonable to anticipate that biological mothers of children with FAS, who may have reason to do so, might feel guilty.

The following study examined a sample of not only mothers but also fathers of children with difficulties and whose behavior had no causal link to their child/children's diagnosis. These findings might help provide some indirect insights regarding birth mothers of children diagnosed with FAS. Ferriter and Huband (2003) interviewed the parents of 22 patients diagnosed with schizophrenia and receiving treatment in a secure forensic setting. The parent interviews of the 22 patients were comprised of 12 interviews with the mothers only, six with the fathers only, and four with both parents. The purpose of their study was to explore the emotional burden experienced by the parents and examines three hypotheses: parents with children with schizophrenia blame themselves for the disorder; self-blame arises from the belief in a pathological parenting

model of schizophrenia; and self-blame arises from the perception of being blamed by others. All parents were interviewed in their homes. Ten theories on the cause of schizophrenia were drawn from the literature and presented randomly to the parents. Familiarity with each theory was rated on a 3-point Likert scale: 2 = *recognized by name*, 1 = *not recognized by name but recognized from description*, 0 = *not recognized*. Opinion and explanative importance of each theory was rated on a 5-point Likert scale: 4 = *prime importance*, 3 = *very important*, 2 = *moderate importance*, 1 = *some importance*, 0 = *no importance/don't know*. Opinions regarding the helpfulness of others in relation to their son's or daughter's illness were rated on a 3-point Likert scale: 2 = *very helpful*, 1 = *helpful*, 0 = *not helpful* (Ferriter & Huband, 2003).

The authors examined the recalled experiences of the parents over a number of years as opposed to viewing only the most current experiences with a desire to avoid overemphasis on the recent crisis. As the patients were confined to a secure forensic setting, a focus solely on current experiences could potentially over emphasize the burden based on recent crises. The authors utilized a computer random number generator using patient hospital numbers to select at random, parents of Caucasian patients diagnosed with schizophrenia receiving treatment at that hospital. Only patients diagnosed with schizophrenia as their only significant mental disorder were included.

Several weaknesses should be noted. The sampling method utilized was very restrictive and included only White participants and excluded ethnic minority groups. This severely limits the generalizability of these results. Although the authors do examine the parents' recalled experiences over a number of years to decrease overemphasis on current experiences, it is noted that many of the patients had a history of serious legal offenses which may serve to intensify the emotional burden of the parents. Additionally, the authors do not differentiate the results of the mothers from the fathers. Although direct narratives attributed to "a father" or "a mother" are delineated

within the paper, the authors note that when both parents of a patient with schizophrenia were interviewed (4 of the 22 patients) and their ratings disagreed, the mean score was utilized.

The parents provided their views on the causes of schizophrenia by giving information on familiarity with and importance of ten theories of causation drawn from the literature, including: genetic, neurotransmitter disorder, life event, viral, structural brain pathology, scapegoating, family imbalance, double bind (receiving different or contradictory messages), schizophrenogenic mother, and fragmented family communication. Biological and life events theories of causation of schizophrenia were rated both as most familiar and most important. However, parents expressed guilt in more than half the interviews. Ferriter and Huband (2003) found that even though participants did not place importance on pathological parenting theories on the cause of schizophrenia, they expressed guilt in terms of “doing, or not doing” something that could have contributed to, or caused, their children’s schizophrenia. Thus, even if parents logically understand that they did nothing to cause their children’s illness, they can still feel guilty.

Although not directly related to this study, these studies as well as the previously reviewed research by Jackson and Mannix (2004) do lend support to the assertion that parents are apt to experience guilt and self-blame even in the face of evidence to the contrary. It follows that biological mothers of children diagnosed with FAS may experience guilt and self-blame as related to their children’s diagnosis.

### **Theoretical Framework**

Several theories can be utilized to guide and frame my research. The first, addictions theory, provides a rationale for the use of alcohol during pregnancy. Although the dangers of drinking during pregnancy are widely agreed upon, the disease concept or medical model of addictions supports the position that the use of alcohol is out of the

control of the alcoholic. The disease compels people to drink. The disease model of addiction/alcoholism was first presented in 1960 by E.M. Jellinek. However, the use of this model as a frame is problematic as it leads to the assumption that every birth mother who drinks during pregnancy and produces a child with FAS is an alcoholic. A child has the potential to develop FAS if the mother drinks any alcohol at all during pregnancy. It is entirely possible that a child with FAS is born to a mother who does not have the disease of alcoholism. A possible scenario is the mother who drank moderate amounts of alcohol until she learned she was pregnant and subsequently abstained from alcohol for the remainder of the pregnancy. Therefore, for the purpose of this study, it is important not to assume that all mothers who give birth to a child with FAS have alcoholism.

A second theory, attachment theory, helps to frame our understanding of the mother/child relationship. Originated through the work of John Bowlby, attachment theory offers a framework for understanding interpersonal relationships. This theory stipulates that an infant is in need of a secure relationship with his/her caregivers. The mother's provision of safety, protection, and security is the basis of the relationship (Bowlby, 1958). Infants appropriately bond to adults who are emotionally sensitive and responsive to them. It is possible that the mother-child relationship may be affected at two potential points of reference: if alcohol abuse has occurred through the pregnancy and extended through and beyond the post-partum period, the security and basis of the bond may be disrupted; and the relationship may be affected by the mother's erratic behavior due to continued alcohol abuse and/or maternal guilt over harm done due to drinking during the pregnancy.

Finally, cognitive dissonance theory helps describe what is happening for this population. The theory holds that a person will naturally attempt to decrease the inconsistencies or dissonance between what one knows or believes and the actions one



takes. In an effort to reduce this dissonance, one will “actively avoid situations and information which would likely increase the dissonance,” or develop or maintain cognitions that reduce the dissonance (Festinger, 1957, p. 3). When one is not successful in decreasing the dissonance, psychological discomfort follows (Festinger, 1957).

Cognitive dissonance theory fits quite well with the previously discussed literature on smoking during pregnancy. Festinger (1957), who proposed the theory of cognitive dissonance, utilized smokers to illustrate his theory. The theory states that when this inconsistency occurs, one can change his/her cognition about his behavior by changing his/her actions (i.e. smoking cessation) or changing his/her knowledge or beliefs (i.e. internalizing the justifications for smoking—“Not everyone who smokes gets sick, maybe it isn’t that bad”).

The study by Hotham, Atkinson, and Gilbert (2002) concluded with three pregnancy specific barriers to smoking cessation including: skepticism about smoking harms, stress about harm leading to increased smoking, and stress due to societal attitudes. Dissonance theory could be applied to these findings. Following this theory, the first barrier is an attempt at reducing the dissonance by changing one’s knowledge (“Her baby’s fine,” “My friends have big, healthy babies and smoked”). Cognitive dissonance will decrease if the smoker believes that smoking may not be harmful. The second barrier can also be seen as an effort to decrease cognitive dissonance by reconciling the knowledge of the harm of smoking with continuing to smoke. The smoker is aware of the harm but the stress related to that knowledge leads the smoker to smoke. (“I’m worried that something might happen to the baby, which makes me feel stressed and when I’m stressed I need to smoke”). This again suggests a link between stress and continuation of the harmful behavior. The third barrier is continued smoking due to increased stress as a result of health messages to stop smoking. Some smokers

regarded health messages and anti-smoking statements as an incentive to quit. However, others regarded these messages as triggers for stress that led to an increase in the behavior, much like those in Hotham, Atkinson and Gilbert's (2002) study that discussed the second barrier. It seems the women are justifying their smoking in each of the three barrier domains. In the last two, they are justifying their smoking by thinking it is caused by stress. Perhaps they believe stress is more harmful than smoking and reducing their stress will benefit their babies more than quitting smoking.

Similarly, Irwin, Johnson, and Bottorff's (2005) study discussed ways the mothers framed their tobacco use and maintained the discourse of a "good mother." Each of the five ways the mothers framed their tobacco use demonstrated utilization of cognitive dissonance reduction and allowed the mothers to feel they could continue smoking. For example, one quoted mother stated "I go out to the carport." This mother had tempered her cognitive dissonance by minimizing the effects of tobacco.

As previously stated, it is reasonable to assume that there may be some similarities between smokers and drinkers. It is conceivable that women who drink alcohol during pregnancy will use cognitive dissonance reduction to attempt to explain the inconsistency between the knowledge that alcohol may damage the developing fetus and drinking alcohol during pregnancy. Identifying those explanations was a goal of this study.

### **Summary of Literature Review**

The literature presented reveals that children with FAS face challenges in many areas as a result of prenatal exposure to alcohol. It follows that parenting these children may lead to increased stress due to added parental responsibilities. While research on foster parents provides information on parenting issues, it cannot speak to the unique experience of the biological mother caring for her child with FAS. Although the Fetal Alcohol Syndrome Prevention Study (Astley et al., 2000a, 2000b) suggested a profile of

biological mothers, parenting issues were not covered and the majority of the children did not reside with their biological mothers.

Research on women who smoke during and after pregnancy and studies that examine parental guilt provided some insight into the possible experiences of biological mothers raising their children with FAS. Knowledge gained from this study might benefit not only the mothers, but also their children by illuminating their unaddressed needs so services can be improved. A greater understanding of this group of mothers may prevent future children from suffering the effects of prenatal alcohol exposure.

### **Research Questions**

1. What are the parenting experiences of birth mothers who parent their children diagnosed with FAS?
2. What are the mothers' thoughts, feelings and behaviors surrounding the etiology of their children's diagnosis?
3. What coping strategies do mothers employ?
4. What support services do these mothers perceive are or could be most helpful?

## CHAPTER III

### METHODOLOGY

#### **Design**

This research was designed as a qualitative study. Creswell (1998) discussed the choice between qualitative and quantitative research and favors the former when a particular topic or group requires exploration. Qualitative research offers the researcher the ability to tell the participants' stories. As relatively little is known about the experiences of this very distinct population it was reasonable to undertake an in-depth and detailed study utilizing myself as an instrument of data collection as a means to uncover and interpret phenomena and to contribute to knowledge and our understanding of a complex problem.

Similarly, Patton (1990) views qualitative research as non-manipulative, unobtrusive and non-controlling: "studying real world situations as they unfold naturally" (p 40). Although theory development was not a primary goal of this research, this study's findings provide insight that confirms and even adds to the application of dissonance reduction theory. Most importantly in this research is the need to present a detailed, in depth view of the experiences of a population, namely of birth mothers (Patton, 1990).

After examination of the qualitative traditions of inquiry, phenomenology was chosen because it is most appropriate for this study. Phenomenology was deemed the most applicable as its intent is to describe the meaning of the experience for the participants (Creswell, 1998). The goal of this research was to capture, describe, and understand the thoughts and experiences of birth mothers of children with FAS. The phenomenological approach aims to capture and describe the meaning of the experience or a concept as conceptualized by several individuals.

The phenomenological approach shares commonalities with other qualitative approaches. These commonalities include: a concentration on the wholeness and meaning of the experience, utilizing first person accounts of the experience, and “viewing experience and behavior as an integrated and inseparable relationship of subject and object and of parts and whole” (Moustakas, 1994. p. 21). This study intensively interviewed 11 biological mothers parenting their children with FAS, giving an individual voice to each participant and joining those individual voices together to create a composite of their experiences—to tell their collective story by gathering the details of their individual stories.

Moustakas further delineated his model as a transcendental phenomenological approach and described differences in the “launching” and in methods of data collection and data analysis. When launching a study from a transcendental phenomenological approach, the researcher engages in the Epoche process. The Epoche process is a method of systematically setting aside any prejudgments regarding the phenomenon under study. The goal of this process is to “launch the study as far as possible free of preconceptions, beliefs, and knowledge of the phenomenon from prior experience and professional studies” (Moustakas, 1994. p. 22). The researcher is to be an active learner, “completely open, receptive, and naïve” in taking in the described experiences of the subject” (Moustakas, 1994. p. 22). This is particularly important in relation to this study. When undertaking a study to examine a topic laden with societal judgments and values it is paramount to begin without opinion, bias, and value judgments. Not only is this important for the validity of the research design, but in addition, it is necessary in order to enhance the process of engagement with the participants and to construct a trusting environment where the participants do not feel judged.

### **Sample and Data Collection**

Non-randomized, purposeful, sampling was utilized (Patton, 1990). Participants included birth mothers of children under the age of 24 diagnosed with FAS. Participants were limited to mothers of children who have the full FAS diagnosis as those children suffer the most complex and comprehensive effects of maternal prenatal alcohol exposure. Data for this study were gathered through telephone interviews as outlined by Creswell (1998). I developed an open-ended questionnaire to guide the data collection interview process. An expert in the field of FAS, Susan Adubato, PhD. reviewed and approved the interview protocol.

Individual, in-depth interviews were conducted with eleven birth mothers gathered through contact with the National Organization on Fetal Alcohol Syndrome (NOFAS). A flyer describing the study and inviting mothers to participate was mailed and emailed to the aforementioned organization. NOFAS emailed the flyer to their members. Interviews were conducted by phone and audio-recorded, with permission of the subjects. Average time for the interview was 1 hour and 40 minutes. Face to face interview could not take place as participants were located in various states in the United States. Following the interview, the entire interviews were transcribed verbatim by the researcher. As the researcher's intuition plays a role in the transcendental phenomenological approach (to be defined subsequently), the same author conducted and transcribed the interviews furthering a connection among the researcher, participant and data, deepening the understanding of the data thus assisting in thorough data analysis.

One interview was conducted as a pilot. After the first interview, the transcript was reviewed with the committee chairperson, Michael LaSala, Ph.D., LCSW. Following the pilot interview, the researcher shared a summary of the interview with the participant to ensure that her responses were accurately captured. In addition, the researcher

solicited input from the respondent on additional questions/information that should be included in the study. As this study falls under Title 45 of the Code of Federal Regulations, Part 46 (45 CFR 46), application to the IRB at Rutgers University was submitted and approved.

The following table details the characteristics of the sample. The sample was diverse in both the ages of the participants and the ages of their children. The mean age of participants was 43 years old with the youngest participant 28 years old and the oldest 56 years old. The mean age of their children was 17 years old with the youngest 8.5 years old and the oldest 24 years old. One participant was from of Canada. The remaining ten participants hale from throughout the United States including: the Midwest (3), North (3), West (1), Northwest (1), Southwest (1), and Northeast (1).

Table 1

*Participants*

Participant	Age	Name of child	Age of child	Age at formal diagnosis
Vicki	56	Tara	21 years	16years (suspicion raised at age 9)
Leah	40	Natalie	14 years	2 years
Kara	45	Jonathan	20 years	11 years
Evelyn	45	Tim	18 years	4 years
Yasmine	40	Sarah	13 years	2.5 years
Laurel	36	Richard	16 years	9 years
Kendra	28	Chris	8.5 years	3 years
Ellie	44	James	11 years	8 years (suspicion at age 6)
Claudia	51	Samantha	24 years	3 years
Danielle	44	Stacy	19 years	13 years
Maeve	46	Charlie	20 years	Few days old

*Note.* The names of all participants and their children have been changed.

### **Data Analysis**

Utilizing Transcendental-Phenomenological Reduction, “each experience is considered in its singularity, in and for itself” (Moustakas, 1994. p 34). Moustakas

(1994) described the steps of phenomenological reduction as follows: 1) Bracketing: the researchers place brackets around material in the transcripts that is the focus of the research, any other commentary is set aside to maintain focus on the topic and research questions; 2) horizontalization of the data: the investigator examines the interviews in search of how the individuals experience the phenomenon and lists out the significant statements. Each statement has equal value. The goal is to achieve a list of non-repeating, non-overlapping statements; 3) Clustering: the statements are collapsed into meaning units or themes. The units are listed with a description of the “textures,” which can include verbatim examples from the interviews; 4) Imaginative Variation or Structural Description: the researcher constructs a description of how the phenomenon was experienced by seeking all potential meanings and varied perspectives including a reflection on the researcher’s own description of the phenomenon. During this process, the researcher is open to varied meanings within the statements and seeks to uncover underlying themes within the data. For example, I anticipated varied descriptions of participants’ substance use histories. These descriptions yielded unknown numbers of potential meanings and contexts. Through my openness to and efforts at viewing these meanings from multiple or different perspectives/angles, I threaded these descriptions to derive a unified description of the phenomenon (their experiences). The goal of Imaginative Variation is to conceptualize the structural essences of the experience, to create “the unity of an identifying synthesis (Moustakas, 1994 p 35).

### **Validity and Reliability**

Patton (1990), though not self-identified as a phenomenologist, discussed validity in qualitative research as “hinging to a great extent on the skill, competence, and rigor of the person doing fieldwork” (p 14). All interviewing in the study was conducted solely by this researcher. Moustakas (1994) states that researchers must first reflect on the meaning of the research for themselves and then validate their ideas with the



participants. To enhance credibility, I reviewed the findings with the participants, giving them an opportunity to react to the results and, if needed, provide corrective feedback (Patton, 1990). This task is supported by Patton as the credibility of research would be called into question if the participants themselves are unable to relate to the description and analysis (Patton, 1990). Furthermore, Moustakas (1994) advanced the idea that the researcher look to the participants to establish “intersubjective validity.” Similar to descriptions of “member checking” by Lincoln and Guba (1985) and by Patton (1990) intersubjective validity is a process by which the researcher’s understanding is examined by the participant for correctness.

