

# Fetal Alcohol Spectrum Disorder

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by

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## CHAPTER ONE

### INTRODUCTION

What is the harm of one drink? Is not one glass of red wine healthy for you? There is a lot of confusing information present about drinking during pregnancy. One pediatrician might say it is OK to drink during the end of one's third trimester, while another will say drinking at all during pregnancy presents an unacceptable risk to one's fetus. It is important to know the facts about prenatal drinking. Fetal Alcohol Spectrum Disorder (FASD) is the term given to a child who has been affected by exposure to prenatal alcohol. Drinking during pregnancy can lead to several physical, neurological and behavioral effects.

The physical characteristics for children with FASD help in diagnosis. Some of the effects can be seen in lower height and weight (Streissguth, 1997). Alcohol during pregnancy also affects the motor skills for children. There are also defining facial characteristics that are caused by exposure to alcohol in the womb (Streissguth, 1997).

Neurological effects have also played an important role in diagnosing children with FASD. With recent technology the neurological effects have been studied and researched in more depth. Images allow for researchers and scientists to get a closer look at the physical and chemical changes in the brain for a child with fetal alcohol spectrum disorder. Exposure to prenatal alcohol changes the structure of the brain (Autti-Rämö, 2002; Archibald, Fennema-Notestine, Gamst, Riley, Mattson and Jernigan 2001; Spadoni, McGee, Fryer and Riley, 2007; Devinsky & D'Esposito, 2004; Riley, Mattson, Sowell, Jernigan, Sobel and Jones, 1995; Sowell, Thompson, Mattson, Tessner, Jernigan and Riley, 2002; Lebel, Rasmussen, Wyper, Walker,

Andrew, Yager, 2008) but also the function of the parts of the brain as well (Fagerlund, Heikkinen, Autti-Ramo, Korkman, Timonen and Kuusi, 2006; Kodituwakku, Kalberg and May 2001).

Behavioral effects, like physical and neurological effects, affect the development of children with FASD. The behavioral effects of prenatal alcohol exposure on children can be seen during infancy, throughout childhood, and into their adult lives. During infancy, babies may have trouble with parent-child attachment and have irritable temperaments (Coles, Brown, Smith, Platzman, Erikson and Falek, 1991). During childhood, children with FASD have a difficult time with schooling and with interacting socially with their peers (D'Onofrio, Van Hulle, Waldman, Rodgers, Rathouz and Lahey, 2007, Kelly and Streissguth, 2000, Famy, Streissguth and Unis, 1998, Hellemans, Verma, Yoon, Yu and Weinberg, 2008, Jirikowic, Kartin and Olson, 2008, Streissguth, 2007, Green, Mihic, Nikkel, Stade, Ramussen and Munoz, 2009).

As demonstrated above, there are many detrimental effects caused by drinking during pregnancy, but interventions have been seen to help (Bertrand, 2009). Working with children with FASD and their families takes a lot of time, patience, support and commitment. Intervention programs have been established to help minimize the behavioral effects of prenatal alcohol exposure. Educational, psychosocial, pharmacological, nutritional, play therapy and familial interventions have all been seen to help improve the lives for children with FASD (Bertrand 2009, Chandrasena, Mukherjee and Turk 2009, Liles and Packman 2009).

Family interventions, in particular, are promising because they create the best living environment for children with FASD and their families. The family dynamics and marital relationships have been shown to become more stressful and challenging when there is a child with FASD (Bertrand 2009). Interventions like Families Moving Forward, Parent Child

Interaction and Parent-Assisted Child Friendship Training are three examples of family interventions that can change the lives for the better for children with FASD and their families (Bertrand 2009, Chadnrasena et. al., 2009).

Providing a pamphlet of family intervention to families with children with FASD will bring awareness of helpful and beneficial programs that will help their lives. Within the pamphlet there will be a description of the goals, duration and outcomes of each family intervention program. There will also be contact information for parents if they want to pursue an intervention program they found to be interesting and would work for their family. The pamphlet can be distributed to parents in health clinics, doctor offices, hospitals, lectures and workshops on FASD and/or at adoption services.

Given the numerous implications that FASD can have for development and family functioning, and given the available interventions that can offset some of these negative outcomes, the pamphlet of family interventions for families with children with FASD can be used to inform parents about the help that is available. This pamphlet of family interventions provides parents the knowledge of intervention programs that have been show to help improve the lives for their children and family. It is important to recognize that this pamphlet is only the starting point for parents. In this pamphlet there is only a brief explanation of interventions. Parents need to use the contact information to learn more about these programs and to see which will work for their family the best.