The researcher reviewed samples of coded segments of the interview transcripts with a researcher and clinician with expertise in the field of FAS who was trained in human subjects research and included in the IRB protocol. A professional outside of the study could provide a more objective view of the coding. Polkinghorne (1989) suggested ways to evaluate whether phenomenological findings specifically address the extent to which the idea is well-grounded and well-supported through the asking of questions such as “Does the general structural description provide an accurate portrait of the common features and structural connections that are manifest in the examples collected? Did the interviewer influence the contents of the subjects’ description in such a way that the descriptions do not truly reflect the subjects’ actual experience? In the analysis of the transcriptions, were there conclusions other than those offered by the researcher that could have been derived? Has the researcher identified these alternatives? Is it possible to go from the general structural description to the transcriptions and to account for the specific contents and connections in the original examples of the experience?” (Polkinghorne, 1989, p. 57) The coding and theory were discussed with the chair of the doctoral committee. In addition, I reviewed coded segments of the data with the

aforementioned colleague using these questions to evaluate the validity of my findings. I did this to help ensure that I was interpreting my data free of my own bias.

Dukes (1984) described additional procedures for verification that include comparing the perspective of both the researcher and the outside reviewer. First, a second researcher can view the data to look for “identical patterns.” Second, an outside reader can examine the logic of the experience and how it coincides with his/her own experience—described by Dukes (1984) as the “eureka factor.” Third, the researcher examines whether the patterns fit together logically and whether the data could be re-arranged to fit an entirely different and logical pattern—described as “rational analysis of spontaneous recognition.” Finally, the researcher and the outside reviewer evaluate whether the findings are potentially transferable to other phenomena (Creswell, 1998). I looked to my research and clinical colleague, as an expert in the field of FAS and experienced in the counseling field, to help me evaluate my findings using these criteria. The outside researcher and clinician read portions of the transcripts and coded each statement independently. Any instances of discrepancy between my coding and my colleagues coding evolved into a discussion around the context of the participants’ statements. These discussions resulted in consensus in coding for all participants’ statements.

## CHAPTER IV

### RESULTS

Results of the study revealed main themes of traumatic experiences and guilt. Most participants suffered abuse as children, including physical, psychological, and/or sexual abuse. In addition, several participants described instances of witnessing domestic violence as children. Most of the women who had witnessed domestic violence as children experienced violence in their adult relationships.

This group of biological mothers expressed guilt around causing Fetal Alcohol Syndrome in their children. These feelings of guilt were continuous no matter what the age of the child or the length of time since the diagnosis. All of the mothers interviewed had found a way to understand for themselves why they drank during their pregnancies including: utilization of the disease model of addiction, stating inaccurate or incomplete knowledge of the danger of taking alcohol during pregnancy, following the advice of others (family members, friends, physicians) and stating that they were unaware of their pregnancy. These frameworks offered assistance in understanding their actions though they did not completely mitigate their feelings of guilt.

Several themes emerged when discussing how these mothers found ways to reconcile their actions and move forward with their lives after the diagnosis of FAS is rendered including: reliance on spirituality, desire to help others or having devotion to a cause, the realization that their children need them, the support of family, friends or support groups.

#### **Traumatic Experiences**

*Merriam-Webster's Collegiate Dictionary* defines trauma as “a very difficult or unpleasant experience that causes someone to have mental or emotional problems usually for a long time.” Ten of the mothers participating in this study have had experiences that they described as traumatic according to this definition.

The following table provides an overview of the extensive abuse experienced by this group of women. Ten participants described experiences of abuse, and several suffered several types of abuse. It can be said that all of the women who witnessed domestic violence during childhood were subjected to psychological abuse as there is a strong psychological component for anyone who has been exposed to domestic violence or experienced physical or sexual abuse.

Table 2

*Participants' Experiences of Abuse*

	Child physical abuse	Child sexual abuse	Witnessed domestic violence as a child	Adult partner abuse	Psychological Abuse as a Child
Claudia		X			
Danielle	X		X	X	X
Ellie					X
Evelyn	X	X			
Kara	X		X		X
Kendra	X		X	X	X
Laurel		X	X	X	X
Leah	X		X	X	X
Maeve		X			
Vicki	X	X	X	X	X
Yasmine					

**Childhood Trauma**

**Familial physical and sexual abuse.** The participating mothers described experiencing horrible events at young ages, which, in many instances left them with emotional scars and wounds. Nine of the women reported either being physically abused as children (55%), sexually abused as children (45%), or both. Ellie, did not report physical or sexual abuse, but did detail experiences of psychological abuse at the hands of her stepfather. Yasmine was the only participant to report that her childhood was a happy one, free from any type of abuse. The proportion of participants who experienced physical or sexual abuse is comparable to that found in the Fetal Alcohol

Syndrome Prevention Study (Astley, 2000b). Of the 80 women profiled in their study 46.2% had been physically abused as children and 57.5% had been sexually abused.

Ten of the 11 women offered descriptions of childhood abuse—many accounts very brutal. Vicki was severely abused by both her mother and father. Both of her parents had mental illness; her father was diagnosed with schizophrenia. Her mother operated a “whorehouse” out of the home and prostituted Vicki between the ages of 9 and 11. Her mother was able to get away with prostituting Vicki and other women as her mother’s probation officer was a customer. In addition, Vicki witnessed domestic violence as a child and was physically abused by both her parents. Vicki recalls the abuse:

When I was a little girl I remember fighting all the time. My Dad would sit me on his lap and tell me I’m going to kill your Mom tonight and make me sit in a chair while he would get butcher knives and stand over her while I tried to pull him off her.

Vicki was abused by her father right up to the time of his death. She attended her father’s funeral when she was 10 years old with the bruises that her father inflicted the night before he died. Vicki was so bruised that when her older sister saw her she called the police. When police arrived at the funeral home, older family members were able to provide false explanations to dismiss the concerns. Vicki viewed herself as an unprotected child. She received no protection from her mother and father, her extended family, nor from the public safety structure (i.e. police, probation officer).

Evelyn too disclosed abuse. She now has a very positive relationship with her parents, but recalled that as a teenager: “My dad beat me up because he found out I was sleeping with a boy.”

In addition to Vicki, four other women interviewed expressed that they had been sexually assaulted as children/teenagers. Evelyn was molested around the age of 10 by her great grandfather. She recalls that when she asked him for money he sat her on his

lap first and put his hands up her shirt to feel her chest. When Evelyn told her mother, she refused to believe her. Maeve, who is the youngest of 14 children in her family, described many instances of sexual abuse within her family. One of Maeve's sisters was molested by one of Maeve's older brothers and a brother was molested by another older brother. Her father fondled her niece and had a history of exposing himself in public. She remembers watching a lot of television in bed with her father, but has no vivid or specific memories of sexual abuse; however, it is discussed and accepted within the family that Maeve had been molested by her father.

**Non-familial sexual assault.** Two mothers also experienced sexual assault outside of their families. Claudia was thirteen when she was raped.

It was with a friend –at a fairgrounds. Her parents left and my friend and I got drunk on beer and somebody drove by and we said, hey, you got more beer and he said, 'yeah, come with me' and I did...I got raped. My first drunk and yes, I got raped.

It was around this time in her life that Claudia and her younger sister started to sneak out of the house at night to look for a party. Claudia did not tell anyone or report the rape to authorities. She did talk to someone years later, but did not receive any treatment. When asked how she was able to get through it, Claudia answered "I think I just kept drinking."

Laurel was fifteen when she was sexually assaulted. She knew her attacker, but, similar to Claudia, did not tell anyone or report the assault. "I decided that I was just gonna' continue my life and leave it alone, but, it didn't want to leave me alone." Years later, after giving birth to her son, Laurel sought treatment.

And at that point they said that I should consider pressing charges. And I thought, well, this is how long ago? Why would I do that now kinda' thing? But the worker really thought it would be a benefit to do this. So I went through the proceedings to try and get this done and it basically boiled down to my credibility- -because I had been drinking, it was worth nothing, he wouldn't have gotten any time.....So they threw it out because of my credibility and that destroyed me. And that is where I turned back to the booze.

In addition, to her own assault, Laurel's sister was raped by her father. She learned of the event in school, by being taunted by a peer: "Your father raped your sister." The father was tried and incarcerated.

Studies have noted a relationship between childhood abuse and adult alcohol related problems (Miller, Downs, Gondoli, & Keil, 1987; Waldrop, Santa Ana, Saladin, McRae, & Brady, 2007; Widom & Hiller-Sturmhofel, 2001; Widom, Ireland, & Glynn, 1995; Wilsnack, Vogeltanz, Glassen, & Harris, 1997). The association between child abuse and alcohol abuse may be stronger for women compared to men. Among a sample of 1575 children (908 with documented abuse and neglect histories and 667 with no such history), Ireland and Widom (1994) conducted a prospective study and found that a history of childhood victimization significantly predicted adult women arrests for alcohol and other drugs, yet did not find as strong a relationship among adult men. In addition, alcoholic women and/or women with alcohol problems were found to be more likely than non-alcoholic women to have suffered sexual abuse as a child (Miller et al., 1987; Wilsnack et al., 1997). Waldrop et al. (2007) found that victims of childhood trauma who were suffering from PTSD as a result, begin drinking alcohol earlier and to advance to heavier alcohol use earlier than victims of adulthood trauma. The reports from this group of mothers are in keeping with the findings of this literature as almost all experienced abuse in their childhood years.

**Witnessing domestic violence.** In addition to experiences of physical and sexual abuse, five of the 11 participants were subjected to witnessing domestic violence between parents. Elbow (1982) discusses that child witnesses to domestic violence had been known as "forgotten victims," as the effects of witnesses domestic violence had been virtually overlooked by clinicians and investigators. However, this is no longer the case. Although being witness to domestic violence may not be considered a direct abuse, studies suggest that child witnesses to domestic violence may have behavioral,

relationship and psychological difficulties (Edleson, 1999; Kilpatrick, Saunders, & Smith, 2003; Widom, 2000). Many theories have been suggested to explain this relationship such as: the idea that witnessing domestic violence may result in the development of maladaptive models of interpersonal relationships resulting in poor problem solving skills into adulthood (Zimet & Jacob, 2001). Witnessing domestic violence may lead to emotional insecurity and negative emotional arousal resulting in insecure attachments to parents (Zimet & Jacob, 2001). In addition witnessing domestic violence can result in inconsistent parenting as the parents are not consistently emotionally available to the child (Holden & Ritchie, 1991; Holtzworth-Munroe, Smulter, & Sandin, 1997). Among their sample of 17,336 Healthcare HMO members, Dube, Anda, Felitti, Edwards, and Williamson (2002) noted a connection between exposure to domestic violence during childhood and the risk of self-reported alcoholism in adulthood. Furthermore, the researchers noted that in their sample as the frequency of domestic violence in the childhood home increased, self-reported alcoholism in adulthood increased.

The participating mothers described instances of witnessing domestic violence as events that further traumatized their early years. In addition, as found in the previously discussed literature, this group of mothers described instances which resulted in their own parents/step parents being both physically and emotionally unavailable. For some of the women, this interpersonal violence was further complicated by their parents' alcohol use. Danielle recalled,

And he (mother's boyfriend) was violent?"—Yes, when he was drinking. They'd go on binges when they would drink for 5 days straight" .....She was in and out of emergency rooms—I remember one time that her fist went through the window. I don't remember if she put her fist through the window to get out or whatever—you really try not to remember all of it—I know she was also in the hospital for some broken ribs—in and out that way...and she was in and out of rehab a few times too. As I got older I got smarter—I wouldn't try to break up the fight. We had a neighbor and I'd run across the road and hide and call my sister or my grandparents so I wouldn't end up in foster care.



Leah also described domestic violence between her mother and step-father, who was an IV drug user:

With my mom it was always domestic violence. And she dealt with a lot of that. The kids remember that. I remember him coming when he finally got out of jail, he would put a gun to her head and all kinds of things. Kids remember that—I remember that. She doesn't really talk about it but she acts like it wasn't a big deal. But it was a big deal for me. We hid in closets and all kinds of stuff.

This group of women experienced multiple forms of abuse. The witnessing of violence was further complicated by physical and/or sexual abuse for some. It is possible that experiencing multiple forms of abuse served to compound the trauma, potentially leaving deeper and longer lasting wounds. It is clear that this group of women had very detailed and clear recollections of their abuse even though it occurred years before.

**Separation and loss.** Four members of this group of participants also experienced a significant amount of loss and separation from their mothers and/or fathers. Kara, Leah, Ellie and Danielle each lived through childhood interruptions in their parental relationships that came to the surface during the interview process. When Kara's parents separated, she did not have contact with her mother for several years. She also spent some time living with relatives, in foster care and eventually in group homes. Leah describes her biological father as "absent altogether" due to his drinking while she was young. Additionally, her mother attempted suicide and was hospitalized. Ellie's father committed suicide when she was 12. Her mother had "kept [her] apart from him for much of [her] life." Danielle had seen her father only half a dozen times in her life prior to his death just a few years ago. She also endured separation from her mother when, at age 12, her mother had a fight with her husband and Danielle ran from the house and stayed with a friend for one month. As previously described, theories on the effects of witnessing domestic violence describe the potential negative impact of inconsistent parenting or physical or emotional unavailability of the mother. In this

instance, Danielle fled after an incident of domestic violence. After a month, her mother decided to leave her husband and picked up Danielle who had felt abandoned: “She waited about a month and then came and got me and then we moved out.” Kara was sent to live with a family friend and when that didn’t work out she entered foster care. Vicki also was raised by parents who were intermittently unavailable as they were suffering from mental illness.

Experiences of separation and loss had a profound impact on this group of women. It appears that some separations resulted in feelings of abandonment, for example, when parents were physically separated from their children due to the parents’ own alcohol issues or mental illness. However, the effects of parents being emotionally unavailable to their children are apparent as well. When a parent suffers from untreated mental illness, as Vicki’s parents did, the parents are often unable to parent consistently and effectively.

In sum, it is clear that this group of women suffered terribly during childhood from multiple sources and in many ways: physical abuse, sexual abuse, witnessing violence in the home, psychological abuse and loss. Many too, continued to experience traumatic events into adulthood which, combined with childhood abuse has compounding effects.

### **Adulthood Trauma**

**Partner abuse.** Five of the six women who discussed witnessing abuse in the home as a child went on to discuss partner abuse in their adult relationships (Danielle, Leah, Laurel, Kendra and Vicki). As previously discussed, witnessing domestic violence as a child may, in adulthood, adversely affect psychological and interpersonal functioning (Diamond & Muller, 2004). Adding more complexity, all five had experienced physical abuse as children; all of which may have set the stage for being victimized as adults. For example, Danielle, who had been previously quoted as fleeing her home

when her mother's boyfriend became violent, discussed her own escape from domestic violence years later:

We left in the middle of the night—I picked up my baby and my toddler and went to the women's shelter in the middle of the night. When I left with them I had cracked ribs and a dislocated jaw.

It is conceivable, that after suffering such extensive and lengthy trauma, this group of women used alcohol to escape or numb their emotional pain.

**Possible undiagnosed fetal alcohol syndrome.** Danielle, Laurel and Vicki expressed the fear that they too have Fetal Alcohol Syndrome. Additionally, Vicki stated her belief that Fetal Alcohol Syndrome is under-diagnosed among the biological mothers of children with FAS. Not only does Danielle believe that she has FAS in addition to her daughter, she believes that she is more affected than her daughter:

I've always struggled with my memory. I struggle with a lot of things. While she (her daughter) was going through all this testing and I was answering all these questions for her, you know the paper part of it, I wasn't in the room for the other parts of it, I was thinking—"this is me, this is me." I would say that I am probably more affected than she is. But, with Fetal Alcohol we are survivors. We learn how to figure things out and how to make things work.

Danielle states that her mother had alcoholism and drank until her death. She wonders about getting formally evaluation for FAS, but is not clear how it would be helpful to her. Her family members do not see the benefit of such an evaluation. At the time of the interview, she stated her decision not to be evaluated.

Laurel too is aware that she was exposed to alcohol prenatally. She would like to be tested, but believes it to be too costly as it is not covered by her health insurance. In addition, her mother is not supportive of this testing. According to Laurel, her mother says that Laurel did not exhibit the same symptoms as Laurel's son so, therefore, Laurel is not affected. Laurel said that her mother is not open to "the whole picture" [of Fetal Alcohol Syndrome] meaning that her mother does not want to learn of the breadth of symptoms and challenges exhibited by persons with Fetal Alcohol Syndrome.

These three mothers are faced with the realization that not only did they harm their own children, but were also potentially harmed by their own mothers. Yet, none of these mothers has undergone formalized testing. They do not have the benefit of formal diagnosis or services. They are raising children with disabilities and may have disabilities of their own. It is possible that these three mothers may be able to empathize and relate to the struggles of their children. However, children with FAS experience a myriad of behavioral, educational and emotional challenges. Raising children with FAS is challenging for parents without disabilities. Mothers who may have FAS may be even further challenged by their children.

Overall, this group of participating women suffered trauma and victimization as children and adults. For many in the group, parents were perpetrators of their victimization. Additionally, the presence of alcohol use and addiction was heavy within most of the families possibly resulting in lack of protection and support. This may have left these women vulnerable to further trauma and alcoholism. Considering these findings and previously reviewed research, it is likely that trauma played a role in this group of women's alcohol abuse, which ultimately led them to drink during their pregnancies.