## CHAPTER TWO

### LITERATURE REVIEW

Fetal alcohol spectrum disorder (FASD) is a term used to describe the effects of prenatal exposure to alcohol. It is a spectrum because the effects can fall on a wide range of severity, ranging from the severe deficits associated with “fetal alcohol syndrome” to the mild afflictions associated with “fetal alcohol effects.” FAS is caused by drinking high amounts of volume of alcohol during pregnancy. Some of the effects of FAS, according to the American Pregnancy Association (2007), are “mental retardation, malformations of the skeletal systems and major organ systems (specifically the heart and the brain), growth deficiencies, central nervous system problems, poor motor skills, mortality, and problems with learning, memory, social interaction, attention span, problem solving, speech and/or hearing” (para. 3). FAE is due to moderate drinking during pregnancy. FAE is broken down into two categories; Alcohol-Related Neurodevelopmental Disorder (ARND) and Alcohol-Related Birth Defects (ARBD). According to the American Pregnancy Association “ARND describes the mental and behavioral impairments such as learning disabilities, poor school performance, poor impulse control, and problems with memory, attention and/or judgment. ARBD describes the malformation of the skeletal system and major organ systems such as defects of the heart, kidneys, bones and/or auditory system” (2007). Although FAE is not as severe as FAS, both lead to lifelong effects. According to American Academy of Pediatrics (2000), ethanol, also known as alcohol, is not only one of the most common substances that negatively influences brain development, but it is

also the most preventable cause of birth defects, mental retardation and neurodevelopment disorders. All effects of prenatal exposure to alcohol are unnecessary and easily preventable.

Although there have been concerted efforts to minimize FASD, the fact remains that 10 out of 1,000 children are born with fetal alcohol spectrum disorders (Ramadoss, 2009). In the United States, 40,000 babies are born each year with FASD. Not only is this unfortunate for these individuals and their families, but providing resources for children afflicted with FASD costs around \$1.4 million per child, for a total of about \$6 billion a year (Ramadoss, 2009). Although these statistics are presented to the general public and prevention measures are beginning to be addressed to pregnant women, it is also important to educate parents and those working with children as to what FASD is and interventions that are available to help the development of children with FASD.

Attention to the effects of prenatal exposure to alcohol is nothing new. Jones and Smith (1973, as cited in Handmaker, Rayburn, Meng, Bell, Rayburn and Rappaport, 2006), published one of the first modern clinical reports describing the offspring of alcohol-abusing women. The reports indicated that the children had several brain and behavioral issues. Jones and Smith (1973) offered a more formal definition of children with fetal alcohol syndrome by highlighting a triad of characteristics: (1) evidence of central nervous system dysfunction, (2) craniofacial anomalies and (3) pre- and/or post-natal growth deficiencies. Since then numerous studies have been conducted to gain further knowledge about the effects of ethanol during pregnancy.

### **Effects of Prenatal Alcohol Exposure**

Heavy exposure to alcohol on the fetus leads to detrimental effects in several areas of a child's development, including physical, neurological, and socioemotional. Consideration of these negative outcomes can inform the development of effective intervention programs.

## **Visible Physical Effects**

Children exposed to prenatal alcohol are not only in many physical ways. For example, although gross motor abilities for children with FASD are typically similar to those of children without this condition, fine motor skills may actually lag behind the more advanced abilities of children with typical development (Streissguth, 2007). In addition, children with FASD also have growth deficiencies, and tend to be of below average height and/or weight (Streissguth, 2007). Finally, children with FAS show characteristic facial features which include: Short palpebral fissures (the width of the eye slit), flat midface, short nose (in the young child), indistinct philtrum (the two ridges that run between the nose and the lips, and a thick upper lip (see Appendix A for an image of a children with FAS) (Streissguth, 2007).

## **Neurological Effects**

Neurological effects due to ethanol exposure are mainly found within the brain of the child. Damages to the developing brain of the fetus lead to many physical and behavioral issues throughout life. Comparing children with FAS to typically developing children has helped researchers to determine how alcohol affects the brain's abilities. A large body of research has discovered that children with FAS may have impairments in balancing, reaction time, two-handed activities, memory, attention, thinking, and/or planning. Each of these outcomes is likely due to the influence of alcohol on brain development and functioning.

Recent technologies such as, magnetic resonance imaging (MRI), functional MRI (fMRI), diffusion tensor imaging (DTI), magnetic resonance spectroscopy (MRS), positron emission tomography (PET) and single photon emission computed tomography (SPECT), make it possible to look at structural and functional changes in the brain due to parental exposure to ethanol. Use of these tools has revealed that several areas of the brain are affected, such as the cerebellum,



corpus callosum, parietal lobe and white and grey matter in the brain. In addition, the functioning of the brain is affected, leading to problems with learning, mental cognition, reaction time and other difficulties.

**Structural effects.** Areas of the cerebellum and corpus callosum are especially vulnerable to prenatal alcohol exposure. Prenatal alcohol exposure results in reduced surface area (Autti-Ramo, 2002) and volume of the cerebellum (Archibald et. al., 2001). The cerebellum is related to motor functions such as posture, balance and coordination (Spadoni, et. al., 2007). Other research also has led to the understanding that the cerebellum plays a role in attention and learning (Spadoni et al., 2007). The corpus callosum is the area of the brain that connects the left and right hemisphere and facilitates communication between the two. The corpus callosum is also a region of the brain important for bimanual motor tasks, sustained attention, vision, and spatial and visual working memory (Devinsky & D'Esposito, 2004). Individuals with FASD show various changes in the shape of the corpus callosum (Riley et al., 1995). As a result, conducting a shaped-based analysis of the corpus callosum can be helpful for diagnosis of FASD. Seeing the affected area of the brain and the damages done to the cerebellum and corpus callosum due to prenatal alcohol exposure explain why those diagnosed with FASD are more likely to show problems with balance, bimanual coordination, attention and verbal learning abilities (Spadoni et al., 2007).

In addition to the cerebellum and corpus callosum, the parietal lobe appears to develop differently due to prenatal exposure to alcohol. Due to prenatal alcohol exposure increased grey matter and decreased white matter affect the parietal lobe (Sowell et al., 2002). The parietal lobe is the area in the brain that plays a crucial role in senses and understanding numbers. Grey matter passes what the body picks up through its senses to the central nervous system to create a

response. White matter is tissues that are used to send messages between different areas of grey matter. Without grey and white matter, communication between one's senses and the brain would lead to the body not having a response (Sowell et al., 2002). For example, when one touches something hot his or her reaction is to pull away. Without proper amounts of functioning grey and white matter, one would not pull away or not pull away fast enough to avoid getting a burn.

Lebel et. al., (2008) used brain images to explore differences in white and deep gray matter in the parietal lobe in children with FASD. Results showed that there is a change in both white and gray matter volumes and total brain volume for the children in the FASD group (Lebel et. al., 2008). These findings explain why individuals with FASD report slower reaction times (Spadoni et al., 2007).

**Functional effects.** Fagerlund et. al., (2006) examined whether and how brain metabolism is affected by prenatal alcohol exposure. Study participants included 10 adolescents with varying levels of FASD adolescents In addition, a control group consisting of 10 healthy children with similar age, sex, head circumference, handedness and body mass measures participated. MRI's were conducted on all participants. Compared to adolescents in the control group, FASD adolescents showed lower metabolite ratios in the parietal and frontal cortices, frontal white matter, corpus callosum, thalamus, and cerebella dentate nucleus Results also indicated that these changes in brain metabolism due to prenatal alcohol exposure were long-term or permanent (Fagerlund et. al., 2006). The results of lower metabolite ratios correspond with the findings that individuals with FASD have difficulties with problem solving, abstract thinking, planning and flexibility of thought process (Kodituwakku et al., 2001).

## **Behavioral Effects**

Neurological and other physical deficits are not the only problem with which children with FASD are faced; there are several behavioral effects of prenatal exposure to alcohol. Many of these behavioral effects begin in infancy and are carried into childhood. Children with FASD are challenged by disruptive behaviors, ineffective social interaction skills, and poorly developed cognitive abilities throughout their childhood.

**Infancy.** Changes in behavior due to prenatal alcohol exposure can be seen early through newborn attachments. Typically, attachment relationships are measured using the strange situation procedure in which infants are exposed to various levels of separation from primary caretakers. Coles et al., (1991) used this paradigm to examine the relationship between prenatal alcohol consumption and mother-infant attachment. The participants in the study were infants born to middle-class women who were social drinkers. A high number of infants displayed a disorganized style of attachment, characterized by conflicting and confused behavior (Coles et al., 1991). Furthermore, infants who were exposed to prenatal alcohol show high levels of irritability (Coles et al., 1991). A temperament of irritability in infancy is an indicator of future difficult temperament and behavioral problems in the child (Kelly et. al., 2000). The uneasy interactions between the infant and the primary caretaker lay the foundation for future social interaction problems.

**Childhood.** Prenatal alcohol exposure has been associated with a host of disruptive behavioral, emotional, and adaptive concerns during childhood. D’Onofrio et al. (2007) investigated conduct problems of children exposed to prenatal alcohol by using maternal reports of conduct problems and standardized assessments. They report that prenatal alcohol exposure is positively correlated with conduct problems for children between the ages of 4 and 11 years. Such problematic behaviors may intensify as children get older. Kelly and colleagues (2000)

report, people with FAS have a higher probability of delinquency and/or criminality than individuals without FAS.