### **Feelings of Guilt**

Some mothers had an intense moment of guilt when they learned of the pregnancy and connected their drinking to the potential harm of the baby. Other mothers stated the diagnostic process brought guilt and negative feelings. Once the feeling of guilt began, it was always present to some degree, persisting regardless of any other factors including the presence of means of coping (the age of the child, length of time since diagnosis, support system). Laurel described the endurance of guilt:

I felt guilty. I still feel guilty. I compare it to when you're driving a car in the winter and say there is black ice and you don't see it and the car slips and you hit somebody with the car. You know that you didn't mean to hurt that person. You

really didn't have a choice. Your car went off the road and you hit them. But you still will always feel that guilt.

### **Receiving the Diagnosis of FAS**

Both Yasmine and Claudia suggested the possibility of a Fetal Alcohol Syndrome diagnosis with their daughters' physicians. Yasmine, recalled,

When I was pregnant with Sarah, the treatment facility that I was in had a poster on the wall of a woman with her son. It was an unusual picture and said, 'these are the legs of Fetal Alcohol Syndrome'. This was back in 96...Fast forward to 1999 when they are saying we just don't know what's wrong [with her daughter]. That's when I said to the physician's assistant, 'could you give me some information about Fetal Alcohol Syndrome?' I contacted the University ....and they sent me a big packet... when I read every diagnosis of FAS, I said [to her pediatrician], I believe Sarah has Fetal Alcohol Syndrome. So her doctors did an assessment and it was confirmed.

Claudia recalled the moment she realized her then three year old daughter had FAS:

Have you heard of [the author] Michael Doris? He did an interview on 20/20 called, 'what's wrong with my child' and I was at my mom's house playing [with my daughter] and watching... and I knew—that's it...I knew that was my child without a diagnosis. So everyone kept saying—she's fine, she's fine—and I was crying and said, 'Let's go home'. I called the pediatrician and said, 'I need a diagnosis'.

A feeling of relief was described by some mothers when the FAS diagnosis was rendered. Claudia and Yasmine discussed feeling relief that they knew the cause of their child's symptoms and issues. In addition to relief, these two mothers now had confirmation of a tangible diagnosis to help explain their children's challenges which allowed for a starting point to seek treatment. Claudia said, "I was so relieved—now I can do something. Now I know. And I cried of course. [But] I was relieved to have a diagnosis." Yasmine simply stated, "I was just relieved that they found a diagnosis."

Leah, described a far more destructive response to learning of her daughter's diagnosis:

I wanted the weekends so I could drink and go away from this guilt and pain I'm carrying. Nobody understands this. I didn't tell anybody I was around... I drank myself into a coma. That's what I did for 5 years. That was when my body shut down. I was medicating myself. With alcohol and drugs. I drank every night, every morning, sometimes before work, sometimes in the middle of the afternoon at work. But I was so good at my job nobody ever knew.

Although she knew that drinking alcohol was bad for the baby, Leah said she had never heard of FAS until Leah's father brought her two year-old daughter to the doctor and came home to tell her of the diagnosis. The guilt she describes was immediate and severe lasting for five years and beyond the time she suffered a brain injury and coma due to her drinking.

Although this group of biological mothers began feeling guilt starting at certain points either during their pregnancies, after the birth of their children or after receiving the FAS diagnosis, as previously stated, feelings of guilt were prevalent throughout their lives. Additionally, although some mothers conveyed thoughts of relief when doctors diagnosed their children with FAS, this relief was related to finally knowing what was wrong with their children and the belief that a diagnosis would help doctors to effectively treat the symptoms.

#### **“How Could I Have Done This?”: Persistent and Ongoing Guilt**

“How could I have done this?” A common theme for these women as they try to reconcile their actions. At the time of interview, none of the participating mothers were abusing alcohol—many were years into recovery. All of the women interviewed had a thorough understanding of FAS and its origins in their children. When asked about how their children were functioning at the time of the interview, it was clear that some were higher functioning than others. Some of the children were still in public school, some in vocational programs, others were homeschooled. Some suffered behavioral problems or educational struggles. The children were all different, yet the one prevailing emotion experienced by every participating mother was a profound sense of guilt.

To no surprise, each of the eleven mothers directly expressed guilt during the interview process. These feelings of guilt were continuous no matter what the age of the child or the length of time since the diagnosis. The expressions of guilt came in the form of dislike, even hatred, towards oneself:

I robbed my daughter from getting married, not going to college, not getting the life that I had. I robbed her and I hated myself. I still don't love myself. (Leah)

I'm not worth it, because I'm a piece of shit... Oh shit, Oh my God—push it down. You're so bad (Ellie)

How could I have done this? And how could I have been so stupid? (Kara)

Guilt debilitated some of the mothers:

I have days or hours and days when I can't, I feel like I can't function. I can't focus. I can't think about it. I just cry. I can't feel good. I feel that sensation which a lot of alcoholics feel anyway even if they didn't have a child like this—"I'm different, I'm not good (Ellie)

Some days I just crawl into a hole and cry. (Laurel)

Ellie described her response to realizing that she had potentially harmed her baby while she was pregnant:

And I felt like such shit. I remember feeling guilty and I couldn't put my finger on why. I think I felt bad. And I went to my house and I frickin' cleaned my whole house. I felt like crap. And I was so sick and I drank water and I made all these special vitamin drinks and natural juices and crap. How stupid! And I took my prenatal vitamins. I remember singing to the baby (still in the womb)—"I love you. I can't wait for you to be here."

As described in Chapter II, the literature suggests that maternal guilt is universal and experienced by mothers regardless of the ages of the mothers or whether or not the children experiences significant difficulties. Therefore, the expressions of guilt offered by the participating mothers are not surprising, given that the children have all been formally diagnosed and the cause of their children's problems have been formally assigned to mother's drinking during her pregnancy. From the point of diagnosis or when they were first aware that something was wrong, the mothers (and theoretically many others) will be aware of the origin of the child's issues—a sort of permanent scarlet letter to bear.

### **Making Sense of Their Actions**

However, it appears that this group of mothers had gone through a process of finding a way to make sense of their actions. They seemed to need to find answers to

the questions: “How could I have done this?” “Why did I drink during my pregnancy?” for themselves. For some, this process seemed to assist in processing and working through the guilt. Perhaps this also mitigated some of the guilt so that the mother was not immobilized. Although none of the mothers were able to completely relieve or eliminate their guilt, all of the mothers interviewed had found a way to understand and frame their drinking (whether before, during or after their pregnancies) for themselves. There are several ways participating mothers reconciled and conceptualized their drinking during pregnancy.

**Disease model.** Adoption of the disease concept of alcoholism was utilized to cope with and mitigate some of the guilty feelings and explain or rationalize their drinking during pregnancy. According to the disease concept or medical model of addictions the use of alcohol is out of the control of the alcoholic (Jellinek, 1960). The disease compels the person to drink. This conceptualization of their behavior served to redirect the focus of blame away from the mother and directly focuses blame on an “outside entity” of sorts—the disease of alcoholism. If a disease takes command of the person then it is that disease that can shoulder some of the responsibility for the actions of the alcoholic, thereby releasing the alcoholic from at least some of the blame. It is clear that this perspective does not eliminate guilt, but may offer a rationale for what is seen by some as inexcusable or illogical behavior.

Ellie, who was previously quoted as feeling as if she was “no good” and was at times unable to function or focus due to guilt, described her addiction:

I am the responsible one because I am the one that had the disease. I am the one who was pregnant. I feel horrible about that. I try to let go of some of the shame in the sense of—you have a disease and how could you control that?”.....And what I was doing and some of the stuff in AA where I was going—this is so cliché—the disease working, I think what was happening for me, I was looking for all signs that would give me permission to drink and be okay. So that’s what I did...But what I didn’t recognize is and people around me also didn’t—not that you can blame anyone else—is that I had this terrible disease and I didn’t know I was pregnant for a little while...I found out and I remember



thinking if I should drink. That means for an alcoholic like me that means I shouldn't drink the way I drank.

Two of the mothers involved with this study described attempts to control or lessen their drinking during the pregnancy. This is very complex, as these mothers were allowing for the idea that they were aware that their actions could be harmful to their unborn children, yet at the same time they described efforts to protect the child (drinking less than usual). Both women who described attempts to control or lessen their drinking described themselves as having alcoholism. Perhaps failed attempts at drinking in moderation lend credence to the disease model. Leah, who drank during her pregnancy as a result of her alcoholism and is previously quoted as hating herself for having robbed her daughter, related,

Part of that looking back—I was in denial because I really didn't want to quit drinking.

So you tell an alcoholic to moderate--that gives them permission to drink, which is ridiculous. And like I said, I thought I was moderating. My doctor never told me either way. If you give an alcoholic permission to drink, they are going to drink...I tried to drink vodka, not all the time and not everyday cause I don't want anybody to smell it. But everybody smelled it anyway. I know it's all stupid. And I didn't drink everyday, off and on in the bar and I was hiding it as usual. Nobody knew I was drinking. That's just what alcoholics do...I kinda knew I was an alcoholic when I was drinking. I kinda knew I was doing things wrong but I couldn't control it. But that's what alcoholics do. I didn't drink everyday, but that was in the part of my pregnancy that I was in denial I was even pregnant.

Evelyn also described attempts at moderation:

I was working at the time and I remember trying, once I found out I was pregnant, trying to cut back or cut down or whatever. And so I would go to the bar and I would try to modify my drinking. I remember smoking pot, because I was thinking pot's got to be better, after all, it's natural, right? Then I remember taking codeine one time and I took so much of it that he didn't move and I thought I killed him. I remember thinking—oh my gosh—for a while and then he finally started kicking again. It was so weird though, but I think it scared me and then I don't think I did that again.....Because I had tried so hard to go to the bar and just sit there and drink a soda or just drink one beer and there was no such thing. It really hit home because it felt like way back in my heart of hearts there were these little signs that say "drinking may harm the baby." And that was way back in '92, I guess, when they had first put those signs up. It wasn't like I knew the full extent, but there was something that said, this can't be good. I would try to

stop and I would think, if I can't even stop because he is inside of me, then there is a problem.

The theory of cognitive dissonance, as proposed by Festinger (1957), lends a perspective that may explain these women's efforts at moderation. The theory states that when an inconsistency or incompatibility occurs between what one knows or believes and the actions one takes, discomfort or tension, known as a cognitive dissonance, results. A person will naturally attempt to act or think in ways to decrease the discomfort; this is known as dissonance reduction. Two ideas or behaviors that are incompatible or inconsistent for the respondents in this study are drinking alcohol and being pregnant. One part must be altered, the drinking or the beliefs/knowledge. By minimizing the effects of or use of alcohol while pregnant, the mother can temper her cognitive dissonance or reduce the discomfort. Perhaps moderation might be a slight or subtle attempt to decrease some of the discomfort without a complete change. For example, drinking just one beer (as opposed to several) or switching from alcohol to marijuana may be an attempt at harm reduction. If so, the attempt at harm reduction could mitigate the discomfort or dissonance. Although some of the mothers interviewed did answer the question of "why" with the knowledge that the disease of alcoholism robbed them of control, this in no way eliminated their feelings of guilt. Instead, this explanation may serve to somewhat mitigate their guilt, but this does not mean that these mothers do not feel guilty. Possessing this explanation may assist them to function day to day. Ellie is in recovery, yet does not escape her feelings of guilt: "when someone has done something so bad because of their disease—it's hard for me to feel worthy." Not one mother who discussed her struggle with the disease of alcoholism is without persistent feelings of guilt. The disease model was not used as a way to decrease culpability, but as a mechanism to understand their actions and/or perhaps mitigate (not eliminate) guilt.

As a matter of fact, the understanding that a woman is an alcoholic could make a mother feel worse and could serve as a sad reminder of the “sign of a sick mind” that led to behaviors that harmed their children. Evelyn, whose addiction to alcohol fostered her drinking during her pregnancy stated, “Having this justification of sorts makes it worse. Looking back, it makes me sad and is discouraging to think about because now I see how it doesn’t make sense.” Evelyn views the way she perceived her drinking before she received treatment and got sober as flawed. Therefore, this conceptualization understanding that a woman drank alcohol during pregnancy because of the disease of alcoholism does not work for everyone.

**Lack of knowledge?** Several mothers claimed to have mixed reports or inaccurate or incomplete knowledge of how much they knew about the consequences of drinking while pregnant. Is there an awareness that they ignored or repressed? Leah described some level of knowledge but also some lack of clarity that drinking could harm her baby. “I was doing a lot of the controlled drinking thing...I love my daughter and I didn’t know I was hurting her. I mean I kinda’ do. Ya’ know it’s so very hard to explain.”

Evelyn discussed seeing posted signs that alcohol could damage the baby. The information may not have been as available as it is today. At the time, she rationalized that there was a possibility that alcohol may not damage the baby. “I had to justify the continuation of the drinking when somewhere in you, you know it is not ok... it wasn’t 100% that any was bad. So it seemed to be that having a little is ok.”

Claudia described not being fully aware of the dangers of drinking alcohol during pregnancy, but potentially being somewhat aware: “I had convinced myself that the placenta would stop the alcohol from getting to her, but I’ve since learned that that is not true that alcohol crosses over to her.”

It is possible that Leah’s, Evelyn’s and Claudia’s lack of knowledge is related to the disease model. Their addictions allowed for a thought process that made drinking

alcohol a safe and acceptable thing to do. Additionally, by believing that the placenta would protect her baby, Claudia had reduced her cognitive dissonance by holding onto her belief or knowledge. She therefore was able to rationalize continued drinking. This is also noted with Evelyn and Leah. Furthermore, it is possible that had they consciously acknowledged their awareness of the danger of their actions, they may have been in some way forced to change their behavior. At that time, a change in behavior may have been too daunting a task. Following with the theory of dissonance reduction, it is possible that there were signs that they chose to ignore in order to reduce the cognitive discomfort.

**Advice of others.** This conceptualization is partially related to the above theme of lack of knowledge in that the women are acting upon incomplete or inaccurate knowledge. Several mothers understood their drinking to result from a reliance on either their own incomplete or inaccurate knowledge (lack of knowledge). However, other mothers understood their drinking during pregnancy to result from a reliance on the incomplete or inaccurate knowledge or advice of others (advice of others). Some of the mothers “explained” or conceptualized their drinking to partially mitigate their guilt by recalling the advice of family and friends during their pregnancies. Such advice served to minimize the danger to the baby if the mother admitted to already drinking alcohol or encouraged or gave permission for the mother to drink during the pregnancy.

Unfortunately, for some members of this group of mothers, their support system or group of friends and/or family were often alcohol and/or drug involved too and, therefore, were not able to provide safe and sound advice. Kendra, who witnessed domestic violence in her childhood and was also abused by her partner, moved out on her own at the age of 18. She did not have a supportive partner. She was isolated except for her friends, who were also problem drinkers, so it is understandable that she relied on the advice of friends who “didn’t tell me not to drink...They drank with me.”

And Ellie recalled,

So I remember telling to someone—I drink too much a couple of times in work and it was this gal I don't really know and she said, "Yeah, I did that. It will be ok"...I was sitting in a bar and I was pregnant and I don't know who was there...there's this gal and she was pregnant. And she was sitting there and she goes—This is my second baby and you can have some wine. And I was like, "Really? Yeah ok." So I had a glass of wine at the bar. She had a glass of wine. She said she had 2 glasses of wine everyday during her pregnancy. Her babies were beautiful and smart and perfect...Mother said like, "It's ok." I think I worried about it—and she'd say, well you know, I think Patty and Linda had some wine when they were pregnant and Linda smoked pot. So, it's ok honey.

Laurel who had previously described feeling so guilty she "wanted to crawl into a hole," recalled, "And I went to the bar with my mum. She was the one that said—oh you know it is ok as long as you don't overdo it—kind of thing."

Leah who previously discussed how the disease of alcoholism made her unable to control her drinking during pregnancy also recalled,

I was also involved with so many alcoholics at the time. I could remember saying, I'd love to have a drink and I wouldn't have one. And this other woman, a complete alcoholic—now you look at me, I'm educated, really good job and I don't look like an alcoholic—I can clean up nicely—but this woman at the bar says—oh we all drank when we were pregnant.

Similar to the function of the disease model, utilizing the advice of family and friends serves to take some of the responsibility away from the mother and helps her explain her drinking to herself. A parallel can be drawn between this line of thinking and that described by Hotham, Atkinson, and Gilbert (2002) in their work with mothers who used tobacco during their pregnancies. Hotham, et al. (2002) described pregnancy-specific barriers to smoking cessation. One of the barriers is the use of anecdotal experiences (e.g.. another woman known to the respondent smoked and "her baby's fine") to serve as a reason to continue smoking much the same way as some of the present group of mothers received reinforcement from other women for drinking ("Yeah, I did that. It will be ok").

Cognitive dissonance theory can be applied to each of these reasons including the disease model, lack of knowledge and following the advice of others. At least a few of the mothers interviewed knew on some level that drinking alcohol while pregnant is dangerous for the fetus. For example, as previously quoted, Evelyn remembered seeing signs that alcohol could be harmful to the baby. In order to decrease the dissonance between their actions (drinking alcohol) and their knowledge (alcohol is dangerous for the pregnancy) a change in either the action or in their belief/knowledge has to occur. To reduce this discomfort either the action of drinking alcohol must change, or the belief that alcohol is dangerous for the pregnancy must be altered. Perhaps, in this instance, the change was to internalize the justification for alcohol use (e.g., “Oh you know it is ok as long as you don’t overdo it” or “We all drank when we were pregnant”) thereby decreasing the discomfort.