In addition to conduct problems, children with FASD struggle with emotional difficulties. Famy et al., (1998) used clinical interviews of 25 individuals with FASD to determine some of the emotional effects of prenatal alcohol exposure. Famy and colleagues found that individuals with FASD have higher rates of depression and anxiety disorders compared to control groups (Famy et al., 1998; Hellemas et al., 2009). Individuals with FASD report higher suicide rates than those not afflicted by FASD (Famy et al., 1998). There is no clear evidence why suicide is higher but, Mrazek (1994, as cited in Famy, 1998) suggests that the awkward social behavior of children with FASD can lead to a lack of social support, which may increase suicide rates.

There is empirical support for the idea that social interaction is an important skill with which children with FASD need help. Jirikowic and colleagues (2008) compared caregiver-reports of adaptive and maladaptive behaviors between children with FASD and children with typical development. They noticed that children with FASD had difficulties using social conventions and rules of engaging with other people; for example they struggled with taking turns, asking for food to be passed and playing games by the rules. Children with FASD had even more difficulties in comprehending and effectively using language during daily tasks that become even more important with age (e.g, following directions and using verbal and written communication skills) (Jirikowic et al., 2008). It is important for caretakers of children with FASD to realize that there are communication barriers for children with FASD when they are interacting with others. Being aware of these communication barriers will allow for caretakers to constructively help children with FASD to maintain and create a healthy social development.

Children with FASD often have difficulties following directions and lack persistence (Streissguth, 2007). This may lead to problems learning daily life skills, as well as later workplace performance (Kelly, 2000). Jirikowic and her colleagues (2008) created a study to compare the day-to-day skills of a group of children with FASD to children with typical development. Caregivers for each participant reported both adaptive and maladaptive behaviors using the Scales of Independent Behavior-Revised. Results indicated that the mean scores on three of the four adaptive clusters (Social Interaction and Communication, Personal Living, and Community Living) were significantly lower for the group with FASD than for typically developing children (Jirikowic et al., 2008). On average, the children with FASD performed 1 to 2 years below the control group of peers. The only area that was similar was motor skills, domestic skills (e.g., clears table, puts belongings in proper place), and home/community orientation (e.g., looks at a clock when it is "time" to do something, locates day and month on a calendar).. Thus, Jirikowic and her colleagues showed that children with FASD need more support and supervision to perform daily activities and manage challenging behaviors than their age level peers with typical development. Children with FASD showed lower age-appropriate skills in dressing, meal time and toilet domains (Jirikowic et al., 2008). However, children with FASD showed strength in personal self-care and the "domestic skills" of taking care of the home environment through activities like household chores (Jirikowic et al., 2008). The strength of the report of personal living skills remains strong into adolescence and adulthood for individuals with FASD (Streissguth, 2007). However, with earlier intervention and help during the younger years, children with FASD develop the self-help skills that they need to live their own life.

Perhaps contributing to the problematic social skills and life skills characteristic of children with FASD are deficits in such cognitive abilities as problem solving, attention,

planning and spatial working memory (Green et al., 2009). Ninety-seven participants, aged 8-15 years and diagnosed with fetal alcohol syndrome, partial FAS (pFAS) or alcohol-related neurodevelopment disorder (ARND), along with 92 control group participants of the same sex and age, were tested on 4 tasks from the Cambridge Neuropsychological Tests Automated Battery (CANTAB<sup>®</sup>). This series of tests was used to measure participants' problem solving skills, spatial working memory, decision time and movement time. Results showed that children with FASD exhibited: 1) longer reaction/decision time latencies; 2) a decrease in the number of problems solved in the minimum number of moves, an increase in the mean number of moves and a decrease in the initial thinking time; 3) increased errors and poorer use of strategy and 4) little or no difference in performance across the diagnostic subgroups (FAS, pFAS, ARND). This shows that FASD does lead to problems with attention, planning, strategy and use of working memory (Green et al., 2009). Green and his colleagues also concluded that it did not matter what subgroup the children with FASD were in, they all showed significant lower scores on the tests, indicating that any amount prenatal alcohol exposure affects even the basic cognitive processes that underlie more complex behavioral abilities.

### **Interventions**

The effects of FASD can be very overwhelming; however there is hope for children with FASD and their caregivers. Several interventions have been studied to determine how children with FASD can be best helped. Interventions to help children with FASD function within society are important because it will allow for FASD individuals to be highly functioning, independent individuals. Educational, psychosocial, family, pharmacological and nutritional interventions have all been shown to result in positive outcomes for children with FASD.

**Educational Intervention.** Education for children with FASD should focus on structure and routine in order to create a more predictable learning environment for the children (Chandrasena et al., 2008). Visual learning methods “such as color coding, separating areas for specific activities and clear labeling of tasks using schedules and calendars” are useful to children with FASD (Chandrasena et al., 2008 p. 165, ). While working with children with FASD in an educational setting, it is also essential to break a task into smaller components with a beginning, middle and end so that children with FASD can focus on one task at a time. Although not subject to formal empirical tests of their effectiveness, these educational recommendations are expected to provide “predictability, clearer understanding, and an optimal environment for children to learn” (Chandrasena et al., 2008 p. 165).

One area in which empirical work on educational strategies has been undertaken is in the domain of mathematical thinking. Problems in mathematical functioning have been reported consistently among individuals with FASD (Bertrand, 2009). Georgia-Sociocognitive Habilitation is an intervention aimed to improve the behavioral and mathematical functioning of children with FASD using the math interactive learning experience (MILE) program at Marcus Institute. Children in the program went through intensive short-term individual instruction by the research team, and caregivers and teachers of the children were given training so that they could continue the care in other settings. The main goal of this 6 week intervention was to provide children with a consistent method of instruction of mathematical concepts across therapeutic, home, and school environments (Bertrand, 2009). Caregivers were given instructions for supporting mathematics at home, and children were given weekly home assignments to complement the tutoring the child received. Participants were tested before the intervention, and within 4 weeks of completing some of the tutoring. Results showed that whereas 58.6% of the

children in the intervention group showed improvement in mathematics, only 23.1% of the control group, who did not receive 6 weeks of tutoring or instructions for caregivers, improved their scores (Bertrand, 2009). These findings suggest that interventions that include the caregivers are crucial for helping children with FASD to excel in school and increase their academic achievement levels.

**Psychosocial Intervention.** Children with FASD need extra help and guidance with developing social relationships. Child Friendship Training (CFT) is a very common intervention for children with FASD. The goal of this intervention is to promote healthy social interactions and development. O’Conner et al., (2006, as cited in Chandrasena et al., 2009) suggests that through modeling, rehearsal and performance feedback, CFT provides children with FASD with instructions on how to behave socially. This hypothesis was supported by clear evidence of improvement for children who engaged in CFT, and the improvements were still present three months later (O’Conner et al., 2006, as cited in Chandrasena et al., 2009)

Project Bruin Buddies is another social skills training program that uses CFT to improve peer friendships for children with fetal alcohol spectrum disorders. Conducted by researchers at the University of California at Los Angeles, this study was created to look at the effects of parent-assisted children’s friendship training (CFT) on the social skills for children, ages 6-12 years, with FASD. “Skills taught included: (a) social network formation (b) informational interchange with peers leading to a common-ground activity, (c) entry into a group of children already in play, (d) in-home play dates, and (e) conflict avoidance and negotiation. Skills were taught didactically through instruction on simple rules of social behavior; modeling, rehearsal, and performance feedback during treatment sessions; rehearsal at home; homework assignments; and coaching by parents during play between children” (Bertrand, 2009, p.990). Children in the



CFT group showed significant improvement in their knowledge of appropriate social behavior, increase of actual social skills and a decrease in problem behaviors (Bertrand, 2009). This change in social behavior was still present and even increased after a 3 month follow up, indicating that a more permanent growth in social development was possible and that children were still benefiting from their treatment.

**Pharmacological Intervention.** . Although there is no specific drug treatment for children with FASD, many clinicians have started to treat children with FASD as they would children with ADHD (Chandrasena et al., 2008). O'Malley, Koplin and Dohner (2002, as cited in Chandrasena et al., 2008), conducted a study to compare the usage of dextroamphetamine versus methylphenidate (drugs used for ADHD patients). O'Malley and his colleagues found that 79% of the FASD individuals in the study had a positive clinical response to dextroamphetamine, compared to only 23% of the individuals using methylphenidate. Although this study demonstrates that some drug use may be beneficial, the results need to be interpreted with some caution due to concerns over a small sample size, the length of treatment and an unclear definition of positive response. Clearly, additional research in this area would be helpful.