Several of the women who followed the advice of others also utilized the disease model. It is possible that merging these two lines of thought is useful in furthering our understanding. If the disease/addiction or need for alcohol drives and controls the person and that person is given encouragement or at least permission from others to use alcohol while pregnant, it is reasonable to understand that it would be very difficult for that person to resist the urge to drink during pregnancy.

In addition, it is important to note that five of the participating mothers had interactions with their physicians which they believed condoned their continued drinking during their pregnancies.

Doctor said a little bit wouldn’t hurt you. I did what the doctor said—how could it be wrong? (Vicki)

Some women perceived that their physicians not asking about their drinking indirectly gave them permission to drink.

I went to the doctor, but they never questioned the drinking and drugs. (Kendra)

Earlier, Leah's friends told her it was ok to drink, [but] "my doctor never told me either way."

Leah's comment demonstrates the convergence of many of the explanations proposed—the disease concept, the unrealistic nature of moderation for women in this circumstance, and the advice of her physician. As discussed above, it is possible that Leah's addiction drove her to look for permission to drink and to accept what she perceived as permission from her physician. However years later and in recovery, Leah now believes that an alcoholic should not receive any message to drink "in moderation" as this is not possible for a person with this illness.

Not only did Laurel's mother tell her it was ok to drink during her pregnancy, according to her report, her physician was not concerned: "I told my doctor, right up front when I first found out that I was pregnant because I had been partying quite hard that first five weeks. And he said, "Well, you know, everything should be fine." Danielle reported a similar experience: "My doctor—I think he lied—because when I told him I was pregnant and I said, "Oh my God I was drinking," he said, "It's the early stages, it doesn't matter, its fine" and it was never brought up again."

One could conclude that this group of women did not receive a clear message from their family and friends, and even in some cases from their physicians, of the dangers of drinking during pregnancy. It is not difficult to believe, that during pregnancy, women will trust the advice of other women, especially friends and family members, and of course the advice of their own physicians. According to this group of mothers, their physicians either did not address the dangers of drinking during a pregnancy at all or downplayed the potential damage that may have already occurred when they told their physicians that they had already drank during the pregnancy. Others gave the vague recommendation of a small or moderate amount of drinking. During the process of member checking, several women were adamant that their physicians said it was ok to

drink alcohol. The danger in recommending a small amount of drinking is that physicians may be unaware of the presence of addiction. This is well illustrated by Leah's comment above. In addition, the physician may be unaware of the mother's perception/definition of a small amount of alcohol. It is possible that physicians did not have complete or accurate knowledge to pass along to their patients at the time even though the Surgeon General's warnings against drinking alcohol during pregnancy were first reported in 1981 (United States Department of Health & Human Services Press Office, 1981, 2005).

It is perhaps possible that these mothers, many of whom described themselves as alcoholic were looking for permission or a reason to drink and therefore misinterpreted their physicians' instructions in a way that allowed for them to continue drinking. This may serve to reduce cognitive dissonance and rationalize their drinking. Additionally, like the conceptualization of alcohol as a "disease," the physician can shoulder some of the responsibility for the actions, thereby releasing the person from at least some of the blame.

**Denial.** Furthermore, the concept of denial, as utilized throughout the literature on addictions, may help us further understand this process. Many explanations of denial exist throughout the addictions literature as (i.e. moral deficit/lying, mental impairment or precontemplative stage of change (Howard et al., 2002; Rinn, Desai, Rosenblatt, & Gastfriend, 2002; Stoddard, Dare, & Derigne, 2010). Nevertheless, all have in common an underestimate or minimization of the impact that alcohol has had on the person's life and/or health, the amount of alcohol consumed, and/or the duration of the existence of the drinking problem, etc. If a mother is minimizing the amount of her drinking or minimizing her dependence on alcohol, one might conclude that she is in a state of denial. It is further possible that denial may be utilized by the women in this study to decrease cognitive dissonance. The denial may be a part of accepting others' advice on



the safety of drinking on moderation or even in their own perceptions of moderation. Again, as previously stated, for the mothers in this study, this perspective does not eliminate guilt, but may offer another rationale for what is seen by some as inexcusable or illogical behavior.

**“Yeah—I did drink. [but] I didn’t know I was pregnant.”** It is not unusual for a woman to be one to two months pregnant and not be aware of the pregnancy. Three of the participating women (Kara, Danielle and Maeve) stated that they were not aware of their pregnancies during the time that they drank. Both Danielle and Maeve consider themselves to have had alcoholism, Kara does not. However, of the three, Maeve is the only one to consider herself a problem drinker at the time of her child’s conception. Both Danielle and Kara stated that their drinking had been problematic in the past, but not at the time of their children’s conceptions. Each was able to stop drinking once they learned they were pregnant, although their children would later receive the diagnosis of FAS. Although each woman was able to stop immediately upon learning she was pregnant—the guilt prevailed. The damage was already done to the child. Danielle was only two months along when she learned she was pregnant. Maeve and Kara were four and five months along in their pregnancies, respectively.

It is plausible that a woman who is drinking or perhaps alcoholic may become pregnant and not recognize the signs. It is also possible that a woman in that circumstance, pregnant and drinking alcohol, may not *want to* recognize the signs of pregnancy if she is aware of the dangers of drinking during pregnancy. Trauma experienced in life prior to the pregnancy may have affected body image and body awareness. The further along the pregnancy progresses, the more likely the woman is to recognize the signs, although it is worth noting that there have been cases of women who were not necessarily drinking but who gave birth without knowing they were

pregnant. In fact, substance use is a risk factor for denial of pregnancy (Hatters Friedman, Heneghan, & Rosenthal, 2007).

Leah raised an interesting notion when she stated,

For a long period of time I didn't know I was pregnant. Part of that looking back I was in denial because I really didn't want to quit drinking...I didn't drink everyday, but that was in the part of my pregnancy that I was in denial I was even pregnant.

It is possible that a woman may suspect that she is pregnant on some level but not want to confirm the pregnancy. As previously discussed, acknowledging the pregnancy may confirm the need to make lifestyle changes (i.e. stop drinking) that the woman is not prepared to make at that time. In addition, other factors (psychosocial/health/relationship) may contribute to a woman's denial of a pregnancy, even for a brief time. For example, Maeve had also struggled with an eating disorder which had caused her some severe health problems.

Nevertheless, it is understandable that a woman does not take action to protect a pregnancy that she is unaware of. This explanation may serve to mitigate guilt similarly to the disease model in that one cannot be held responsible for actions out of her awareness. This group of women is *less responsible* for their drinking during the time they did not know they were pregnant. Again, it is worth noting that this is a way for some of these mothers to answer for themselves the question of why they drank during their pregnancies. It does not appear to be a way to remove responsibility and definitely does not serve to eliminate guilt. The guilt is pervasive, no matter how the woman understands or conceptualizes her drinking during her pregnancy. This is clearly described by Danielle:

Oh my God, how could this happen? I was drinking. I was drunk. How could this happen? ... What damage is this going to do? I thought that—what's going to happen?...I was blacked out drunk at least twice a week.....I would have never made that choice, if I had known I was pregnant. If I had been more in tuned with my body—there's no way I would have ever drank. I stopped as soon as I found out.

Maeve stated of her realization that she was pregnant: “It was probably just terror. Knowing that I had been drinking so much.” Kara recalled, “What the hell did I do?...I rolled up in a ball and I cried for days [when I found out I was pregnant].”

This line of thought too, can be applied to the theory of cognitive dissonance. As previously discussed, to decrease one’s cognitive dissonance, either the belief/knowledge must change (alcohol is dangerous for the pregnancy) or the action must change (drinking alcohol). In this instance, when these three women learned they were pregnant, each woman changed the action (stopped drinking). The cognitive discomfort is reduced. Of the several perspectives presented, this is the only one in which the action of drinking has been modified in order to reduce the cognitive dissonance.

The process of answering the question of “Why did I drink during my pregnancy” appears to be important for this group of mothers. It appears to provide a rationale for actions that seem illogical or inexcusable. The rationales discussed include: the disease model, lack of knowledge, taking the advice of others and unawareness of the existence of the pregnancy.

### **Coping and Going Forward**

For this particular group of mothers, after they endured adversity in their childhood years as well as during adulthood, and faced the challenges of raising a child with Fetal Alcohol Syndrome, it is reasonable to wonder how were they were able to go on. How were these mothers able to function as productive members of society? As mothers, how can they face the burdens of caring for children with disabilities caused by their own behavior? How can they advocate for their children? Danielle summed up this sentiment for so many of this group of mothers:

How do you not look at the child every day and think, “oh my God that’s all my fault”? How do you overcome that and do what you need to do as a parent? Because you have to get over the guilt, you have to get over that.

What assisted this group of mothers after their children have been diagnosed with Fetal Alcohol Syndrome? Several themes emerged when discussing how these mothers were able to move forward after the diagnosis of FAS was rendered.

**Spirituality.** By far, the most prevalent theme raised by the participating mothers around coping and going forward was spirituality. Ten of the eleven mothers described their spirituality as a main support; not necessarily in the form of organized religion, but rather the belief in a higher power or being. One mother, Evelyn, had a very individualized perception on the interplay of her alcoholism, her son and spirituality: “Here’s the thing about the God thing—I think Tim was sent to me because he was the only thing that would have gotten me sober at that point.”

Many of the mothers rely on daily prayer, to assist them in living day to day. Although several of the women are involved in 12-Step programs to assist them in the recovery process, their responses are separate and in addition to the belief in a higher power as taught within the 12-step model. Ellie stated,

I’m very, very spiritual—that’s how I live, how I have to live with my program. I have a spiritual program that I keep for my sobriety. What I am saying is, I have not been attending church... But know, I’m very spiritual. I believe in Christ’s teachings, but I practice some Buddhism.

Laurel, who previously stated that she would always feel guilt described how her faith is a support for her: “Because I have hope. And that help when you are depressed because you can always think about the fact that the Lord has everything in control even if it doesn’t feel like it.”

Maeve relies on her sense of spirituality:

I am spiritual, but I’m not into organized religion. I am more into nature and—I don’t know, it’s hard to explain—I am an atheist. I tend to feel more like the Native American thoughts on nature controlling what happens.

For Maeve this belief provides support and comfort.

Kara, who was previously quoted as wondering, how she could have been so stupid as to expose her child to alcohol, now finds a solid support system within her church and its congregation:

And thank God we found our church almost 3 years ago. We wouldn't have the foundation and the fortification we have now... Oh yes. And they have nothing but good to say. How do you hold something back like that! My pastor is 87 years old. You would want to give this guy a hug even though you've never met this guy. He is so real, so down to earth. He is so realistic.

Kara described being welcomed by her church's congregation. Her family did not feel judged. They offered understanding, tolerance and flexibility to her family.

Interestingly, mothers who were a part of a more organized religion described the need for acceptance and flexibility regarding their children within those churches. Again, this points to the need for greater understanding of the challenges faced by children with FAS and their families. Both Kara and Vicki discussed the difficulty in finding a congregation that is non-judgmental and understanding of children with special needs. Vicki recalled the interplay between her belief system and the challenges to the formal practice of her religion:

I believe in God. I believe in the Father, Son and Holy Ghost. I pray every day. I don't go to church often. Because of my lifestyle with my daughter it's hard to get out. We've been asked to leave [church] sometimes because she turns the lights on and off. She wants everybody's coffee.

Perhaps spirituality is similar to the way in which the disease model and the advice of others helps to conceptualize the respondents' drinking during pregnancy. A belief in a higher power assists in sharing the burden of responsibility and their path in the future. The use of prayer, belief in God or Nature lessened the burden for this group of mothers and is something that can be relied upon. A sense of spirituality provides an external focus, outside of the mother, which, some believe, is a caretaker in control of their destiny. For mothers who are in the process of recovery, within or without a 12-step program, faith and spirituality not only supported them as they faced their children's

challenges, but also supported them in their sobriety. Spirituality was described as a backdrop for all other activities of life.

**Devotion to a cause/giving back.** More than half of the mothers interviewed made reference to a desire to help others which assisted them in their own process of moving forward. Some mothers were focused directly on helping mothers of children with FAS or advocating for the needs of children with FAS. Others were focused more broadly towards helping others. When noting this during the interview process with those mothers, each had the perspective that mistakes of the past cannot be changed, but perhaps their efforts may help someone in the future. It is worth noting that three of the eleven mothers had even enrolled in schools of social work. It is possible that working to help others serves several purposes for this group of mothers. First, focusing on the future may be more positively productive than dwelling on the past. It may serve to further ease the burden of guilt. Also, this group of mothers may be better in touch with the feelings and programmatic/emotional/practical needs of this very specific population of birth mothers and therefore well-positioned to address the needs of these mothers and children.

Leah previously talked about she had been immobilized with guilt at times and still struggles to not hate herself. Yet she speaks at support groups and in her own program (AA) meetings. She related, "That's the last thing I want to do is tell all the crap that I've done in my life [but if] I can talk about it and if I can help another person that helps me."

The mothers in this study have done everything from forming support groups for parents of children with Fetal Alcohol Syndrome, advocating for educational services for children to working with state legislators towards setting up housing and respite services for children/young adults with FAS to setting up on-line support groups. Laurel started an FAS support group in her town several years ago that is still going strong. In

addition, one mother, Ellie, mentors at-risk mothers and another plans to work in the area of substance abuse treatment; “People need help out there—either they’ve already had a child or they are struggling with alcoholism and are in the childbearing years. More needs to be done, that’s all I’m saying. I can’t let it go.”

Maeve wants to give back: “After going through the treatment centers.....I thought I had something to offer. And having been down in the dumps and I’m in recovery—you never recover I don’t feel—but I want to be able to give something back.”

Many of this group of mothers expressed a desire to help others. It appears that as they were assisted, either in achieving sobriety or accessing services for their children, they now wished to extend that assistance to others who are struggling. As can be seen by the previous quotes, one perspective of this cause is related to a desire to have others (healthcare/mental health/addictions/education professionals) understand their struggles and intentions with the hope that this will allow them to assist other women. This may help this group of mothers by building up their self worth and esteem with the knowledge that they positively impact others.

### **Children need them.**

We can’t undo the past, but we can keep going forward and not let those things happen to our kids. (Vicki)

It is no surprise that the children of the participating mothers have challenges. Although many of the children are now young adults, their need for specialized daily assistance and supervision persists and likely will for years to come. Each of the children has required special education services through school and some have required additional outside services such as counseling, speech therapy and occupational therapy. Some children required 24 hour supervision and specialized daily assistance, even as young adults. Kara’s son, Jonathan is now 20 years old, but functions as a 12 or 13 year old. At birth he had double pneumonia and lacked the sucking ability. He has

cerebral palsy on his left side and no feeling from the back down. He is incontinent and requires around the clock supervision and care. Laurel's son has severe learning delays and has had issues with the legal system. Many of the mothers interviewed spent significant amounts of time advocating for their children with doctors and school systems to secure needed services for their children. Evelyn's son, Tim, was able to hold a part time job, but required transportation to and from work. These needs further served to motivate and focus this group of mothers and helped many of them to "go on." Kendra, when discussing her persistent guilt, discussed how she is able to go on:

I realized—This is it. This is my life. This is who my kids are. The only thing I can do is look at my kids and give them the best that I have. And try to think positive about things.

Ellie, who was previously quoted as saying, in her lowest moments, "I'm not worth it, because I'm a piece of shit" is very focused on doing the best for her son: "What can I do to help the circumstances today? How can I help my children? How can I be the best that I can be?"

Danielle adds,

Knowing that I have to do this for her and I have to be able to help her deal with this—things that need to be dealt with.....I did this. I made this choice. I am the one that chose this. I am the one that put my child in the position that she is in. So that means I am the one that has to try and fight it. Give her the tools and the knowledge to be able to survive this life. I can't fix what I did—there's nothing I can do to make it better—but I think I can make it easier.

Maeve and Danielle, in addition to other ways of going on, described the benefit of a "fresh start" and starting each day anew. Perhaps this serves as a needed break for the emotional stress and a more removed perspective. Maeve and her family moved to a different state:

I got away from all the past. Sometimes, geographical change doesn't help, but this time it did. And it has helped Charlie. We have met people, it is a small community, and people got to know us before they judged us.

Danielle, who previously described fears that she also has FAS stated,



I had my depression—and it's true that there are times that I crawl in my room and say, "I can't deal with her, I can't deal with her." There are days that I will do that and I have to take that and then you pick yourself up and say "Ok, this is reality now and you have to go forward, you have to do what you have to do. You've had your pity party now let's go on."

This group of women are mothers to children with psychological/emotional/behavioral, physical and educational challenges. Their children need them on a daily basis. Even the children who have reached the age of adulthood continue to require support services. Claudia's daughter, Samantha (now 24 years old) relies on constant support and assistance from her mother. This group of women does not have the "luxury" of falling apart and taking care of their guilt--their children need them.

Many of the participating mothers were able to offer family environments to their children to serve as protective factors against secondary disabilities in individuals with FAS including a stable and nurturing home, having basic needs met and a stable living situation (Streissguth et al., 1997, 2004). Along with the many needs and challenges their children face on a daily basis, many of the mother's interviewed offered specific strengths and positive attributes of their sons and daughters.

Quotes from participants include,

Sarah proved them all wrong. She knows how to do the computer, she knows how to write, she knows how to read, she knows her numbers, and she talks very well. Very, very, very smart. She's a happy child, a loving child. She's not angry. She doesn't have violent kicking at all about her. She's adorable (Yasmine).

He was a happy baby, that helps, he was a smiley baby (Maeve).

He is so eager to learn. (Ellie).

He does have his driver's license. He is a very good driver (Maeve).

He doesn't have a temper, at all. He'd cry before he lashed out at anybody. He's very much...like if we say something to him, he tries really hard to listen to the rules. He's not rebellious. (Laurel)

She was a great baby. (Leah)

Last year he got two pins in (wrestling wins) and lettered in wrestling. (Evelyn)

**Support from others.** Four of the mothers (Maeve, Leah, Kara, Ellie)

interviewed cited the support of others was key in helping them to go on. They each noted significant people in their lives who listened to them and understood them, without judgment. Although Leah described her father as “absent altogether” due to his drinking while she was young, she noted that when she gave birth to her daughter, her father, who was in recovery by that time, was a source of support. He encouraged her not to “beat yourself up” after her daughter was diagnosed with Fetal Alcohol Syndrome. In fact, it was Leah’s father who first suspected a problem with her daughter’s development and he who brought the child for evaluation at the age of 18 months.

Ellie credits a core group of people in her AA meetings that help her. As well as a best friend who: “...knows almost everything and she, for some weird reason, almost unconditionally loves me anyway. I don’t know what is wrong with her (then laughs).”

Maeve’s husband provided very direct, focused support to assist her. She noted that this proved a very effective means of support for her. He stated, “Did you do the damage? Yes. Now you can continue it or you can get your shit together and we can help him.”

One very specific support structure is offered through the National Organization of Fetal Alcohol Syndrome Birth Mother’s Network, also known as the Circle of Hope. This group is comprised of a network of women who drank alcohol during pregnancy and may have one or more children with Fetal Alcohol Spectrum Disorders. This support group is open only to birth mothers (as opposed to foster or adoptive mothers raising children with Fetal Alcohol Syndrome). The women in this group lend support to each other in addiction recovery and/or through the challenges of raising a child with Fetal Alcohol Spectrum Disorders. The group meets approximately once a year at different locations throughout the United States. In addition, the women are in touch via

telephone and internet and are invited to participate in a monthly conference call. Four of the participants were members of this group. The group is best described by Vicki:

And so once a year we go out without any anxiety and you can laugh and cry. We even have a hugger in the group who will come and hug us if we need it. And we are taught that high profile women, low income women—we can be anything we want....

Through this group, women support each other. They draw each other out and draw support from one another. Kara, stated,

It took me five years to come out of it. Basically, I was very bitter, very angry from day one from a lot of stuff that stemmed from my (whole) lifetime and I never really fully dealt with it. (name) knock on wood, Thank God for her and one or two others that kinda' gave me the swift kick in the backside and said, "Kara, snap out of it" so to speak and do what you need to do and get out of your swamp because you are very bitter, you are very angry and you need to quit. Susan was one of the first people to draw me out.

Connecting to the internet has also made an impact in terms of support for Claudia. She stated, "I really didn't have any great support for a long, long time....until I got connected to the internet a year ago." She was able to gain general information and access the NOFAS website ([www.nofas.org](http://www.nofas.org)).

**Feeling judged.** Conversely, having good support was not the case for all participants. Several participants (Kendra, Claudia, Danielle, and Vicki) noted feelings of isolation since giving birth to their children and learning of the FAS diagnosis. Kendra stated simply, "I learned very early you can not depend on nobody but yourself." Laurel described the support of family and friends only in the weeks after she had a difficult labor and delivery with her son, long before his diagnosis. He was diagnosed with FAS at the age of nine. She stated, "so I had good support for the first little bit, but then I lost everything. Everybody was like—you're better now so deal with it. So I felt very abandoned."

Other mothers have noted not only a lack of support and isolation, making it much more difficult to move on, but also feelings of judgment and stigma by others. It is

possible, as Vicki's previous quote about her church infers, that the challenging behaviors of the child (i.e. Vicki's daughter turning the lights on and off and wanting everyone's coffee has resulted in her leaving the church) may bring on judgment and stigma. This may certainly be seen as a barrier for their progress and healing. The following quote from Danielle demonstrates the constant feeling of being scrutinized and judged, branded for life as the person who caused her child's problems:

When they [people in her town/school] found it was Fetal Alcohol [Syndrome] ...someone said to me "I would never guess you drank, you used to be a drunk?"... Some people think that she is adopted and when I say, "no, I gave birth to her"...then they don't know what to say... how do you help get rid of the stigma that every birth mom has felt?...And this is my hometown—a lot of the teachers were there when I was a drunken child. These people are looking at me and I'm a single mother with 2 kids and [they are thinking] "Oh yeah, she's just like her mom."

Similarly, during the interview process, Kendra stated that she has always felt judged. She discussed taking a class about Fetal Alcohol Syndrome when her son was first diagnosed: "I remember the first day they said something about birth parents. They were very negative and I remember looking straight at her and I said, "I am a birth parent." She never said a damn word again."

Ellie discussed the "catch 22" dilemma of advocating for needed services for her son, but at the same time knowing that divulging his diagnosis will bring judgment and stigma onto her:

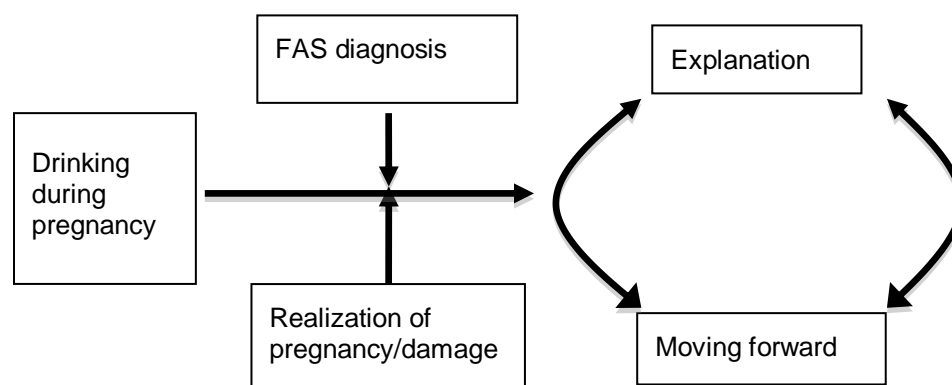
Today I can only say that I try to help him. But there is nothing [educational/mental health services] catered to him and then of course, if it was, then I'd have to come out and admit it. Then I'm dealing with shame and judgment.

Although many of the participants in this study described receiving support from various sources and leaning on that support to cope and go forward with their lives, it is clear that this group also continues to feel judged and stigmatized.

**Relationship between understanding their actions and moving forward.** The relationship between drinking during pregnancy, FAS diagnosis, understanding prenatal

alcohol exposure and moving on is depicted below. This is a tentative model that seems to be suggested by the data presented, a starting point to help understand the relationship among these variables. Much more research is required including the identification of other moderating and mediating variables.

Either at the time the mother realized that her drinking had damaged her child or at the time of their child's diagnosis, each of the mothers interviewed constructed a framework to explain and understand why they drank alcohol during their pregnancies. This framework did not immediately lead to increased coping and moving forward with their lives. Possessing a framework for understanding their actions does not serve as a stepping stone or necessary process in order to cope and go on with their lives.



*Figure 1.* The relationship between and amongst drinking during pregnancy, FAS diagnosis, understanding prenatal alcohol exposure and moving on.

### Summary of Results

In summary, this group of eleven biological mothers of children with Fetal Alcohol Syndrome overcame obstacles and found ways to reconcile their actions and move forward with their lives. Most participants suffered traumas, both in childhood and adulthood including physical and sexual abuse at the hands of family members and sexual assault by non family members. In addition to suffering physical and sexual abuse as children, several participants described instances of witnessing domestic

violence. These events appear to have further traumatized either their early years, resulted in their own parents/step parents being both physically and emotionally unavailable or both. In addition, several women expressed feelings of abandonment when they were separated from their parent(s), for example, due to the parents' own alcohol issues or mental illness. As adults, most of the women who had witnessed domestic violence as children experienced violence in their adult relationships.

When asked about the cause of Fetal Alcohol Syndrome in their children, feelings of guilt were prevalent throughout the lives of this group of mothers. These feelings of guilt were continuous no matter what the age of the child or the length of time since the diagnosis. All of the mothers interviewed had found a way to understand and frame their drinking (whether before, during or after their pregnancies) for themselves including: utilization of the disease model of addiction, stating inaccurate or incomplete knowledge of the danger of taking alcohol during pregnancy, following the advice of others (family members, friends, physicians) and stating that they were unaware of their pregnancy. The framework offered assistance in understanding their actions.

Although each of the mothers interviewed had a framework to understand why they drank alcohol during their pregnancies, this did not automatically lead to increased coping and moving forward with their lives. Yet, each of the mothers came to an understanding of their drinking and also offered reasons and/or motivations for coping and moving forward with their lives.

Several themes emerged when discussing how these mothers are able to go on with their lives after the diagnosis of FAS is rendered. By far, the most common theme offered was a reliance on spirituality. Spirituality was described as a main support, not only in the form of organized religion, but rather the belief in a higher power or being. Many of the mothers rely on daily prayer and described spirituality as a supplier of hope. A second theme was the desire to help others or described as a devotion to a cause.

Some mothers were focused directly on helping mothers of children with FAS or advocating for the needs of children with FAS. Others were focused more broadly towards helping others. This group of mothers formed support groups, mentored other women and advocated for educational services and support services. Helping others assisted these mothers in their own process of moving forward. The realization that their children need them served as another theme in moving forward. Although many of the children are now young adults, their need for specialized daily assistance and supervision persists and likely will for years to come. Meeting these needs further served to motivate and focus this group of mothers and helped many of them to “go on.” Finally, utilizing the support of family, friends or support groups emerged as the final theme. Several mothers noted significant people in their lives who listened to them without judgment. Other mothers discussed the support they gain from support group meetings, both in person and through the internet.

## CHAPTER V

### DISCUSSION

#### **Overview**

Biological mothers who parent their children with FAS face unique and profound challenges. They must cope with the daily struggles of parenting a special needs child who may suffer with a variety of neurobehavioral characteristics. In addition, they must also face these challenges with the knowledge that their children's problems are due to their own actions during pregnancy, namely their alcohol use.

There is a paucity of research focused on birth mothers of children with FAS. The vast majority of information in the literature has been obtained from foster parents, and not from birth mothers themselves. This study is one of the first to directly interview a group of biological mothers of children with FAS. Biological mothers raising children with FAS have many of the same needs as the foster parents described in the literature. Adoptive/foster parents of children with FAS are familiar with the stresses and struggles of parenting, but are not considered to blame for the damage to the children. Their experiences are potentially different from those of biological parents whereas they do not have the additional complications of maternal guilt regarding the origin of the children's syndrome. An increased understanding of thoughts, feelings, and impressions of biological mothers of children with FAS will help not only this unique group of mothers, but also the children in their charge. With greater knowledge and understanding of this vulnerable population come increased opportunities for prevention of future cases of FAS. Augmenting our understanding of this population of women may improve interventions for pregnant women who drink alcohol, thus decreasing alcohol exposure during that pregnancy and lessening the chances of alcohol exposure during subsequent pregnancies. Ideally, having a greater understanding of the thoughts and feelings of biological mothers of children with FAS will help us to screen and identify women at the



greatest risk of having a child with FAS and provide prevention services. In addition, we may be better able to assist those women who are currently coming to terms with drinking alcohol during their pregnancies.

The eleven biological mothers of children with Fetal Alcohol Syndrome who participated in this study overcame obstacles and found ways to reconcile the action of drinking alcohol during pregnancy and generally function in their lives. Most participants suffered traumas, both in childhood and adulthood, including physical and sexual abuse at the hands of family members and sexual assault by non family members. In addition several participants described instances of witnessing domestic violence during childhood. These events appear to have traumatized their early years, resulting in their own parents/stepparents being both physically and emotionally unavailable or both. In addition, several women expressed feelings of physical and psychological abandonment when they were separated from their parent(s); for example, due to the parents' own alcohol issues or mental illness. As adults, most of the women who had witnessed domestic violence as children experienced violence in their adult relationships.

As stated in the literature and by the women who participated in this study, abuse plays a potential role in women becoming alcoholic. There may be a relationship between suffering abuse in childhood, alcoholism and FAS. Most of the women in this study experienced abuse during childhood. This is in keeping with the previous literature connecting suffering abuse as a child and alcohol abuse as an adult (Ireland & Widom, 1994; Miller, Downs, Gondoli, & Keil, 1987; Waldrop et al., 2007; Widom & Hiller-Sturmhofel, 2001; Widom et al., 1995; Wilsnack et al., 1997). Following the disease model of addiction and assuming that the individual is not able to control her drinking, it is possible that if an addicted person becomes pregnant, that child may suffer from FAS.

Feelings of guilt around causing their children's FAS were prevalent throughout the lives of this group of mothers and persisted no matter what the age of the child or the

length of time since the diagnosis. However, all of the mothers interviewed found a way to understand and frame their drinking (whether before, during or after their pregnancies) for themselves in a way that included: utilization of the disease model of addiction, recalling being told inaccurate or incomplete information of the danger of taking alcohol during pregnancy, following the advice of others (family members, friends, physicians) and stating that they were initially unaware of their pregnancy when they were drinking. The framework adopted by each mother offered assistance to them in understanding their actions. Although each of the mothers interviewed developed her own framework to help her understand why she drank alcohol during her pregnancy, the existence of her framework did not immediately lead to increased coping and moving forward with her life.

Several themes emerged when discussing how these mothers were able to go on with their lives after learning of the damage caused by alcohol. Most common was a reliance on a sense of spirituality. Many of the mothers relied on daily prayer and described spirituality as a source of hope. A second theme was devotion to a cause including a desire to help others. Some mothers were focused directly on helping mothers of children with FAS or advocating for the needs of children with FAS. Others were focused more broadly on helping others, for example, through starting support groups and speaking to legislators and even enrolling in social work education programs. Helping others assisted mothers in their own process of moving forward, perhaps in receiving fulfillment through focusing positive energy and attention on others.

The realization that their children needed them served as another way these women found to help them cope and move forward with their lives. Meeting these needs further served to motivate and focus this group of mothers and helped many of them to “go on.” Finally, utilizing the support of family, friends or support groups emerged as a coping strategy. Several mothers noted significant people in their lives who listened to

them without judgment. Other mothers discussed the support they gained from support group meetings, both in person and through the internet.

Although this is a small sample and therefore generalizability is very limited, the findings do contribute to the existing literature. This study provides insight about an unexplored and vulnerable population of women and offers a conceptual explanation describing their experiences. In addition, this study has potentially important implications for practice, policy and directions for future research.

### **Implications for Practice**

#### **Mental Health Professionals**

**Children.** All mental health clinicians, including psychiatric social workers and psychologists, need to be aware of the indicators of Fetal Alcohol Syndrome, including facial features and neurobehavioral symptoms. This is useful for children presenting for services both identified with FAS and those not yet diagnosed. Children with FAS struggle with an array of neurobehavioral symptoms such as: slight to severe learning disabilities, cognitive impairment, problems with executive functioning, issues with attention and impulsivity and poor social judgment. In addition, children with FAS are vulnerable to a host of secondary disabilities including: mental health problems, criminal justice involvement and addiction. These symptoms and the needs of the children are a significant challenge for any parent.

When any child presents to a mental health professional for treatment it is important that the clinician take a thorough history including a prenatal and post natal history of mother's use of alcohol and other substances. If during the initial assessment process it is found that the mother drank alcohol during pregnancy, and the child presents with any of the broad range of neurobehavioral symptoms, there is a possibility that the child may have FAS and therefore will need a specialized assessment by practitioners (usually a physician, psychologists and/or social worker) with advanced

knowledge of FAS diagnostics. Some states, such as New Jersey, have FAS diagnostic clinics where a multidisciplinary team of specially trained professionals are located to assess and diagnose children with prenatal alcohol exposure ([www.nofas.org](http://www.nofas.org); [www.beintheknownj.org](http://www.beintheknownj.org) ). In states without specialty clinics, an evaluation by a developmental pediatrician should be pursued because he/she may have advanced knowledge of the effects of prenatal alcohol exposure.

When a child already diagnosed with FAS presents to a mental health professional for services, that professional can be very helpful to both mother and child if the professional has some FAS specific knowledge. During the course of treatment, it may be helpful to understand the origin of the child's struggles. Often oppositional behaviors may be viewed as willful actions committed by choice. While the child's behaviors and symptoms are a challenge for any parent, perhaps understanding the behaviors as a result of the brain damage from prenatal alcohol exposure as opposed to oppositional or defiant behaviors may assist in helping to address behavior at an appropriate level of development on a daily basis. Additionally, with a sensitivity for and knowledge of the challenges facing both child and parent, the professional can assist in linking the child to further services if needed and in advocating for his/her educational needs.