**Nutritional Interventions.** . Choline is an essential nutrient that can be found in foods like beef, liver, egg yolks and soy. Choline “forms part of the neurotransmitter acetylcholine which is associated with learning and memory and for repairing the brain” (Chandrasena et al., 2008 p. 166). Therefore, providing greater availability of choline into the diet of those afflicted with FASD may lead to improved learning, memory and cell function. Although human studies have not yet been conducted, Thomas et al. (2007, as cited in Chandrasena et al. 2008), found that providing choline supplements to rats with FASD reduces learning deficits and hyperactivity. The behavioral benefits lasted long term due to improvements in brain structure,

connectivity and functioning (Chandrasena et al., 2008). Although these data seem promising, thus far choline has only been tested on animals and several factors need to be further analyzed before human testing is conducted. Choline still however, remains a hopeful treatment for FASD.

**Play Therapy.** Play therapy has much support as a means for intervention with children with FASD. Landreth (2002 as cited in Liles and Packman 2009) says “play is the child’s symbolic language of self-expression and can reveal (a) what the child has experienced; (b) reactions to what was experienced; (c) feelings about what was experienced; (d) what the child wishes, wants, or needs; and (e) the child’s perception of self” (p. 199). Although no current studies have specifically looked at the use of play therapy for children with FASD, there have been several research findings for children who exhibit many of the same difficulties with attention and hyperactivity as children with FASD. The main objectives, as with any play therapy, would be: “1. Develop a more positive self-concept 2. Assume a greater self-responsibility 3. Become more self-directing 4. become more self-accepting 4. become more self-accepting 5. Become more self-reliant 6. engage in self-determined decision making 7. Experience a feeling of control 8. Become sensitive to the process of coping 9. Develop an internal source of evaluation 10. Become more trustworthy of himself” (Liles & Packman, 2009, p.202). Play therapy for children with FASD would be identical to typical play therapy sessions except “limit setting will need to more directive and repetitive” (Liles & Packman, 2009, p. 202).

Liles and Packman believe that play therapy creates learning opportunities for children with FASD. Play therapy would be helpful with children with FASD to understand cause and effect, and connecting consequences to their behavior choices. Those working with children with FASD need to be very specific, directive and repetitive when setting limits, especially when time is involved, for children with FASD.

Group play therapy is another intervention option that may be very beneficial in promoting a healthy social development for children with FASD. Modeling appropriate social interactions between peers during group play therapy will help children with FASD to learn skills in communication and making friends (Liles & Packman, 2009). Group therapy may also give children with FASD the chance to see repeated practice of appropriate social skills. During these play therapy sessions it is important for the children to receive positive feedback and encouragement in order to promote a more positive self-concept (Liles & Packman, 2009). Positive relations between child and counselor will also help children as they encounter emotional, academic and social struggles. Although play therapy, according to Liles and Packman, is a great intervention program for children with FASD, not enough research and studies have been conducted to verify its effectiveness. More actual studies need to be done using play therapy as an intervention method for children with FASD to help in their social development.

**Family Intervention.** There are a variety of interventions that target the family as a context for therapeutic efforts. Parent-Child Interaction intervention, for example, aims to reduce behavior problems among children with fetal alcohol spectrum disorders by providing both the parent and the child with a live, coached opportunity to practice parenting skills. (University of Oklahoma Health Sciences Center) . In contrast, Parenting Support and Management is a parent-only program. Direct comparisons of these interventions for children with FASD that were aimed to reduce a.) behavior problems among children with FASD and b.) parental stress among their caregivers (Bertrand, 2009). One group used Parent-Child Interaction Therapy, which provided both the parent and the child with a live, coached practice of parenting skills. The second group used Parental stress and negativity paired with the difficult behavioral problems for children with

FASD have a detrimental effect on the development of the child (Bertrand, 2009). This is why it is important to provide parents and children with FASD an intervention that aims to reduce the behavioral issues of the child and stress and negativity of the parents.

Parent-Child Interaction Therapy (PCIT) consists of parental training to effect a behavior change in the child. The goal of PCIT is to enhance parent-child relationships, increase appropriate social skills, reduce inappropriate behavior, and input a positive discipline program (Bertrand, 2009). Although it is a short program, lasting only about 12-16 sessions, decrease in conduct problems and improvements in child's self esteem are some of the results of this program.

In the intervention for children with FASD, families were placed into the parent-child interaction therapy or Parenting Support and Management. Each treatment program lasted for 14 weeks, with a weekly session each lasting 90 minutes. There was no significant difference between the programs. In each group, children's behavior problems decreased for children and there was improvement for parent distress over time (Bertrand, 2009). Although there were no significant results when comparing the groups, the results do indicate that any form of parental-child intervention will help improve the behavioral issues for children with FASD.