**Biological mothers.** Due to the complexity of the parenting relationship, understanding and supporting this group of mothers is necessary. In addition to the child receiving specialized services, the mother may need specific support. She may face guilt, especially if she has recently learned of the diagnosis, as participants noted a strong and pervasive sense of guilt. Practitioners should be advised to assess for guilt and its effects, and treatment with the mother around improving support and coping during times of increased feelings of guilt may be indicated.

Another area that should not be overlooked by mental health clinicians treating biological mothers of children with FAS is the potential role of trauma. If the mother describes experiences of alcoholism, it is important to ask specifically about the mother's trauma as that trauma could impact her daily living and her parenting. The vast majority of mothers who participated in this study were abused as children, many quite severely. Practitioners may have to take into account a history of trauma (potentially never before treated), or at least screen for a history of trauma, in a mother who presents for treatment and assess the effect of trauma on her own daily functioning and parenting.

The mental health practitioner can also be helpful in guiding the mother towards an explanation or understanding of her actions. Though it may be difficult and perhaps impossible for a mother to completely forgive herself for drinking during pregnancy and harming her child, the women in this study provided potential guilt mitigating explanations of why they did so such as: utilization of the disease model of addiction, stating that they had inaccurate or incomplete knowledge of the danger of taking alcohol during pregnancy, following the advice of others (family members, friends, and physicians) and stating that they were unaware of their pregnancy. However, it must be kept in mind that this study had only 11 participants; therefore a larger number of explanations (such as: mental health issues include psychotic disorders, coercion by partner or family members) may exist and larger samples need to be studied to determine if there are other such explanations.

In addition, the mental health practitioner may be helpful in guiding the mother towards effective coping strategies. As discussed, the women in this study were supported by their spirituality, through helping others, by knowing their children needed them, and by relying on the support of others. Perhaps these areas may be beginning suggestions for women have difficulty finding motivation and coping strategies. This research does not suggest when these "moving on" strategies could be utilized. For

instance, a woman whose child is newly diagnosed may not be ready to help others, but as time passes she may find this strategy helpful. The timing can be dictated by when the mother appears ready, for example, when she is feeling psychologically stronger and is less consumed by her own guilt.

Referral to the National Organization on Fetal Alcohol Syndrome (NOFAS) website ([www.nofas.org](http://www.nofas.org)) may be a useful recommendation by clinicians to their clients as a source of greater information and support. The NOFAS Birth Mothers Network is a source of support to any women who consumed alcohol during pregnancy and may have a child affected by prenatal alcohol exposure and this support is provided by women who have been through similar circumstances. The Birth Mothers Network offers peer support and mentoring, referrals for FAS evaluation/diagnosis and addiction treatment services, a monthly conference call and attendance at an annual retreat (expenses paid). Mothers offer support to each other through email, phone and some in-person contact. This group of mothers supports each other through addiction recovery (if applicable) and/or through the challenges of parenting a child suffering the effects of prenatal alcohol exposure. The mentoring system was previously discussed as a great source of support, and an opportunity for experienced mothers to share their wisdom, successes and failures with families of newly diagnosed children (Devries & Waller, 2004; Guinta & Streissguth, 1988). Mothers participating in this study noted feelings of judgment and anger when attending support groups also attended by adoptive/foster parents of children with FAS. Support/information groups specifically for birth mothers may create a more comfortable, nonjudgmental and accepting environment. Through support services specific to birth mothers, information about characteristics of FAS, parenting techniques and suggestions can be disseminated. In addition, topics such as prevention of alcohol exposure during subsequent pregnancies, recovery, stigma and guilt could be included as well. Although the benefits of NOFAS Birth Mothers Network

are clear, it may not be a good fit for every birth mother. The group officially meets in person only on an annual basis. Some of the participants wanted to meet other mothers in person on an ongoing basis but the lack of local support groups prevented this. Thus, the establishment, further development of existing and/or utilization of local support groups, such as more local or regional chapters of NOFAS may be an effective way to further assist such mothers and their children.

Community based case management programs, such as the Parent-Child Assistance Program (PCAP) in Washington State and the First Steps program (Alberta, Canada) are a good source of one-on-one case management and support (Grant, Ernst, Pagalilauan, & Streissguth, 2003; Rasmussen et al., 2012). PCAP is a 3 year program offering home visits and individual support to women who abuse alcohol or drugs during pregnancy with the goal of preventing future births of children with prenatal alcohol and drug exposure. The program begins during pregnancy or after the birth of a child. Case managers develop a positive relationship with their clients, connect them with needed services and teach clients to access services independently in the future. Case managers also assure that clients' children receive appropriate healthcare and have a safe environment (Grant et al., 2004). In 1999, PCAP expanded its services to enroll women diagnosed with FAS or FASD, or suspicion of prenatal alcohol damage. Specific training and programming was offered to program case managers to take into account the potential needs of a mother suffering her own damage from prenatal alcohol exposure. This is particularly important as 3 of the mothers in this study suspected they too suffer from prenatal alcohol damage and therefore may benefit from this type of support and knowledge.

Clinicians encountering women with a child with FAS should pay particular attention to their own thoughts and feelings around bias and judgment. Clinicians may find themselves feeling angry or have an impulse to shame the mother. This is

understandable given that the child has been harmed by the mother's actions. However, this research begins to demonstrate that this group of women were trapped by addiction, overwhelmed by their own histories, and/or misinformed by friends and family members. Alone or in concert, this led these women to act in ways that harmed their children. This research demonstrates that this group of mothers did not feel callous or uncaring toward their unborn child. There was never intent to harm and clinicians should keep this in mind as they attempt to empathize and assist their clients. Clinicians should search for more information and seek quality clinical supervision around these difficult, emotionally-charged issues.

**Addictions specialists.** Addictions specialists play an important role in both treatment of women and prevention of future occurrences of FAS. Every woman of fertility age should be screened and educated about the dangers of drinking while pregnant or before becoming pregnant and addictions specialists need to clearly and emphatically communicate to their patients that there is no safe amount of alcohol during a pregnancy. This recommendation is in light of the finding that several of the participating mothers said that they perceived that family members, friends and even physicians supported their drinking during pregnancy. In light of the link found in the literature between childhood abuse and trauma and alcoholism in adulthood, addictions specialists, if they are not doing so already, should screen for underlying childhood trauma. Issues of trauma and childhood abuse may be major contributing factors leading to substance abuse and may be an underlying cause of addiction. Furthermore, unexamined or unresolved emotional difficulties resulting from such trauma and abuse could interfere with a mother's ability to effectively parent—particularly a child who has special needs.

Also, addiction programs can offer education about the dangers of drinking alcohol during pregnancy to both men and women receiving addictions treatment. It is



never too early to provide accurate information to both adolescents and adults receiving addictions treatment. Women should not bear the burden of helping to ensure a healthy pregnancy and baby alone. Their partners and expecting fathers should have the same education and information in order to offer support and assistance. As stated previously, several participating mothers perceived that their family members, friends, and even their physicians gave permission for alcohol intake during pregnancy. Addictions professionals are a good source for accurate information that can clarify misinformation and discourage thoughts and intentions of drinking during pregnancy.

**Health care professionals.** A surprising and troubling finding of this study is that several mothers insisted that they received permission *from their physicians* to drink during pregnancy. Even when discussed during the member checking process, several participating mothers reiterated that their physicians gave them the message that it was ok to drink some amount of alcohol.

As stated throughout this dissertation, there is no safe amount of alcohol use during pregnancy. Health Care professionals must screen all women of fertility age and provide education and counsel on care of their bodies pre-pregnancy including the dangers of tobacco, alcohol and other substances, good nutrition, and exercise (van der Zee et al., 2011).

Mainstream public health messages urging women to abstain from drinking alcohol during pregnancy have been disseminated for some time, beginning with the 1981 Edward Brandt, Jr. Surgeon General's Advisory on Alcohol and Pregnancy which asserts: "The Surgeon General advises women who are pregnant (or considering pregnancy) not to drink alcoholic beverages" (United States, Surgeon General Advisory. "Surgeon General's Advisory on Alcohol and Pregnancy." FDA Drug Bulletin, Volume 11, Number 2, 9-10. July 1981). This message is supported by the United States Surgeon General (2005), United States Department of Health & Human Services, National

Institute on Alcohol Abuse and Alcoholism, Centers of Disease Control and Prevention, the United States Institute of Medicine, the March of Dimes and the American Academy of Pediatrics (American Academy of Pediatrics, 2000; March of Dimes, 1994; National Institute on Alcohol Abuse and Alcoholism, 1991; Schydlower et al., 1993).

This recommendation has been offered for 30 years, yet only one mother in this study referenced awareness of messages that drinking may harm the baby. It is not known how widely this information has been disseminated, or whether the information reached the hometowns of the participating mothers. While more research utilizing larger sample sizes to assess the knowledge of the dangers of drinking during pregnancy is necessary, it appears that continued education focused on our society at large on the dangers of drinking alcohol during pregnancy is also necessary. Physicians, nurses, midwives and other health care professionals must clearly and consistently discuss with patients the surgeon general's guidelines that there is no safe amount of alcohol intake during pregnancy. Increased/improved public health information is essential to counteract inaccurate information from pregnant women's friends, family members and possibly physicians.

Furthermore, it is critically important that accurate and clear education continue to be provided to physicians currently practicing and also be included in the curricula in medical schools. Health care practitioners including physicians, nurses, and midwives must thoroughly screen every pregnant woman for alcohol use and be clear in their messages to women that any amount of alcohol use could cause damage to their babies. The CDC website ([www.cdc.gov](http://www.cdc.gov)) is an invaluable source for healthcare providers and includes access to the "FASD Prevention Tool Kit" made available by the American College of Obstetricians and Gynecologists (ACOG) in collaboration with the CDC. Also offered on the CDC website is the "Women and Alcohol Website" which provides resources for health care providers in identifying women who drink excessively

and provides information on brief educational counseling to reduce or eliminate alcohol use.

Accurate and clear information is equally important to include in the education of addictions professionals, mental health practitioners and social workers. These professionals must be clear that there is no safe amount of alcohol to take during pregnancy to assist in prevention of future occurrences of FAS. In addition, information on indicators of Fetal Alcohol Syndrome, including facial features and neurobehavioral symptoms should be included in the curricula of these groups of professionals so that they may serve as screening and referral sources. Finally, the addiction and mental health professionals must have information on the behavioral and psychological outcomes of the FAS diagnosis, such as the results of this study, so that they may have the knowledge to assist this population of mothers and children.

In 2010, NOFAS was awarded a 4-year cooperative agreement with the CDC encompassing 2 main goals: 1) increasing the availability and coordination of FASD related prevention and support services at the local, state and national levels and 2) increasing awareness of FASD through the dissemination of accurate information through professional and public health networks and the media. This multi-year project has the potential to greatly benefit mental health professionals, addictions specialists and health care professionals in their work with children affected by prenatal alcohol exposure and their families.

A recent executive summary and study posted by NOFAS on its website entitled "Alcohol and Pregnancy: What Pregnancy Books Say to Women" evaluated seven mainstream pregnancy books for content regarding recommendations to pregnant women around alcohol use during pregnancy:

- *The Expectant Father: Facts, Tips and Advice for Dads-to-Be* (2nd ed.; Brott & Ash, 2001);

- *The Mother of All Pregnancy Books: The Ultimate Guide to Conception, Birth and Everything in Between* (Douglas, 2002);
- *Your Pregnancy Week by Week* (5th ed.; Curtis & Schuler, 2004)
- *Mayo Clinic Guide to Healthy Pregnancy* (Harms, Johnson, & Murry, 2004);
- *What to Expect When You're Expecting* (3rd ed.; Murkoff, Eisenberg, & Hathaway, 2002);
- *The Girlfriends' Guide to Pregnancy* (Iovine. 2007); and
- *Taking Charge of Your Fertility, 10th Anniversary Edition: The Definitive Guide to Natural Birth Control, Pregnancy Achievement and Reproductive Health* (Weschler, 2006).

Of the seven books reviewed, five mention the Surgeon General's warning, but only three recommend complete abstinence and highlight the importance of the Surgeon General's message. Only three of the seven books recommend abstaining from alcohol while trying to conceive a baby. Two of the books, one stated to be the most popular, "What to Expect When You're Expecting," rationalize some alcohol use during pregnancy.

As previously discussed, following the disease model, women who are addicted to alcohol may not have the power to control their alcohol use. Therefore, it is reasonable to assume that for that subset of women, receiving public health information may not be enough to stop drinking. However, perhaps public health information more effectively disseminated may lead this group of women to seek substance abuse treatment.

### **Implications for Policy**

These findings suggest policy implications in the areas of: medical education, public/societal education, and ongoing funding of services. As discussed, the dangers of taking alcohol during pregnancy should be a mandatory component of the curricula

taught to health care professionals. Guidance for presenting the information in clear, focused language to patients must be included. School curriculums must discuss the dangers as well to begin in elementary school through college. Information on school-based education for students and teachers developed by NOFAS is available on both the NOFAS and CDC websites.

Continued public education must be funded and targeted to society at large including not only to pregnant women, but all women and men as findings demonstrate that many pregnant women rely on the advice of family and friends. There has been a greater push for public education, such as public education warnings in bars, liquor stores and restaurant bathrooms, but it must be broadened, for example, to include billboards, sides of buses, public service announcements of television and radios and bigger and bolder warnings on alcohol containing products. Funding should be used proactively, for prevention—screening and education. The Governor's Council of the State of New Jersey established the Fetal Alcohol Spectrum Disorders and Other Perinatal Addictions Task Force. This group serves to educate all residents of the State of New Jersey about the possible effects of alcohol, drugs and tobacco upon fetal development. Perhaps more state governments can create similar groups to better disperse the message of the seriousness of the problem.

Funding for services to screen and diagnose children who have been exposed to alcohol must be expanded and there must be an expansion of services for children when they are diagnosed. As more health care providers, addictions specialists and mental health clinicians gain information about prenatal alcohol exposure they will need specialists and clinics available for diagnostics and services. Even though this sample is small, the mothers in this study described difficulty in locating specific treatment. Though the mothers brought their children to services, the services were not necessarily specific to children with FAS, nor rendered by professionals with FAS specific

knowledge. As suggested by the findings, mothers are in need of services to address their own issues and to receive support during their parenting journey. Groups such as NOFAS could benefit from funding so that they may expand and reach more people.

Treatment and services for alcoholism and other addictions must be available; particularly for women as the extensive social and economic costs of treatment of children with FAS can be prevented. FAS results directly in increased education, and healthcare costs and lost productivity/wages and indirectly through secondary disabilities including justice system involvement, mental health care costs, and residential treatment costs (Bouchery, Harwood, Sack, Simon, & Brewer, 2011; Lupton, Burd, & Harwood, 2004). Many agencies receive public funds and are contracted to provide services to pregnant women and for addictions. A requirement of receiving public funding and contracts could be the inclusion of screening women for addiction. Perhaps guidelines for accreditation for agencies might include attention to education on the dangers of alcohol use during pregnancy and screening for prenatal exposure to alcohol. The network of support could be increased further by the start up of local support groups that meet face to face on an ongoing basis, a service that many of the participants stated was lacking. This might be accomplished through further expansion of NOFAS state affiliates or through local mental health or addictions centers or the creation of specialized treatment centers those prenatally expose to alcohol.

### **Implications for Cognitive Dissonance Theory**

These findings add to the literature on cognitive dissonance theory (Festinger, 1957). A portion of the early research on cognitive dissonance theory studied mothers who smoke. Mothers who smoke have done something potentially harmful to their children and left their children at risk to a host of health issues including increased risk of childhood cancer and Sudden Infant Death Syndrome. However, the smoking/tobacco group is somewhat different from mothers of children with FAS as mothers of children

with FAS have done something attributable to harm done to their children. There is a direct link between the action of drinking alcohol during pregnancy and the child's FAS diagnosis and that link is known to all who encounter the child and are aware of the diagnosis. The findings in this study validate cognitive dissonance theory whereby they demonstrate attempts at decreasing cognitive dissonance both by changing thoughts and beliefs and by changing behavior. For these women their understanding of the uncontrollable nature of addiction seemed to play a role in their dissonance reduction. Thus, it is possible that a belief in the disease model of addiction decreases cognitive dissonance not by changing thoughts and beliefs, nor by changing behavior, but by some other mechanism; namely, having a perception of decreased control of one's actions. Dissonance may be reduced through the belief that culpability of actions is reduced when an addiction is active. Therefore, the belief in the disease model of addiction is enough to decrease cognitive dissonance without changing thoughts or beliefs (the knowledge that alcohol is detrimental for a developing baby remains intact) nor changing behavior (drinking during pregnancy continued). Although for the mothers participating in this study, the dissonance was reduced long after the action of drinking during pregnancy, the role of addiction in explaining behavior and reducing cognitive dissonance may be an area for further research.

### **Limitations and Areas for Further Research**

Several limitations to this research are evident and offer direction and opportunities for further study. To start, the racial and ethnic diversity of the sample is very limited. Within this sample of women only one was African American and one an indigenous Alaskan native. The sample was not large or diverse enough to capture cultural differences. Research on a group of mothers with more diverse racial and cultural backgrounds may offer more information on differing community belief systems and supports. For example, had this study's sample been predominantly comprised of

African American mothers, the results may have been different. Hill (1972) and Boyd-Franklin (1989, 2003) discuss strengths of African American families including: the bond of the extended family, adaptability of family roles, strong religious orientation, integral belief in the value of education and work ethic, and the ability to develop and use effective coping skills in the face of economic hardship. If this sample had more African American mothers participate, it is possible that the results would show a varied or greater role played by the extended family. Perhaps the mothers would have received different or more support from their extended family, included a variation on the findings of the perception that family members provided permission to drink alcohol during pregnancy. It is possible that a more involved extended family may provide more messages not to drink during pregnancy. Additionally, a reliance on a sense of spirituality emerged as the most common theme provided by the participating group of mothers in assisting them to go on with their lives after learning of the damage caused by alcohol. This theme may be further substantiated and strengthened in light of African American families' strong religious orientation. Families from other racial and ethnic groups also emphasize strong family bonds so an ethnically and racially diverse sample would contribute greatly to our understanding of this unique population.

In the current study, a potential sample bias surrounds the length of time since the child's formal diagnosis and the amount of years (for four women more than 20 years) to recall their pregnancies and their children's early years. With the exception of two mothers (ages 28 and 36), all mothers were "older" mothers between the ages of 40 and 56.

Of the 11 mothers interviewed, 8 had been aware of their children's diagnosis for more than half of their children's lives. Two of the remaining three mothers had a suspicion of their child's Fetal Alcohol Syndrome for half of the child's life without formal diagnosis. The final mother had been aware of her child's diagnosis for more than a



third of her child's life. On average, the children have carried the diagnosis for more than 10 years. This is significant as, with the passing of time, it is possible that the mothers have had a greater opportunity to process and understand the diagnosis to a larger degree than a mother whose child has more recently been evaluated and diagnosed. The mothers have had a significant amount of time to reflect and find ways to cope with the diagnosis and their feelings surrounding the cause of the diagnosis. In addition, perhaps with time, comes the ability to note the positives in their children and not be driven purely by the fear of the diagnosis and the thoughts of "brain damage." Having the opportunity to observe strengths and witness progress may offer a more optimistic perspective to the mothers on their parenting and the future potential of their children, thus mitigating some of their guilt. Overall, this group of participants has had time to research, learn about and adjust to the diagnosis, consult with experts and reach out (if desired) for support and greater understanding.

Furthermore, the participating mothers have continued to mature as women since the time of their children's diagnosis. They have gained more life experience and learned more about themselves and their feelings. For those women who consider themselves in recovery, they have moved further along in that process and perhaps gained improved mental health. How these women were able to adjust and move forward from the time of the initial diagnosis could be identified in a future study of this population.

Future studies might also focus on or include mothers of children who are newly diagnosed as one would perhaps expect different findings/outcomes among these women. More research is needed on mothers' initial thoughts on diagnosis and coping mechanisms during that period. Will an "understanding of their actions" or themes of "moving forward" be present? Future studies might examine the mechanisms mothers employed to simultaneously parent a child and process/deal with the guilt immediately

after diagnosis and look at when some of the guilt is mitigated and some self forgiveness occur. It is important to examine how these women's understanding and feelings of their roles as mothers alter subsequent to their children's diagnosis of FAS.

In addition to a focus on mothers of children newly diagnosed (regardless of the age of the child) is the potential to study mothers of children diagnosed in infancy. Only one of the children of participating mothers was diagnosed in the neonatal period and that child is now 20 years old. All other children were diagnosed between the ages of 2 years and 16 years. Child Protective Services was not contacted for the one mother whose child was diagnosed in the hospital. This study did not yield data on the initial phase of coping or if the mothers contemplated whether they should (or could) parent their children at all after the FAS diagnosis or whether to put them up for adoption. Perhaps with an opportunity to study mothers of children diagnosed in infancy researchers would see differences in mothers' outlooks and feelings.

Longitudinal research following mothers starting from the birth of their children and/or their children's formal FAS diagnosis may identify how their thoughts and feelings change over time as they mature and their children develop, and in particular how and when they adopt coping frameworks and behaviors to mitigate their guilt and move forward. Such research would address some of the previously mentioned limitations of this study and also potentially provide information on the best timing for different types of support and intervention.

The sample of eleven women was gathered via contact with NOFAS and volunteered to participate. It is possible that this particular sample of women, because they have been connected to supportive services (to varying degrees) may have feelings, thoughts, life experiences and perceptions that differ from biological mothers without those connections. They may benefit from a greater level of support and knowledge about FAS than other women. This group of women may also be unique in

that all but one of the mothers has primary custody of her child, whereas many children with FAS are not raised by their biological mother. One mother does not have primary custody due to physical health impairment, but has regular contact with her child.

Perhaps the fact that they have retained custody of their children signifies a greater measure of health or greater degree of resources and thus a better ability to cope with the challenges inherent in caring for one's biological child with FAS. The women that clinicians may typically come across may be more debilitated or wounded. The mothers in the greatest need may be out of this study's reach. Even so, the outcomes are still useful as they can provide a model for women who perhaps are not as healthy. It is possible that utilizing their methods of reconciling their behavior and offering their coping strategies as suggestions may assist other mothers in the process of healing.

Nevertheless, it might be helpful to conduct further research that compares a sample such as this one to a sample of women who have lost custody of their children or who placed their children for adoption.

Finally, the interviews were conducted by telephone only, as the women lived throughout the United States and Canada. The telephone interviews did not allow the researcher to observe body language and facial expressions as is allowed by face to face interviews thus presenting a challenge to engagement. However, the telephone interview does allow for some autonomy on the part of the participant.

To be sure, more research on biological mothers parenting their children with Fetal Alcohol Syndrome is warranted. However, this is a difficult population to recruit for research. This is a stigmatized population who are not necessarily connected with support services. The development of new effective recruitment techniques among health care practitioners, diagnostic centers, child development centers and addiction recovery services may yield studies with larger samples resulting in a wealth of useful findings and knowledge. Increased sample sizes with participants from diverse racial,

ethnic, and age backgrounds would be beneficial as well to yield potential information on how drinking during pregnancy is viewed cross-culturally and whether coping strategies vary across women of different backgrounds.

As discussed in the results section, a relationship may exist between reconciling the action of drinking during pregnancy and moving forward (See page 85). This tentative conceptual framework provides hypotheses for further quantitative study. Specifically, each of these components could be considered a variable, could be quantified and then the relationships between the variables could be tested to gain more information on their relationships to one another. Children/adolescents and adults who have experienced trauma, those with addictions, and those who support these groups could benefit from more knowledge of the potential link between trauma and addiction. It is possible that investigators could identify people who are at higher risk due to their childhood histories and intercede, hopefully cutting down on the number of children suffering from FAS in the future. Further information on these potential pathways may lead to more preventive services and allow practitioners and clinicians to be more proactive rather than reactive.

Further areas of potential study are to examine what healthcare providers know now about prenatal alcohol exposure and FAS and what information they need, who should present new information to them and which methods of disseminating further information will work best for them. Given the disparity in the participants' knowledge of prenatal alcohol exposure and the clear need for further public education, a logical starting point is to learn the extent of healthcare providers' knowledge on the topic. Information and education could be disseminated through the curricula in graduate and medical schools and through continuing education courses. Further study may yield information on whether education should be provided by professionals within the field of

study (i.e. physician to physician, social worker to social worker) or if teaching by a particular discipline (i.e. physician) provides the greatest impact.

Although only eleven mothers participated in this study and it is therefore difficult to generalize the findings, the results are still important and informative. This study provides an important first step in recognizing the unique needs of this population of mothers, independent from mothers of other special needs children. It underscores the need for prevention, medical/nursing education and public education and specialized diagnostic and supportive services. Perhaps health care practitioners, including nurses, physicians and midwives, may benefit from further education around Fetal Alcohol Syndrome, dangers of the use of alcohol during pregnancy, and the value of clear and consistent messages to their patients. Mental health care practitioners such as social workers, psychologists and addictions specialists may benefit from the linkage between abuse and alcohol and the potential for Fetal Alcohol Syndrome, as well as the findings on the persistence of guilt and what has assisted this group of women with moving on with their lives.

More broadly, this study may provide information on how we can understand and assist people who have committed regrettable behavior or ignored the dangers of their actions and who therefore need to find ways to cope with the negative consequences. As discussed by Lincoln and Guba (1985) and Padgett (2008), this study may have implications, *or transferability*, to populations in related circumstances. For example, the explanations reported by these women may also be utilized by someone who drove while intoxicated and harmed someone in an accident whereby a person who has had an accident due to driving while intoxicated has committed actions to harm another individual. Similar to a child with FAS, the damage has been done and cannot be taken back. Also similar is the probability that the guilt is long lasting and help would be important to assist the person with moving on. Therefore, perhaps some of the coping

strategies that this group of mothers found helpful, including spirituality, relying on support from others and helping others may also be useful for other groups of people who have caused harm to another.

By studying this group of women we learn of a tentative model of coping that could provide guidelines for those who work with troubled kids and their families, addictions specialists, health care professionals who work with women of childbearing age and policy makers. The experiences of this group of women offer potential lessons in self forgiveness, understanding, addiction, resilience, guilt, and coping that could perhaps benefit us all.

## APPENDIX A

## STUDY FLIER

**PLEASE TELL YOUR STORY!**

## RUTGERS UNIVERSITY SCHOOL OF SOCIAL WORK

**You're invited to participate in a study of mothers.**

This study is gathering information from birth mothers who have a child with FAS who is under the age of 18.  
The study requires a one to three hour interview with the possibility for a brief additional interview.

**Who Can Participate?**

Birth mothers with a child (under 18 years old with FAS)  
The interview sessions occur at your home or an agreeable alternative location.

If you are interested in enrolling in the study or would like to ask questions please contact:

Joelle Zabotka  
Rutgers University School of Social Work  
502 George Street  
New Brunswick, NJ 08901  
(732) 673-8619  
joellem111@aol.com

Michael LaSala, Ph.D  
Rutgers University School of Social Work  
502 George Street  
New Brunswick, NJ 08901  
(732) 932-7520 x 118  
mlasala@ssw.rutgers.edu

## APPENDIX B

### INTERVIEW STRUCTURE

The interview questions will serve to guide the interview process and will not be asked in a strictly ordered fashion. Supportive verbal prompts will be interjected as needed to put respondents at ease during these difficult questions (i.e. I understand that this can be difficult to discuss, let me reassure you that I am not here to judge or criticize you in any way, but to learn from you and other mothers so that we can do a better job of providing services, supporting you, etc.)

#### **Introduction**

Hello, my name is Joelle Zabotka. I am a graduate student at Rutgers University School of Social Work. I'd like to remind you that your name will not be attached to your responses and that you are free to change your mind about your participation at any time. I am interviewing women who have given birth to children diagnosed with FAS. I hope to better understand the essence of your experience as a parent. I seek vivid, detailed and complete descriptions of your thoughts, feelings and behaviors. I'll be asking you a lot of very personal information. Please know that I am not here to make any judgments. The purpose of my research study is to better understand your experiences so that we can develop better programs/ways to support mothers who are in your situation.

I value your participation and thank you for your time and effort. This interview should take between one and three hours. A second interview may be necessary in order to fully gather all of your information. After the interview is transcribed, I would like to discuss with you, either by phone or in person, your statements to confirm that I have understood your intentions.



### Interview Questions

I'd like to collect some basic information first:

Your age:

Your race and ethnicity:

Your educational level:

Your religion/level of spirituality:

Household Income:

Relationship Status:

Relationship Quality: (includes: how supportive do you consider your partner to be)

Number of Children:

Number of Pregnancies:

Number of pregnancy losses (include miscarriage, stillbirth, newborn death, elective abortion)

Number voluntarily released for adoption

Have you ever been diagnosed with a mental health disorder (prompt: such as depression, anxiety)? What type? When?

Your (FAS) child's first name and age:

Stability of housing at time of \_\_\_\_\_'s birth: (permanent, stable/ living with friends or relatives/ transient, emergency shelters, homeless, jail, drug-free housing.

Primary source of income at time of \_\_\_\_\_'s birth:

(The preceding questions are replicated from profile study carried out by Astley et al., 2000a, 2000b)

Do you have other children?—What are their names and ages?—Have any of your other children been diagnosed with FAS? If so, I would like to discuss/go over the questions for each of them individually.

Have you, or do you now have, any concerns about your other children—developmentally, educationally, mental health issues?

I'd like to better understand your experience as a mother of a child with FAS. I'd like to learn about both the years before your pregnancy and the years since. I'll be asking you a lot of questions about your drinking history and history of your pregnancies.

1) How old were you at the time of your pregnancy with \_\_\_\_?

- Was he/she your first pregnancy?
- What was the nature of the parenting relationship at the time of conception?
- What was your life like prior to the pregnancy—school, family of origin, substance use in the family, work history, social supports, experiences of interpersonal violence (as a child, adult, within your relationships)

2) History of substance use.

- Can you recall when you took your first drink? What was it? How much? What did you experience (prompt: sick, guilt, pleasure, etc.)
- Did you use any other substances? Type, amount, pattern?

(The preceding questions are replicated from profile study carried out by Astley et al., 2000a, 2000b)

- How often did you drink before the pregnancy, how much, of what?
- Was your drinking considered problematic—by you, by anyone else?
- Did you receive any treatment for your alcohol use?
- Any other substances? Type, amount, pattern?

3) How did you feel when you learned you were pregnant with (index child)?

- Was your pregnancy planned?
- How did you react?
- How did you feel about being pregnant? (prompt: consider termination, releasing for adoption?)
- How did others react (prompt: father of the baby, family members)?
- What concerns did you have?

4) Tell me about your pregnancy and delivery.

- Did you have any complications?
- Tell me about your drinking while you were pregnant.

- Did your pregnancy go full term?
- Did you take him/her home with you from the hospital?
- Any social service involvement?

5) Was the pregnancy different from your other pregnancies? (Discuss each other pregnancy individually)

- What were your feelings about your other pregnancies (prompt: planned, wanted, etc)?
- Were your reactions different? If so, in what ways?
- How did you feel about being pregnant during your other pregnancies?
- Did you have any concerns during your other pregnancies? If so, how were they similar and/or different to concerns during the pregnancy with (index child)?

6) What was \_\_\_\_'s infancy like?

- Did you receive support—what type? From whom?
- What type of personality did the baby have—difficult to soothe, feed, sleep?

7) (What concerns, if any, have you had about (index child)?

- When did you first become concerned?
- How did you handle the concern?
- What did you do with your concern? Evaluations?

8) When was \_\_\_\_ diagnosed with FAS?

- What were your initial reactions?
- Do you agree with the diagnosis?
- What kind of education did you receive about FAS?
- Who provided this information and how was it delivered?
- If you had the chance to educate others about FAS, what are your ideas about that education?

9) What are your thoughts/feelings about the cause of \_\_\_\_ FAS?

- What did you think, do, feel, when you were told?
- How have you been able to manage these feelings? (prompt: behaviors, coping, seek counseling, social/emotional support)

10) What has been challenging about raising \_\_\_\_?

- What services have been helpful during this process?
- What services are currently useful?
- What services are lacking?
- What/who have provided the greatest support?

11) Thinking back over the years, what services would you have liked to have?

(Questions related to service needs and delivery relate to questions and findings by Brown, Sigvaldason, & Bednar, 2005 and Brown & Bednar, 2003).

## REFERENCES

- Abel, E. L. (1995). An update on incidence of FAS: FAS is not an equal opportunity birth defect. *Neurotoxicology and Teratology*, 17, 437–443.
- Abel, E. L. (1998). *Fetal alcohol syndrome*. New York, NY: Plenum Press.
- American Academy of Pediatrics, Committee on Substance Abuse and Committee on Children with Disabilities. (2000). Fetal alcohol syndrome and alcohol-related neurodevelopmental disorders. *Pediatrics*, 106, 358–361.
- Astley, S. J. (2004). Fetal alcohol syndrome prevention in Washington State: Evidence of success. *Pediatric and Perinatal Epidemiology*, 18, 344–351.
- Astley, S. J. (2010). Profile of the first 1400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network. *Canadian Journal of Clinical Pharmacology*, 17, 132–164.
- Astley, S. J., & Clarren, S. K. (1997) *Diagnostic guide for fetal alcohol syndrome and related conditions: The 4-digit diagnostic code*. Seattle, WA: University of Washington Publication Services.
- Astley, S. J., & Clarren, S. K. (1999) *Diagnostic guide for fetal alcohol syndrome and related conditions: The 4-digit diagnostic code* (2nd ed.). Seattle, WA: University of Washington Publication Services.
- Astley, S. J., & Clarren, S. K. (2000). Diagnosing the full spectrum of fetal alcohol-exposed individuals: Introducing the 4-digit diagnostic. *Alcohol & Alcoholism*, 35, 400–410.
- Astley, S. J., & Clarren, S. K. (2001). Measuring the facial phenotype of individuals with prenatal alcohol exposure: Correlations with brain dysfunction. *Alcohol & Alcoholism*, 36, 147–159.
- Astley, S. J., Bailey, D., Talbot, C., & Clarren, S. K. (2000a). Fetal alcohol syndrome (FAS) primary prevention through FAS diagnosis: I. Identification of high-risk birth mothers through the diagnosis of their children. *Alcohol and Alcoholism*, 35, 499–508.
- Astley, S. J., Bailey, D., Talbot, C., & Clarren, S. K. (2000b). Fetal alcohol syndrome (FAS) primary prevention through FAS diagnosis: II. A comprehensive profile of 80 birth mothers of children with FAS. *Alcohol and Alcoholism*, 35, 509–519.
- Bolby, J. (1958). The nature of the child's tie to his mother. *International Journal of Psycho-Analysis*, 39, 1–23.
- Bottorff, J. L., Johnson, J. L., Irwin, L. G., & Ratner, P. A. (2000). Narratives of smoking relapse: The stories of postpartum women. *Research in Nursing & Health*, 23, 126–134.