Another intervention that focuses on the families of children with FASD is Families Moving Forward. This intervention is a behavioral consultation intervention to improve outcomes for families raising children with fetal alcohol spectrum disorders (University of Washington). The overall goal of this study was to evaluate an intervention designed to improve caregiver self-efficacy, meet family needs, and reduce child problem behaviors (Bertrand, 2009). Fifty-two children with FASD and their families were split into the intervention group or the control group. Families moving forward (FMF) is a 9-11 month intervention program with at

least 16 bi-weekly 90 minutes sessions. FMF measured (a) parenting attitudes of efficacy and child-related stress; (b) stress levels and (c) caregiver ratings of child disruptive behavior immediately after intervention (Olson, Brooks, Davis, & Astley, 2004 as cited in Bertrand, 2009).

Results indicated that FMF intervention showed a significantly improved sense of parenting self-efficacy immediately after the intervention sessions; however, there was no difference in stress level for parents between the two groups (Olson, Brooks, Davis, & Astley, 2004 as cited in Bertrand, 2009). The FMF group also reported that their family needs were met more often and were very satisfied with the intervention (Olson, Brooks, Davis, & Astley, 2004 as cited in Bertrand, 2009). Disruptive child behavior was reported less for the FMF group (Olson, Brooks, Davis, & Astley, 2004 as cited in Bertrand, 2009). Family intervention provides support for parents raising children with FAS which leads to improvement in their child's behavior.

Intervention programs have shown significant improvement for not only the lives of children with FASD but also their caretakers. It is important to make sure that the parents, educators and caretakers of children with FASD are educated and equipped with knowledge about FASD. Once they have fully understood FASD then intervention programs and techniques can be taught. The adults in a child with FASD life need to all work together to make sure everyone is following the same guidelines and teaching methods.

In sum, FASD affects the lives of many children and families. Knowing all the risks of prenatal alcohol exposure is the key to helping decrease the number of children who are diagnosed with FASD. The effects of FASD can be devastating and overwhelming. However, with the research and knowledge gained throughout the years about FASD, interventions have

become more readily available and productive. Parents of children with FASD should be encouraged to seek out these interventions to help foster the development of their child. To aid parents in this process, the goal of the current project was to create a pamphlet of helpful family interventions for children with FASD. By focusing on family interventions, children with FASD and their families will work together to promote the best possible developmental environment for children with FASD.

## CHAPTER THREE

### METHOD

My goal in conducting this project was to assist families with children with fetal alcohol spectrum disorder by providing them with information about family intervention programs. I conducted my investigation into the variety of family interventions available for children with fetal alcohol syndrome and their families by searching for scholarly publications using PsycINFO. Based on my review of the existing literature, I selected three family interventions to profile in a pamphlet. I highlighted these particular interventions because they were shown to have the most improvements for the lives of children with fetal alcohol syndrome and their families. I used a brochure template from Word 2007 to create the pamphlet. Pictures came from my own collection of my aunt and uncle and their adopted children with fetal alcohol syndrome.

## CHAPTER FOUR

### RESULTS

The pamphlet consists of a single double sided page, with each side divided into three sections. The first page of the pamphlet provides the title, “Interventions for Families With Children With Fetal Alcohol Syndrome” and a tagline designed to attract a reader to the resource (“Available intervention programs for you and your loved ones”). The text on the first inside flap, when the title page is opened, describes why family interventions are an important therapeutic focus. The inside three sections of the pamphlet describe the three family interventions profiled in this resource. The far left section is on “Families Moving Forward”, the middle is on “Parent Child Interaction”, the last section on the far right, is on “Parent-Assisted Child Friendship Training”. A description of the goals, duration and typical results of each of the interventions is provided. The last part of each section gives a website for further contact information if parents are interested in a particular program. The very back of the pamphlet provides information on who made the pamphlet and states that it was created as part of a senior project at California Polytechnic State University San Luis Obispo. See Appendix B for the pamphlet itself.



## CHAPTER FIVE

### DISCUSSION

My goal in this project was to provide a resource for families with children with Fetal Alcohol Spectrum Disorder (FASD). Fetal Alcohol Spectrum Disorder is 100% preventable. Understanding the effects of drinking during pregnancy will help more mothers to avoid alcohol consumption during their pregnancy. However, as long as there is alcohol available, many mothers will choose to drink. Drinking during pregnancy will leave children to live with physical, neurological and behavioral effects. Lower height and weight, and the distinct facial features of a flat midface, short nose, and thick upper lip are some physical effects that are not easily reversible (Streissguth, 2007). However the neurological effects, the reduction of size of the cerebellum (Archibald et. al., 2001) and corpus callosum (Devinsky & D'Esposito, 2004), lower metabolite ratios (Fagerlund et. al., 2006) and loss of grey matter (Sowell et al., 2002) are also not easily changeable. However, behavioral effects such as conduct problems (D'Onofrio et al., 2007), difficulties following directions and lack persistence (Streissguth, 2007), hard time comprehending and effectively using language, using social conventions and rules of engaging with other people (Jirikowic et. al., 2008) caused by damages in the brain can be helped through interventions.

Many interventions, educational, psychosocial, nutritional and pharmacological are aimed to guide children with FASD to interact more effectively within society. In addition, families of children with FASD need help guiding their child's development. Family interventions are important for children with FASD to live in an environment that is stimulating and

developmentally appropriate for them. Family interventions are also necessary for families to gain the skills and knowledge necessary in order to best raise their child with FASD. This is why a pamphlet dedicated to family interventions for children with FASD and their families would be beneficial. Families Moving Forward, Parent Child Interaction and Parent-Assisted Child Friendship Training are all great intervention programs that work with the entire family to improve the lives of children with FASD and their families as well as improve family dynamics.

The environment a child grows up in is crucial to their development. For children with FASD this environment plays a major role in how the behavioral effects of prenatal alcohol come into play. My emphasis on parent programs reflects how children with FASD need a structured, supportive and nurturing environment in order to best overcome those behavioral effects. Although this pamphlet provides families with three intervention programs that have been shown to show improvements, it is important that research in this area is continued. Families need more options than three programs. This pamphlet will stimulate further research and studies to be conducted around family intervention programs aimed for children with FASD and their families. Further research will lead to more options for families to choose from and a better understanding of the environment children with FASD need in order for optimal development.

Many children with FASD are adopted. Adoptive parents of children with FASD should be “calm, low-key individuals, who are secure and comfortable with themselves and live stable and predictable lives” (para. 11). These characteristics along with love, treating their child as normally as possible and a firm limit setting will lead to the greatest progress for children with FASD as opposed to parents with high unreachable expectations (adoption.com para 11). According to adoption.com parents who chose to adopt a child with FASD will need “need

medical information, peer support, financial assistance and respite care” (para. 1). Choosing an appropriate family intervention program is a great way for adoptive parents to receive these needs.

My aunt and uncle adopted a child with FASD and they were provided with fact, after fact about the negative effects they and their children with FASD are going to face. In the beginning of the adoption it was very overwhelming for them and crushing for them. Here was a time they thought was going to be joyous and inspiring for helping a little girl survive. If adoptive parents like my aunt and uncle, would have received a pamphlet of family interventions it would be a time for joy and inspiration. It is more important that these parents are given information about intervention programs that will help minimize these effects. This pamphlet will give hope to adoptive parents that there are options and support available that have been scientifically proven to help their new family. These family interventions will help parents to proactively engage in an intervention program that will help the dynamics of their family in order to provide their child with FASD the best opportunities for development.

Before distributing this pamphlet I would suggest that psychologists and researchers, in this area of study, review it. I would also hand it out to adoption clinics, pediatricians and any other facilities that handle FASD to get their feedback and opinion on the pamphlet. Once I have received all the critique I would go back and fix the pamphlet so that it would better fit everyone’s needs. After I have done this I would then test the pamphlet with a group of parents and adoptive parents of children with FASD. I would give them the pamphlet and ask them to review it and give me their comments, questions, concerns and feedback. This will allow for me to see how this pamphlet is helpful and what it may be missing from the parents’ point of view. Once this is done I would again change the pamphlet so the parents’ needs are met. I would also

get a group of parents to participate in one of the three intervention programs. After they have completed the program I would ask for their feedback and for a review of the program. Once I obtain that information I would add a section to the pamphlet that provides a personal account of each intervention program.

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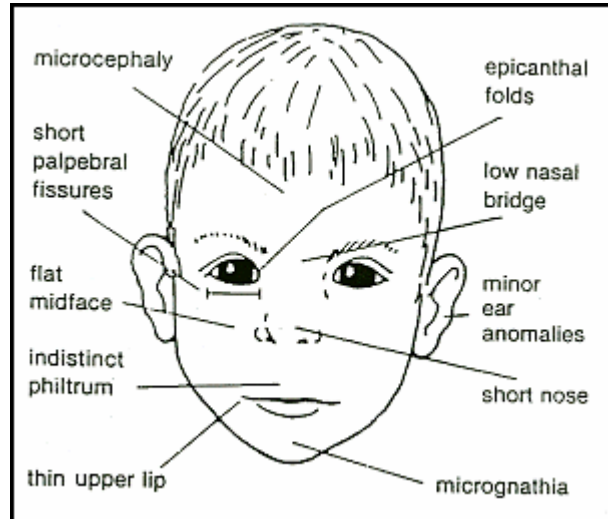


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## APPENDICES

## Appendix A



## Appendix B