- Bouchery, E. E., Harwood, H. J., Sack, J. J., Simon, C. J., & Brewer, R. D. (2011). Economic costs of excessive alcohol consumption in the U.S. 2006. *American Journal of Preventive Medicine*, 41, 516–524.
- Boyd-Franklin, N. (1989). Five key factors in the treatment of Black families. *Journal of Psychotherapy & the Family*, 6, 53–69.
- Boyd-Franklin, N. (2003). *Black families in therapy* (2nd ed.). New York, NY: The Guilford Press.
- Brott, A., & Ash, J. (2001). *The expectant father: Facts, tips and advice for dads-to-be* (2nd ed.). New York, NY: Abbeville Press.
- Brown, J. D., & Bednar, L. M. (2003). Parenting children with fetal alcohol spectrum disorder: A concept map of needs. *Development Disabilities Bulletin*, 31, 130–154.
- Brown, J. D., Sigvaldason, N., & Bednar, L. M. (2004). Foster parent perceptions of placement needs for children with a fetal alcohol spectrum disorder. *Children and Youth Services Review*, 27, 309–327.
- Brundenell, I. (1996). A grounded theory of balancing alcohol recovery and pregnancy. *Western Journal of Nursing Research*, 18, 429–440.
- Burnam, M. A., Wells, K. B., Leake, B., & Landsverk, J. (1988). Development of a brief screening instrument for detecting depressive disorders. *Medical Care*, 26, 775–789.
- Cannon, M. J., Dominique, Y., O’Leary, L. A., Sneiznek, J. E., & Floyd, R. L. (2012). Characteristics and behaviors of mothers who have a child with fetal alcohol syndrome. *Neurotoxicology and Teratology*, 34, 90–95.
- Clarren, S. K., & Smith, D., W. (1978). The fetal alcohol syndrome. *New England Journal of Medicine*, 298, 1063–1067.
- Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24, 385–396.
- Coles, C. D. (2001). Fetal alcohol exposure and attention: Beyond ADHD. *Alcohol Research and Health*, 25, 199–203.
- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.
- Curtis, G., & Schuler, J. (2004). *Your pregnancy week by week* (5th ed.). Cambridge: De Capo Press.
- Devries, J., & Waller, A. (2004). Fetal alcohol syndrome through the eyes of parents. *Addiction Biology*, 9, 119–126.

- Diamond, T., & Muller, R. T. (2004). The relationship between witnessing parental conflict during childhood and later psychological adjustment among university students: disentangling confounding risk factors. *Canadian Journal of Behavioural Science*, 36(4), 295–309.
- Douglas, A. (2002). *The mother of all pregnancy books: The ultimate guide to conception, birth and everything in between*. New York, NY: Wiley.
- Dube, S. R., Anda, R. F., Felitti, V. J., Edwards, V. J., & Williamson, D. F. (2002). Exposure to abuse, neglect, and household dysfunction among adults who witnessed intimate partner violence as children: implications for health and social services. *Violence and Victims*, 17, 3–17.
- Dukes, S. (1984). Phenomenological methodology in the human sciences. *Journal of Religion and Health*, 23, 197–203.
- Edleson, J. L. (1999). The overlap between child maltreatment and woman battering. *Violence Against Women*, 5(2), 134–154.
- Elbow, M. (1982). Children of violent marriages: The forgotten victims. *Social Casework*, 63, 465–471.
- FASD: What the foster care system should know. (2007). Washington, DC: National Organization on Fetal Alcohol Syndrome. Retrieved February 4, 2008, from <http://www.nofas.org>
- Ferriter, M., & Huband, N. (2003). Experiences of parents with a son or daughter suffering from schizophrenia. *Journal of Psychiatric and Mental Health Nursing*, 10, 552–560.
- Festinger, L. (1957). *A theory of cognitive dissonance*. Stanford, CA: Stanford University Press.
- Fetal Alcohol Syndrome: Diagnosis, epidemiology, prevention, and treatment. (1996). Washington, DC: National Academy Press. Retrieved August 3, 2007, from <http://www.come-over.to/FAS/IOPSummary.htm>
- Gardner, J. (2000). Living with a child with fetal alcohol syndrome. *The American Journal of Maternal/Child Nursing*, 25, 252–257.
- Gerberding, J. L., Cordero, J., & Floyd, R. L. (2004). Fetal alcohol syndrome: Guidelines for referral and diagnosis. Atlanta, GA: Centers for Disease Control. Retrieved, August 8, 2007, from [http://www.cdc.gov/ncbddd/fas/documents/FAS\\_guidelines\\_accessible.pdf](http://www.cdc.gov/ncbddd/fas/documents/FAS_guidelines_accessible.pdf)
- Giunta, C. T., & Streissguth, A. P. (1988). Patients with fetal alcohol syndrome and their caretakers. *Social Casework: The Journal of Contemporary Social Work*, 69, 453–459.
- Gosling, P., Denizeau, M., & Oberlé, D. (2006). Denial of responsibility: A new mode of dissonance reduction. *Journal of Personality and Social Psychology*, 90, 722–733.

- Granitsas, J. (2004). Experiences of adoptive parent of children with fetal alcohol syndrome. *Clinical Excellence for Nurse Practitioners*, 8, 22–28.
- Grant, T., Ernst, C., Pagalilavan, G., & Streissguth, A. (2003). Post-program follow-up effects of paraprofessional intervention with high-risk women who abused alcohol and drugs during pregnancy. *Journal of Community Psychology*, 31, 211–222.
- Grant, T., Huggins, J., Connor, P., Pedersen, J., Whitney, N., & Streissguth, A. (2004). A pilot community intervention for young women with FASD. *Community Mental Health Journal*, 40, 499–511.
- Hare-Mustin, R. T., & Broderick, P. C. (1979). The myth of motherhood: A study of attitudes toward motherhood. *Psychology of Women Quarterly*, 4, 114–128.
- Harms, Robert W., Johnson, Robert V., & Mary M. Murry, eds. (2004). *Mayo Clinic guide to healthy pregnancy*. New York, NY: Harper Collins.
- Hatters Friedman, S., Heneghan, A., & Rosenthal, M. (2007). Characteristics of women who deny or conceal pregnancy. *Psychosomatics*, 48, 117–122.
- Heatherton, T. F., Kozlowski, L. T., Frecker, R. C., Rickert, W. S., & Robinson, J. (1989). Measuring the heaviness of smoking using self-reported time to the first cigarette of the day and number of cigarettes smoked per day. *British Journal of Addiction*, 84, 791–800.
- Hill, R. (1972). *The strengths of Black families*. New York, NY: Emerson-Hall.
- Holden, G. W., & Ritchie, K. L. (1991). Linking extreme marital discord, child rearing and child behavior problems: Evidence from battered women. *Child Development*, 62, 311–327.
- Holtzworth-Munroe, A., Smutzler, N., & Sandin, B. (1997). A brief review of the research on husband violence. Part II: The psychological effects of husband violence on battered women and their children. *Aggression and Violent Behavior*, 2, 179–213.
- Hotham, E. D., Atkinson, E. R., & Gilbert, A. L. (2002). Focus groups with pregnant smokers: Barriers to cessation, attitudes to nicotine patch use and perceptions of cessation counseling by care providers. *Drug and Alcohol Review*, 21, 163–168.
- Howard, M. O., McMillen, J. C., Nower, L., Elze, D., Edmond, T., & Bricout, J. (2002). Denial in addiction: Toward an integrated stage and process model. *Journal of Psychoactive Drugs*, 34, 371–382.
- Iovine, V. (2007). *The girlfriends' guide to pregnancy*. New York, NY: Simon & Schuster.
- Ireland, T., & Widom, C. S. Childhood victimization and risk for alcohol and drug arrests. *International Journal of the Addictions*, 29(2), 235–274.
- Irwin, L. G., Johnson, J. L., & Bottorff, J. L. (2005). Mothers who smoke: Confessions and justifications. *Health Care for Women International*, 26, 577–590.



- Jackson, D., & Mannix, J. (2004). Giving voice to the burden of blame: A feminist study of mothers' experiences of mother blaming. *International Journal of Nursing Practices*, 10, 150–158.
- Jauniaux, E., & Greenough, A. (2007). Short and long term outcomes of smoking during pregnancy. *Early Human Development*, 83, 697–698.
- Jellinek, E. M., (1960). *The disease concept of alcoholism*. New Haven, CT: College and University Press.
- Jones, K. L., Smith, D. W., Ulleland, C. N., & Streissguth, A. P. (1973). Pattern of malformation in offspring of chronic alcoholic mothers. *Lancet*, 1, 1267–1271.
- Kerns, J., Don, A., Mateer, C., & Streissguth, A. (1997). Cognitive deficits in nonretarded adults with fetal alcohol syndrome. *Journal of Learning Disabilities*, 30, 685–693.
- Kessler, R. C., Crum, R. M., Warner, L. A., Nelson, C. B., Schulenberg, J., & Anthony, J. C. (1997). Lifetime co-occurrence of DSM-III-R alcohol abuse and dependence with other psychiatric disorders in the National Comorbidity Survey. *Archives of General Psychiatry*, 54, 313–321.
- Kilpatrick, D. G., Saunders, B. E., & Smith D. W. (2003). Research in brief: Youth victimization: Prevalence and implications (NCJ 194972). Washington, DC: National Institute of Justice, U.S. Department of Justice.
- Lincoln, Y. S., & Guba, E. G., (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Ludman, E. J., McBride, C. M., Nelson, J. C., Curry, S. J., Grothaus, L. C., Lando, H. A., & Pirie, P. L. (2000). Stress, depressive symptoms, and smoking cessation among pregnant women. *Health Psychology*, 19, 21–27.
- Lupton, C., Burd, L., & Hardwood, R. (2004). Cost of fetal alcohol spectrum disorders. *American Journal of Medical Genetics Part C (Semin. Med. Genet.)*, 127c, 42–50.
- March of Dimes. (1994). *Alcohol and pregnancy: Make the right choice*. White Plains, NY: Author.
- May, P. A., Gossage, J. P., Brooke, L. E., Snell, C. L., Marais, A. S., & Hendricks, L. S. (2005). Maternal risk factors for fetal alcohol syndrome in the Western Cape province of South Africa: A population-based study. *American Journal of Public Health*, 95, 1190–1199.
- May, P. A., Gossage, J. P., Marais, A. S., Hendricks, L. S., Snell, C. L., Tabachnick, B. Viljoen, D. L. (2008). Maternal risk factors for fetal alcohol syndrome and partial fetal alcohol syndrome in South Africa: a third study. *Alcoholism*, 32, 738–753.
- McBride, A. B. (1973). *The growth and development of mothers*. New York, NY: Harper & Row.
- Miller, B. A., Downs, W. R., Gondoli, D. M., & Keil, A. (1987). The role of childhood sexual abuse in the development of alcoholism in women. *Violence and Victims*. 2(3) 157–172.

- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage.
- Murkoff, H., Eisenberg, A., & Hathaway, S. (2002). *What to expect when you're expecting* (3rd ed.). New York, NY: Workman.
- National Institute on Alcohol Abuse and Alcoholism, U.S. Department of Health & Human Services. (1991). Alcohol alert. Report No. 13 PH 297. Bethesda, MD: National Institute on Alcohol Abuse and Alcoholism. Retrieved from <http://pubs.niaaa.nih.gov/publications/aa13.htm>
- O'Leary, C. M. (2004). Fetal alcohol syndrome: Diagnosis, epidemiology, and developmental outcomes. *Journal of Pediatrics and Child Health*, 40, 2–7.
- Oakley, A. (1992). *Social support and motherhood*. Oxford, England: Blackwell.
- Office of the Surgeon General. (2005, February 21). U.S. Surgeon General releases advisory on alcohol use in pregnancy. Press release. Retrieved from <http://www.surgeongeneral.gov/news/2005/02/sg02222005.html>
- Olson, H. C., Oti, R., Gelo, J., & Beck, S. (2009). "Family matters." Fetal alcohol spectrum disorders and the family. *Developmental Disabilities*, 15, 235–249.
- Padgett, D. K. (2008). *Qualitative methods in social work research* (2nd ed.). Los Angeles, CA: Sage.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods*. Newbury Park, CA: Sage.
- Polkinghorne, D. E. (1989). Phenomenological research methods. In R.S. Valle & S. Halling (Eds.), *Existential-phenomenological perspectives in psychology* (pp.41–60). New York, NY: Plenum.
- Popova, S., Stade, B., Bekmuradov, D., Lange, S., & Rehm, J. (2011). What do we know about the economic impact of fetal alcohol spectrum disorder? A systematic literature review. *Alcohol and Alcoholism*, 46, 490–497.
- Rasmussen, C., Kully-Martens, K., Denys, K., Badry, D., Henneveld, D., Wyper, K., & Grant, T. (2012). 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 Mental Health*, 48, 12–21.
- Rich, A. (1986). *Of woman born: Motherhood as experience and institution*. New York, NY: Norton.
- Rinn, W., Desai, N., Rosenblatt, H., & Gastfriend, D. (2002). Addiction denial and cognitive dysfunction: a preliminary investigation. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 14, 52–57.
- Rotkirch, A., & Janhunen, K. (2009). Maternal guilt. *Evolutionary Psychology*, 8, 90–106.

- Schydlower, M., Fuller, P., Heyman, R., Jacobs, E., Pruitt, A., Sutton, J., & Nackashi, J. (1993). Fetal alcohol syndrome and fetal alcohol effects. *Pediatrics*, 91, 1004–1006.
- Seagram, S., & Daniluk, J.C. (2002). “It goes with the territory”: The meaning and experience of maternal guilt for mothers of preadolescent children. *Women & Therapy*, 25, 61–88.
- Secord, S. (2000). *How women protect their children from environmental tobacco smoke: A smouldering issues*. (Unpublished master’s thesis). University of British Columbia, Vancouver.
- Stoddard Dare, P. A., & DeRigne, L. A. (2010). Denial in alcohol and other drug use disorders: A critique of theory. *Alcohol Research and Theory*, 18, 181–193.
- Streissguth, A. P., Barr, H., Kogan, J., & Bookstein, F. (1997). Primary and secondary disabilities in fetal alcohol syndrome. In A. P. Streissguth & J. Kanter (Eds.), *The challenge of fetal alcohol syndrome: Overcoming secondary disabilities* (pp. 25–39). Seattle: University of Washington Press.
- Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O’Malley, K., & Young, J. K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental and Behavioral Pediatrics*, 25, 228–238.
- U.S. Surgeon General Advisory. (1981). Surgeon General’s advisory on alcohol and pregnancy. *FDA Drug Bulletin*, 11(2), 9–10.
- Van der Zee, B., de Beaufort, I., Temel, S., de Wert, G., Denktas, S., & Steegers, E. (2011). Preconception care: An essential prevention strategy to improve children’s and women’s health. *Journal of Public Health Policy*, 32, 367–379.
- Viljoen, D., Croxford, J., Gossage, J. P., Kodituwakku, P. W., & May, P. A. (2002). Characteristics of mothers of children with fetal alcohol syndrome in the Western Cape province of South Africa: A case control study. *Journal of Studies on Alcohol*, 63, 6–17.
- Waldrop, A. E., Santa Ana, E. J., Saladin, M., McRae, A. L., & Brady, K. T. (2007). Differences in early onset alcohol use and heavy drinking among persons with childhood & adulthood trauma. *The American Journal on Addictions*, 16(6) 439–442.
- Weschler, Toni. (2006). *Taking charge of your fertility, 10th anniversary edition: The definitive guide to natural birth control, pregnancy achievement and reproductive health*. New York, NY: Harper Collins.
- Widom, C. S. (2000). Childhood victimization and the derailment of girls and women to the criminal justice system. In B. E. Richie, K. Tsenin, & C. S. Widom (Eds.), *Research on women and girls in the justice system: Plenary papers of the 1999 conference on criminal justice research and evaluation—Enhancing policy and practice through research* (Vol. 3, NIJ publication no. 180973, pp. 27–36). Washington, DC: U.S. Department of Justice.

- Widom, C. S., & Hiller-Sturmhofel, S. (2001). Alcohol abuse as a risk factor for and consequence of child abuse. *Alcohol Research and Health*, 25(1), 52-57.
- Widom, C. S., Ireland, T., & Glynn, P. J. (1995). Alcohol abuse in abuse and neglected children followed-up: Are they at increased risk? *Journal of Studies on Alcohol*, 56(2), 207-217.
- Wilsnack, S. C., Vogeltanz, N. D., Klassen, A. D., & Harris, T. R. (1997). Childhood sexual abuse and women's substance abuse: National survey findings. *Journal of Studies on Alcohol*, 58(3), 264-271.
- Zimet, D., & Jacob, T. (2001). Influences of marital conflict on child adjustment: Review of theory and research. *Clinical Child and Family Psychology Review*, 4, 317-333.